

VOLUME II

Information about Schizophrenia Relevant to Programme Implementation

Introduction

Schizophrenia is a serious mental illness that can devastate the lives of people who suffer from it and the lives of their families. It usually strikes adolescents and young adults, disrupting their pursuit of educational and occupational goals and drastically reducing their quality of life. It occurs in all countries of the world and is among the ten leading causes of disability in those 18 to 44 years old (Murray and Lopez 1996).

Schizophrenia is associated with a significant amount of stigma and discrimination, which further increases the burden on patients and their families. Individuals with schizophrenia often face social isolation, discrimination in housing, education, and employment opportunities, and other forms of prejudice. The stigma often also extends to family members and to those who provide health care services to patients with schizophrenia. The treatments patients receive may also increase the stigma associated with the illness, especially if they produce the debilitating motor side effects that can result from treatment with certain antipsychotic medications.

Today, there is new hope for those who suffer from schizophrenia. In recent years, an array of new antipsychotic medications and psychosocial interventions has been developed that are helping many individuals with schizophrenia reintegrate into the community, improve their quality of life, and pursue their life goals. However, the stigma and discrimination associated with serious mental illness often make it more difficult for people with schizophrenia to benefit fully from these new treatments and can thus derail their recovery.

For this reason, the World Psychiatric Association (WPA) has launched this worldwide programme to reduce the stigma and discrimination because of schizophrenia. This volume brings together information about the diagnosis, epidemiology, and treatment of schizophrenia and relates it to how stigma develops and how it can best be combated. To facilitate the use of this information in the development of programmes designed to combat stigma and discrimination, marginal annotations are included throughout the volume explaining the particular relevance of the information for reducing stigma and discrimination.

Volume II is organized in two parts:

Part I. What Is Schizophrenia (IA) and How Is It Treated (IB)?

This section provides information on the diagnosis, epidemiology, and treatment of schizophrenia that can be adapted for use in targeted anti-stigma campaigns.

Part II. Decreasing Stigma. This section describes the nature, origins, and consequences of stigma, prejudice, and discrimination and then describes the types of initiatives that can be most effective in reducing stigma and discrimination. Although the material in this section focuses specifically on schizophrenia, much of the information is also applicable to the stigma and discrimination associated with other serious mental illnesses.

[1] Murray CJL, Lopez AD. The Global Burden of Disease. Geneva: World Health Organization; 1996: 270.

IA. What is Schizophrenia?

One of the best ways to eliminate the stigma and reduce the discrimination associated with schizophrenia is to clear up common misconceptions about the illness and replace them with clear accurate information.

This section covers the following topics:

- Symptoms and diagnosis of schizophrenia
- Causes of schizophrenia
- Onset, course, and outcome of schizophrenia

The Symptoms and Diagnosis of Schizophrenia

Schizophrenia is a mental disorder that interferes with a person's ability to recognise what is real, manage his or her emotions, think clearly, make judgements, and communicate. The International Classification of Diseases gives the following description of schizophrenia in the ICD-10 Classification of Mental and Behavioural Disorders: Clinical Descriptions and Diagnostic Guidelines (World Health Organization 1992):

The schizophrenic disorders are characterized in general by fundamental and characteristic distortions of thinking and perception, and by inappropriate or blunted affect. Clear consciousness and intellectual capacity are usually maintained, although certain cognitive deficits may evolve in the course of time. The disturbance involves the most basic functions that give the normal person a feeling of individuality, uniqueness, and self-direction. The most intimate thoughts, feelings, and acts are often felt to be known to or shared by others, and explanatory delusions may develop, to the effect that natural or supernatural forces are at work to influence the afflicted individual's thoughts and actions in ways that are often bizarre. The individual may see himself or herself as the pivot of all that happens. Hallucinations, especially auditory, are common and may comment on the individual's behaviour or thoughts. Perception is frequently disturbed in other ways: colours or sounds may seem unduly vivid or altered in quality, and irrelevant features of ordinary things may appear more important than the whole object or situation. Perplexity is also common early on and frequently leads to a belief that everyday situations possess a special, usually sinister, meaning intended uniquely for the individual. In the characteristic schizophrenic disturbance of thinking, peripheral and irrelevant features of a total concept, which are inhibited in normal directed mental activity, are brought to the fore and utilized in place of those that are relevant and appropriate to the situation. Thus thinking becomes vague, elliptical, and obscure, and its expression in speech sometimes incomprehensible. Breaks and interpolations in the train of thought are frequent, and thoughts may seem to be withdrawn by some outside agency. Mood is characteristically shallow, capricious, or incongruous. Ambivalence and disturbance of volition may appear as inertia, negativism, or stupor. Catatonia may be present. The onset may be acute, with seriously disturbed behaviour, or insidious, with a gradual development of odd ideas and conduct. The course of the disorder shows equally great variation and is by no means inevitably chronic or deteriorating... In a proportion of cases, which may vary in different cultures and populations, the outcome is complete, or nearly complete, recovery. The sexes are approximately equally affected but the onset tends to be later in women (pp. 86-87).

Schizophrenia, schizotypal disorder, and acute and transient psychotic disorders are referred to as the schizophrenia spectrum disorders.

Related Disorders

Schizophrenia historically belongs to a group of mental disorders that were commonly described as "insanity" in the last century. Unfortunately, much of the prejudice and negative image of this term still exists and is attached to the newer term "schizophrenia". The term "insanity" has been gradually replaced by the terms "psychosis" or "psychotic disorders". These descriptive terms broadly refer to symptoms of inappropriate social behaviour and lack of insight accompanied by positive symptoms (see below) such as hallucinations and delusions. However, psychotic symptoms are not specific and can occur in association with many mental disorders in addition to schizophrenia.

The World Health Organization's ICD-10 includes schizophrenia, schizotypal disorder, and acute and transient psychotic disorders in the chapter on schizophrenic disorders. Schizophrenia is the most common and important psychotic disorder. Schizotypal disorder is a personality disorder characterised by traits and symptoms that resemble those seen in schizophrenia but that are less severe, such as inappropriate or constricted affect, eccentric behaviour, a tendency for social withdrawal, suspiciousness, and mild perceptual disturbances and delusions. Acute and transient psychotic disorders are particularly frequent in developing countries (Jablensky et al. 1992). Although the relationship of acute and transient psychosis to schizophrenia remains unclear, patients usually recover completely within 3 months and, in about 80% of cases, no further episode occurs within the first year after onset.

Persistent delusional disorders are probably not related to schizophrenia, although they may be difficult to distinguish, particularly in the early stages of illness. Schizoaffective disorder involves a combination of mood and psychotic symptoms that can occur independently of each other during the course of the illness. Severe depressive or bipolar disorder may also be accompanied by psychotic symptoms. Psychosis can also occur in the context of organic brain disorders such as dementia.

Schizophrenic-like syndromes can also be caused by other conditions such as Wilson's disease, Huntington's chorea, or the cerebral form of multiple sclerosis. Intoxication with substances that increase dopaminergic neurotransmission in the brain, such as amphetamines, can cause a relapse of schizophrenia or, at sufficiently high doses, may cause a schizophrenia-like psychosis. Ketamine and phencyclidine (PCP; angel dust), drugs of abuse which influence glutamate receptors, can cause a schizophrenic-like psychosis with negative symptoms. In all such cases of secondary schizophrenia-like disorders, the underlying causes of the psychosis should always be treated if possible.

In some countries, clear distinctions between the various types of schizophrenia-like disorders are not usually made and disorders characterised by psychotic symptoms may be grouped together under the more general rubric of psychotic disorders.

The stigma associated with schizophrenia can result in physical disorders being undetected or untreated.

Comorbid Disorders

Patients with schizophrenia suffer from a significant degree of comorbidity (co-occurring disorders) (Jablensky 1995). There is a high rate of substance abuse among those with schizophrenia, which may include abuse of alcohol, stimulants, benzodiazepines, hallucinogens, antiparkinsonian drugs, caffeine, and tobacco (Lohr and Flynn 1992). Substance abuse is the most common comorbid psychiatric disorder with schizophrenia, with prevalence rates ranging from 20% to more than 50% of patients with schizophrenia, depending on gender, age, duration of illness, the evaluation criteria used, and regional differences in the populations studied (Jablensky 1995; Hambrecht and Häfner 1996). For a more detailed discussion of substance abuse and schizophrenia, see below.

There is an increased risk of HIV infection and AIDS among individuals with severe mental illness, because they have higher rates of HIV-related risk behaviours such as unprotected sexual intercourse and injection drug use (Cournos et al. 1997; Cournos and Bakalar 1996; Cournos and McKinnon 1997; Susser et al. 1997).

Individuals with schizophrenia have been found to have a higher mortality rate from cardiovascular disease, lung disease, gastrointestinal and urogenital disorders, accidents, and suicide than the general population (Mortensen and Juel 1990).

The symptoms of schizophrenia can make it difficult for patients to recognise or accurately report the symptoms of physical disorders or to follow through with treatments. In addition, the stigma associated with schizophrenia may result in physical disorders being undetected or untreated. It is important for mental health professionals to act as liaisons with general medical practitioners to educate them about how schizophrenia may alter the usual presentation, clinical course, and response to treatment of common medical and surgical conditions (Vieweg et al. 1995).



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- [5] Jablensky A. Schizophrenia: The epidemiological horizon, in Hirsch SR, Weinberger DR, eds. Schizophrenia. Oxford: Blackwell Science; 1995:206-252.
- [6] Jablensky A, Sartorius N, Ernberg G, et al. Schizophrenia: Manifestations, incidence and course in different cultures: A World Health Organization ten-country study. Psychol Med 1992; 22(suppl 20):1-97.
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- [10] Vieweg V, Levenson J, Pandurangi A, et al. Medical disorders in the schizophrenic patient. Int J Psychiatry Med 1995;25(2): 137-172.
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The belief that drug abuse causes schizophrenia can increase the stigma associated with the illness.

Drug Abuse and Schizophrenia

Drug abuse alone does not cause schizophrenia (although it may make people with the illness worse). It is recognised that hallucinogenic drugs like LSD can induce short-lasting episodes of psychosis and that the heavy use of marijuana and stimulant drugs such as cocaine and methamphetamine may precipitate brief, toxic psychoses with features similar to schizophrenia (Bowers 1987; Tennent and Groesbeck 1972). It is also possible, though not certain, that drug abuse can trigger the onset of schizophrenia; however, drug abuse does not appear to cause schizophrenia in someone who would not otherwise have developed the illness. This is known because, in the 1950s and 1960s, LSD was used as an experimental drug in psychiatry in Britain and America. The proportion of those volunteers and patients who developed a long-lasting psychosis like schizophrenia was scarcely greater than might have been expected in the general population (Cohen 1960; Malleon 1971). It is true that a Swedish study found that army conscripts who used marijuana heavily were six times more likely to develop schizophrenia later in life (Andreasson et al. 1987), but this may have been because those people who were destined to develop schizophrenia were more likely to use marijuana as a way of coping with the premorbid symptoms of the illness. In fact, most people with schizophrenia begin to use street drugs after the earliest prodromal symptoms of the illness develop (Hambrecht and Häfner 1996).

If drug abuse triggers a schizophrenic illness that would have occurred anyway, we would expect the age of onset of the illness to be earlier in those who use drugs. Several studies show that this is in fact the case (Breakey et al. 1974; Weller et al. 1988; Tsuang et al. 1982), while a few others do not (Vardy and Kay 1982; Taylor and Warner 1994). On balance, it seems possible that substance abuse may trigger a schizophrenic illness, but does not cause it.

Drug and alcohol abuse may make the course of schizophrenia worse. Several studies have shown that people with mental illness who use street drugs or use alcohol heavily have more psychotic symptoms (Janowsky and Davis 1976; Knudson and Vilmar 1984; Negrete et al. 1986), function less well in the community (Drake and Wallach 1989; Hekimian and Gershon 1968), and are admitted to hospital more frequently (Drake and Wallach 1989; Carpenter et al. 1985; Crowley et al. 1974; Safer 1985). It has also been noted, however, that people with mental illness who use street drugs are less likely to take their medication regularly (Drake and Wallach 1989), which may partly explain why their symptoms are more severe and the course of their illness is worse. In many cases, the use of marijuana and stimulant drugs, such as cocaine, can increase the symptoms of schizophrenia, such as hallucinations and delusions (Janowsky and Davis 1976; Knudson and Vilmar 1984; Negrete et al. 1986). On the other hand, some people with schizophrenia say that they use marijuana because it helps them feel less anxious, depressed, or bored (Test et al. 1989; Warner et al. 1994). Alcohol abuse can be a particularly serious problem for people with

Antipsychotic medications are not addictive.

schizophrenia since it is easy to obtain and can reduce impulse control and exacerbate symptoms.

People with schizophrenia are much more likely than the average person to smoke cigarettes and to smoke heavily. Recent research suggests a reason for this—nicotine produces a brief reduction in hallucinations and other symptoms of schizophrenia (Freedman et al. 1994, 1997).



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- [2] Bowers MB. The role of drugs in the production of schizophreniform psychoses and related disorders, in Meltzer HY, ed. *Psychopharmacology: The Third Generation of Progress*. New York: Raven Press; 1987.
- [3] Breakey WR, Goodell H, Lorenz PC, et al. Hallucinogenic drugs as precipitants of schizophrenia. *Psychol Med* 1974;4:255-261.
- [4] Carpenter MD, Mulligan JC, Bader IA, et al. Multiple admissions to an urban psychiatric center. *Hosp Community Psychiatry* 1985;31:397-400.
- [5] Cohen S. Lysergic acid diethylamide: Side effects and complications. *J Nerv Ment Dis* 1960;130:30-40.
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- [14] Malleon N. Acute adverse reactions to LSD in clinical and experimental use in the United Kingdom. *Br J Psychiatry* 1971;118:229-230.
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- [16] Safer DJ. Substance abuse by young adult chronic patients. *Hosp Community Psychiatry* 1985;38:853-858.
- [17] Taylor D, Warner R. Does substance use precipitate the onset of functional psychosis? *Social Work & Social Sciences Review* 1994; 5:64-75.
- [18] Tennent FS, Groesbeck CJ. Psychiatric effects of hashish. *Arch Gen Psychiatry* 1972;27:133-136.
- [19] Test MA, Wallisch LS, Allness DJ, et al. Substance use in young adults with schizophrenic disorders. *Schizophr Bull* 1989;15:465-476.
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- [21] Vardy MM, Kay SR. LSD psychosis or LSD-induced schizophrenia? A multimethod inquiry. *Arch Gen Psychiatry* 1982;39:141-147.
- [22] Warner R, Taylor D, Wright J, et al. Substance use among the mentally ill: Prevalence, reasons for use and effects on illness, *Am J Orthopsychiatry* 1994;64:30-39.
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The early changes associated with schizophrenia often lead to a loss of friends, acquaintances, and usual social connections, which results in social isolation.

In many cases, the evaluation of schizophrenia should include a physical examination.

Symptoms that suggest schizophrenia should not be neglected because a psychiatrist is not available.

Early Signs

Schizophrenia is usually first recognised because of a change in the person's social and personal functioning for which there is no adequate explanation. The period before the onset of the active symptoms of schizophrenia is called the "prodromal" period and may last for years. In three-fourths of the cases, non-specific and negative symptoms occur long before the first positive symptom. These early symptoms are frequently accompanied by functional impairment. In regions with a well-developed mental health care system, social impairment is generally observed more than 2 years before first admission and is often at its maximum at the beginning of treatment (Häfner 1996). Early signs may also include changes in behaviour such as generalised anxiety, transient mild depression, a loss of interest in or withdrawal from work and social activities that were previously important to the person, suspiciousness, and a marked and conspicuous change in personal habits and values such as grooming, hygiene, dress, or punctuality. The person may act or dress in odd or extravagant ways. Often the explanations offered for these changes and behaviours are symbolic, metaphoric, or bizarre.

The Diagnostic Evaluation

The diagnostic evaluation for schizophrenia should ideally include the following:

- A detailed history of the patient, based on reports from the patient and from others close to him or her (e.g., family members, friends) to assess the patient's personality and global functioning
- A mental state examination
- Physical examination (including neurological examination)
- Standard laboratory evaluation of blood biochemistry and blood count

Although there are no specific physical or laboratory findings that confirm the diagnosis of schizophrenia, the physical evaluations included in the preceding list are needed to rule out other possible causes of the symptoms, such as organic disorders, and to evaluate for comorbid physical illness. Although, in many cases, the diagnosis can be made without difficulty by a well trained physician, in others, an evaluation by a skilled psychiatrist will be needed to confirm it.

In addition to evaluating symptoms, it is also important to obtain information about the individual's social functioning, the environment in which he or she lives, the availability of social support, and the individual's skills, assets, and financial situation, since these factors will be extremely important in planning treatment and implementing reintegration into the community.

The symptoms of schizophrenia are often classified as positive and negative (Andreasen and Olsen 1982). Both types of symptoms can cause special problems in social functioning and contribute to the stigma because of schizophrenia. In most patients with schizophrenia, positive

and negative symptoms are present in different proportions at different periods of the illness.

Positive symptoms

People with schizophrenia may speak and behave in odd or bizarre ways that cause others to fear and avoid them, thus perpetuating the stigma associated with the disorder.

The difficulty that individuals with schizophrenia have in communicating verbally may contribute to the stigma associated with the disorder.

Positive symptoms are associated with the kind of stigma attached to madness. Delusions, hallucinations, disturbed behaviour, and an altered perception of reality are characteristic of those who are considered “crazy” by lay persons. The strange behaviour of those with schizophrenia raises the fear among others that they may lose control of their own behaviour.

Delusions are false beliefs about which a person is firmly convinced despite the absence of concrete evidence. Such false beliefs must be distinguished from culture-specific beliefs that are held by an entire group or society. People with delusions may believe they are being persecuted, have special gifts or powers, or that their thoughts or actions are under the control of an external force. The delusions may be fantastic or bizarre (e.g., being able to control the weather or being in communication with aliens from another world). People holding these false beliefs may be very fearful that they are going to be harmed or may act in unusual ways because of the beliefs.

Hallucinations are imagined sensory perceptions. The most common type of hallucinations that occur in schizophrenia are auditory in which the person hears imagined voices. Sometimes people with schizophrenia hold ongoing conversations with these voices. Sometimes the voices give commands or comment on the character and actions of the person with schizophrenia. Less common types of hallucinations include seeing, feeling, tasting, or smelling things that are very real to the person but which are not actually there. The person may perceive ordinary colours and shapes in a distorted fashion and feel that they possess an urgent personal significance.

People with **thought disorder** have confused thinking that is evident in what they say and how they say it. The person’s speech may be difficult to follow because it jumps from one subject to another with little or no logical connection. Interruptions in the train of thought (thought blocks) may occur. The syntax may be bizarre and appear to make sense only to the speaker. In some cases, people believe their thoughts are being broadcast or stolen from them or that their thoughts are being controlled or influenced by an external agent (e.g., an alien, a demon). These phenomena are referred to as thought echo, broadcasting, insertion, or withdrawal. In severe cases, speech may be so jumbled and disjointed that it is impossible to understand.

Bizarre behaviour: Some people with schizophrenia behave in strange ways or transgress social mores (e.g., undressing in public). They may make odd gestures or incongruous facial expressions and grimaces or assume strange postures for no apparent purpose.

Positive symptoms are relatively easy to recognise because they are so obviously different from normal. However, the presence of positive symptoms such as hallucinations and delusions does not necessarily mean that the person has schizophrenia. These same symptoms may also occur in people who abuse alcohol or drugs or who have severe depression, mania, brain injury, or certain medical illnesses.

Because prominent positive symptoms make it very difficult for the person to function socially, they often result in admission to a psychiatric hospital. Fortunately, antipsychotic medication can eliminate or reduce the intensity of positive symptoms and lessen the chance that they will recur, although the person may still be affected by negative symptoms. A relapse can occur if the person experiences a stressful life event, long-term stressful relationships, or if medications are stopped or the dosage reduced. Relapses can also occur without any apparent trigger even when the person has continued to take a dosage of medication that was previously adequate.

Negative symptoms

Blunted emotions: People with schizophrenia often seem emotionally flat and unresponsive to things happening around them. They may be unable to show emotion by varying their facial expressions, gestures, or tone of voice. The person may not show much response to happy or sad events, or may respond in an inappropriate way. In some types of schizophrenia, especially the hebephrenic or disorganised type (see below), grossly inappropriate and incongruous emotions and actions are among the main symptoms. The person may appear to be misdirected, goalless, playfully intrusive, and often impulsive. The whole personality of the person with schizophrenia often appears to be changed from its previous pattern.

Loss of drive: Schizophrenia may reduce people’s motivation so that they are less able to work or participate in leisure activities. They may seem uninterested in everyday activities such as washing and cooking or, in extreme cases, may be unable to care for their personal hygiene or feed themselves. Indecision, negativism, and passivity may appear, mixed with sudden impulses. In extreme cases, the person may become withdrawn, agitated, or stuporous for no apparent reason.

Social withdrawal: People with schizophrenia may have difficulty making and keeping friends or acquaintances; they may have few, if any, intimate relationships. Their interactions with others may be brief and superficial. In extreme cases, the person may actively avoid all social interactions.

Poverty of thought: Some people with schizophrenia reveal a marked reduction in the amount and content of their thinking. They may only rarely speak spontaneously and may answer questions with short answers that provide no detail. In extreme cases, the person’s speech is limited to short phrases such as “yes,” “no,” or “I don’t know.” Other people with schizophrenia may talk freely, but their speech, while comprehensible, does not really convey any content. They may answer questions in a roundabout way that never gets to the point. Their speech may reflect loose or unrelated associations between ideas and incomprehensible breaks and jumps in the train of thought.

The negative symptoms of schizophrenia are often misinterpreted by others as a sign that the person is lazy or purposely misbehaving to annoy others rather than being seen as part of the illness. Such a misinterpretation contributes in a large way to the negative image and stigma associated with schizophrenia.

In assessing negative symptoms that are not accompanied by positive symptoms, the clinician should evaluate for a change from previous behaviour. Although negative symptoms that occur in the absence of positive symptoms are often missed, the person with negative symptoms only still needs help.

In cultures in which frequent and intense social interaction is the norm (e.g., many Western cultures), the presence of negative symptoms may be particularly stigmatising. It is extremely important to take culture into consideration in evaluating negative symptoms and their impact.

Negative symptoms are associated with the stigma of psychological weakness, lack of will or drive to lead a more active and participatory life, and an inability to take care of oneself. The results of negative symptoms may be perceived as a voluntarily chosen life-style characterised by social withdrawal and a lack of responsibility toward others. Negative symptoms are often associated with the stigma of being lazy.

The person's ability to work, to interact with others, and to care for himself or herself during remission depends to a large extent on the severity of the person's residual negative symptoms.

People with paranoid schizophrenia find it difficult to trust or relate to others. Their bizarre beliefs and perceptions are likely to make other people fear and avoid them.

Unlike positive symptoms, negative symptoms are more subtle deficits in functioning that are often not recognised as symptoms of the illness. Sometimes family members or others misinterpret the negative symptoms of schizophrenia as a sign of “laziness.” For example, if the person is unmotivated and unconcerned about personal appearance, they may think that he or she is just too lazy to bother or is neglecting his or her appearance to annoy the family.

Negative symptoms may also be the result of depression (which can occur at the same time as schizophrenia) or an understimulating environment (such as a prolonged hospital stay), or may actually represent side effects of some antipsychotic medications. It is often hard to tell if negative symptoms are a part of the schizophrenic illness itself or the result of these other problems.

The person's ability to work, to interact with others, and to care for himself or herself during remission depends to a large extent on the severity of the person's residual negative symptoms.

Most people with schizophrenia only have a few positive and negative symptoms at any given time. Typically, the type and severity of symptoms vary considerably over the course of the illness and from one person to another. Some individuals never have hallucinations; others never have delusions; some never have negative symptoms while others suffer from them persistently.

The International Classification of Diseases

Because clinicians need to be able to diagnose schizophrenia reliably in many different settings and cultures, specific criteria for diagnosing the disorder have been developed. The most commonly used system is that provided in the World Health Organization's *International Classification of Mental and Behavioural Disorders* (ICD-10) (WHO 1992). Appendix A to this volume presents the ICD-10 diagnostic criteria with descriptive explanations. Another system that is often used to diagnose schizophrenia is found in the *Diagnostic and Statistical Manual of Mental Disorders*, published by the American Psychiatric Association. The criteria included in the 4th edition (DSM-IV) published in 1994 closely resemble those given in ICD-10. Of course, clinicians also need to rely on their clinical experience and expert judgement in order to make an accurate diagnosis.

Subtypes of Schizophrenia

The ICD-10 diagnostic classification lists four main subtypes of schizophrenia (see Appendix B for more details):

Paranoid: This is the commonest type of schizophrenia and is characterised by prominent delusions of persecution and hallucinations.

Hebephrenic schizophrenia is very disabling and makes it extremely difficult for people to function academically or occupationally. The behaviour and affect of these individuals appear strange and illogical to others, who are likely to avoid them for this reason.

It is extremely difficult for individuals with catatonic schizophrenia to interact socially or carry through tasks.

Because negative symptoms contribute greatly to the social and occupational problems of people with schizophrenia, simple schizophrenia can be very disabling despite the absence of more florid positive symptoms.

The more disturbing a symptom is in terms of local social mores, the more likely that the person with that symptom will be recognised as mentally ill and stigmatised.

Hebephrenic: This type of schizophrenia, which is also referred to as disorganised schizophrenia, typically begins in adolescence and is characterised by predominant negative symptoms, silly or inappropriate affect, and thought disorder and fragmentation.

Catatonic: Catatonic schizophrenia is becoming increasingly rare. It is characterised by predominant motor symptoms and extreme social withdrawal, flat emotions, and a lack of ideas, energy, and motivation.

Simple: Simple schizophrenia is mainly characterised by negative symptoms alone, although there may be occasional oddities in thinking and behaviour and perceptual abnormalities.

ICD-10 also includes three additional categories: undifferentiated schizophrenia (combines features of several of the other types), residual schizophrenia, and post-schizophrenic depression (see Appendix B for descriptions).

Are the Symptoms of Schizophrenia the Same Everywhere?

The WHO International Pilot Study of Schizophrenia, conducted in 1969-76, found that schizophrenia was a fairly ubiquitous disorder with a similar clinical picture in all the settings studied (WHO 1973). **Table 1** shows the ten most frequent symptoms of acute schizophrenia.

Table 1

Ten most frequent symptoms of acute schizophrenia

Symptoms	Frequency
Lack of insight	97%
Auditory hallucinations	74%
Ideas of reference	70%
Suspiciousness	66%
Flatness of affect	66%
Second person hallucinations	65%
Delusional mood	64%
Delusions of persecution	64%
Thought alienation	52%
Thoughts spoken aloud	50%

Source: World Health Organization Report of the International Pilot Study of Schizophrenia (WHO 1973; Jablensky et al. 1992)

Wherever it appears, the characteristic symptoms of schizophrenia are basically the same: delusions, hallucinations, thought disturbance, catatonic disturbances, and negative symptoms. However, the way in which the symptoms appear and the particular types of symptoms that are prominent may vary from individual to individual and culture to culture. Furthermore, because of differences in social customs and expectations, cultures differ in their assessment of the importance of different symptoms. (For a discussion of differences in course and outcome between developed and developing countries, see pp. 31-33.)



- [1] American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM-IV). Washington, DC: American Psychiatric Association, 1994.
- [2] Andreasen NC, Olsen S. Negative vs positive schizophrenia: Definition and validation. Arch Gen Psychiatry 1982;39:789-794.
- [3] Häfner H. When, how, and with what does schizophrenia begin? J Brasil Psiquiatr 1996; 45:7-21.
- [4] Jablensky A, Sartorius N, Ernberg G, et al. Schizophrenia: Manifestations, incidence and course in different cultures: A World Health Organization ten-country study. Psychol Med 1992; 22(suppl 20):1-97.
- [5] World Health Organization. Report of the International Pilot Study of Schizophrenia. Geneva: WHO; 1973.
- [6] World Health Organization. The ICD-10 Classification of Mental and Behavioural Disorders: Clinical Descriptions and Diagnostic Guidelines. Geneva: WHO; 1992.

At present, the stigma associated with schizophrenia includes the idea that violence is inherent in the disorder. However, the violence that is associated with schizophrenia is usually due to the person's response to a lack of appropriate treatment, support, and acceptance.

The risk of violence associated with schizophrenia is minimised by proper treatment and intervention.

Although the risk of criminal behavior is somewhat higher in those with schizophrenia, the overall number of crimes committed by those with schizophrenia is only a very small percent of the number of crimes committed by those without mental illness.

A common fear of the public is that their children are at risk from those with schizophrenia, but there is no evidence for this.

The mistreatment of people with schizophrenia may provoke a violent reaction which is then misinterpreted as a sign of the disease rather than as an understandable response. People with schizophrenia are, in fact, more likely to be victims of abuse or violence than perpetrators.

Is Schizophrenia Associated with an Increased Risk of Violent Behaviour?

The public perception, supported by the media, that mental illness is strongly linked to violence is not supported by scientific evidence. The vast majority of people with mental illness never commit a violent offence (Swanson et al. 1990) and persons with mental illness in general are not more dangerous than healthy individuals from the same population. Individuals with schizophrenia do show a slightly elevated rate for crimes of violence (Häfner and Böker 1982; Arboleda-Florez et al. 1996; Hodgins 1992; Lindqvist and Allebeck 1990), but such acts are only likely to be committed by those who are not receiving treatment or are receiving inadequate treatment (Garmendia et al. 1992; Harris and Morrison 1995; Volavka and Krakowski 1989). Risk factors for violence in the healthy population and in those with schizophrenia include male sex, social disintegration, a history of violent behaviour, and alcohol or substance abuse (Arboleda-Florez et al. 1996; Virkkunen 1976). One important symptom that increases the risk of violence is the delusional belief that one's life is threatened; proper treatment of these symptoms minimises the risk of violence (Link and Stueve 1995; Garmendia et al. 1992; Harris and Morrison 1995). Patients with schizophrenia who abuse alcohol or substances have an increased risk of breaking the law; however, the pattern of criminal behaviour among these individuals is the same as is seen among those without schizophrenia who have alcohol or substance abuse or dependence (Arboleda-Florez et al. 1996; Beaudoin et al. 1993; Swanson 1994).

Most legal offenses committed by people with schizophrenia are minor property offences related to survival. People with schizophrenia are, in fact, more likely to be victims of abuse or violence than perpetrators. Crimes of violence committed by those suffering from schizophrenia are due to different motives and have different victims from those of healthy individuals. The most likely victims of violence are intimate partners and family members, followed by authority figures such as politicians, physicians, and judges (Häfner and Böker 1982).

A group of researchers and advocates for the mentally ill recently reviewed the available research evidence and arrived at the following consensus:

Mental disorder and violence are closely linked in the public mind. A combination of factors promotes this perception: sensationalized reporting by the media whenever a violent act is committed by "a former mental patient," popular misuse of psychiatric terms (such as "psychotic" and "psychopathic"), and exploitation of stock formulas and narrow stereotypes by the entertainment industry. The public justifies its fear and rejection of people labeled mentally ill, and attempts to segregate them in the community, by this assumption of danger.

The experience of people with psychiatric conditions and of their family members paints a picture dramatically different from the stereotype. The results of several recent large-scale research projects conclude that only a weak association between mental disorders and violence

Violence and Schizophrenia: Correcting Misconceptions

- 1) *Treatment dramatically reduces the risk of violence. People with schizophrenia who do not receive treatment are likely to have an increased risk of violence.*
- 2) *The risk of violence is not necessarily due to schizophrenia, but rather to a combination of disorders.*
- 3) *The contribution of those with schizophrenia to the overall incidence of crime is relatively small.*
- 4) *The violence associated with schizophrenia is most often directed at family members.*
- 5) *People with schizophrenia do not pose a risk to children in the community.*
- 6) *Risk of violence in those with schizophrenia appears to be very similar to that in the healthy population when substance abuse is factored out.*
- 7) *Risk of sexual offenses associated with schizophrenia is low.*
- 8) *Only a small percentage of those with schizophrenia are likely to commit violent acts.*

exists in the community. Serious violence by people with major mental disorders appears concentrated in a small fraction of the total number, and especially in those who use alcohol and other drugs. Mental disorders—in sharp contrast to alcohol and drug abuse—account for a minuscule portion of the violence that afflicts American society.

The conclusions of those who use mental health services and of their family members, and the observations of researchers, suggest that the way to reduce whatever relationship exists between violence and mental disorder is to make accessible a range of quality treatments including peer-based programs, and to eliminate the stigma and discrimination that discourage, provoke, and penalize those who seek and receive help for disabling conditions. (Monahan and Arnold 1996, pp. 69-70)



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Although the exact causes of schizophrenia are not known, it appears that the interaction of a number of factors, including genetic factors, complications of pregnancy and delivery that may affect the developing brain, and biological and social stresses, play a role in the development of the illness.

What Are the Causes of Schizophrenia?

Although the exact causes of schizophrenia are not known, it appears that several factors increase a person's risk for the illness. These factors interact with one another to influence the development and the course of schizophrenia (Strauss and Carpenter 1981; Weinberger and Hirsch 1995), and different factors assume importance at different stages in the individual's development. Genetic factors and complications of pregnancy and delivery can each play a part in forming the new-born infant's predisposition to developing the illness. The timing of the onset of illness in later life depends upon the extent of the person's vulnerability and exposure to a variety of stresses. Precipitating stresses may be biological in nature (e.g., hallucinogenic drug abuse) or social (e.g., losing a relative). These and other factors and stresses also affect the course and outcome of the illness (see p. 29).



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Is Schizophrenia Inherited?

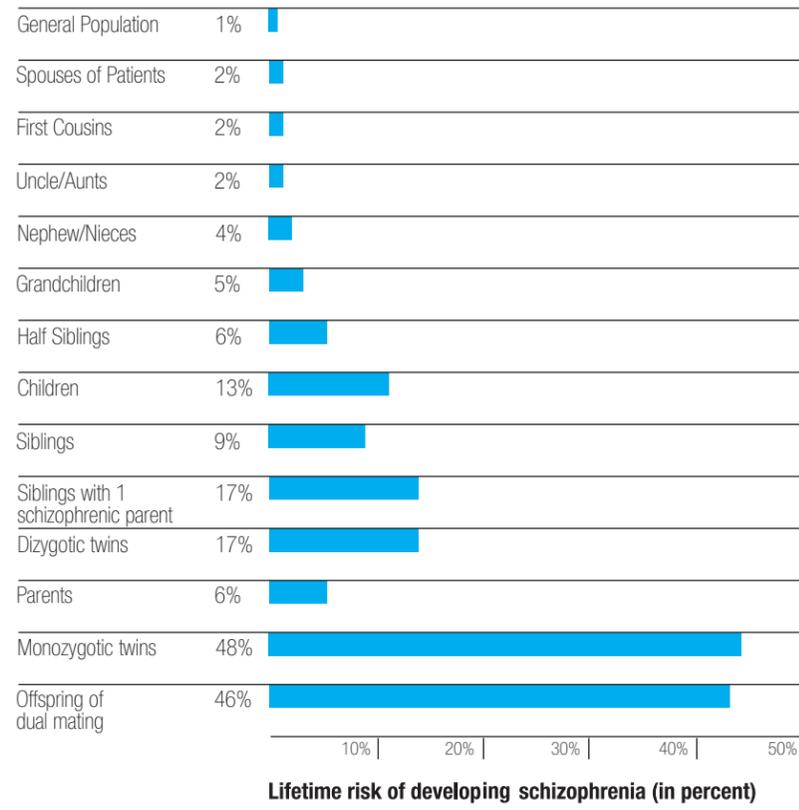
Relatives of people with schizophrenia have a greater risk of developing the illness than others. The risk is progressively greater in relatives who are more genetically similar to the schizophrenic person. Geneticist Irving Gottesman, drawing data from about 40 European studies conducted between 1920 and 1987, has compiled a comparison of the average lifetime risk of developing schizophrenia for people with different degrees of relationship to someone with schizophrenia. His findings, shown in **Figure 1**, indicate that the closer the similarity in genetic make-up, the greater the risk (Gottesman 1991).

Studies of people adopted in infancy suggest that the increased risk of schizophrenia in the relatives of identified cases is related to inheritance rather than environment. The children of people with schizophrenia have a similar increased prevalence of the illness whether they are raised by their biological parents or by adoptive parents. Likewise, the family history of people with schizophrenia brought up by adoptive parents reveals an increased prevalence of the illness among their biological relatives but not among their relatives by adoption (Heston 1966; Kety et al. 1968; Kety et al. 1975; Tienari and Wynne 1994)

Although genetic factors appear to be important in the development of schizophrenia, they are not sufficient to explain the entire pattern of occurrence. If an illness is entirely caused by genetic factors, even if a number of abnormal genes working together are needed to cause the illness, then identical twins should share the same risk of illness—that is, if one twin is ill then both should be ill. In fact, in most studies of identical twins in which one twin is affected, it is rare to find more than half of the other members of the pairs also affected (a risk of no more than 50%

FIGURE 1

The average risk of developing schizophrenia for relatives of a person with the illness; compiled from family and twin studies conducted in Europe between 1920 and 1987.



Source: Adapted with permission of the author. From Gottesman, I.I., *Schizophrenia Genesis: The Origins of Madness*, New York: W.H. Freeman, 1991, p.96 © 1991 Irving I. Gottesman.

with identical genetic material). This suggests that the risk of schizophrenia must also include non-genetic factors. In the case of non-identical twins, the frequency with which the second twin is affected is considerably lower than the rate for identical twins (17%). Non-identical twins share a common environment (the same family setting), but on average share only half their genes; whereas identical twins share the same family setting and all their genes. The data comparing the two types of twins is evidence that the preponderance of risk for schizophrenia is probably genetically determined, but that other factors are also involved.

Schizophrenia is not a simple inherited disease with a Mendelian type of segregation within involving a single gene, but rather is what is called a complex genetic disease. A number of studies are underway to try to identify the various genes that may be associated with vulnerability for schizophrenia, but none has yet produced a definitive answer. Twin studies and epidemiological family studies have proven that not only schizophrenia but also atypical psychosis and non-psychotic spectrum disorders (see p. 5) belong to the same genotype. Recent molecular linkage and association studies have led to the discovery of several suspected gene locations that are each associated with a small proportion of risk; however, a major gene locus has not emerged.

Candidate regions, which are likely to cover at least one susceptibility gene, have been detected by linkage analysis on chromosome 5, 6, 8, and 22. Each of these regions is affirmed in at least two independent family samples (Straub et al. 1997; Schwab et al. 1997). However, in none of the cases has the actual mutation yet been detected. In family studies, the most promising locus has been found on bands 22-24 on the short arm of chromosome 6, which was presumed to be responsible for 15%-30% of 577 cases of schizophrenia, including spectrum disorders. Each candidate region is suspected to host one or multiple contributing genes; each of these genes may host one or multiple mutations with dysfunctional gene products which modulate the risk for the disease. A dysfunctional mutation may have a large effect in a few families loaded with schizophrenia or a small effect in many loaded families (Kendler et al. 1996). The high frequency and variability of the phenotype in relatives of people with schizophrenia suggest that there must be a widespread genetic liability to schizophrenia in the population at large, with additional environmental conditions presumably needed to produce a psychosis (Häfner 1998).



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The Neurodevelopmental Hypothesis

Recently the view has emerged that schizophrenia is a neurodevelopmental disorder (Weinberger 1995a) "in which the primary cerebral insult or pathological process occurs during brain development long before the illness is clinically manifest" (Weinberger 1995b). According to this view, people with schizophrenia might have suffered from some form of cerebral maldevelopment during the gestational phase, in particular during the second trimester of gestation. For a variety of neurobiological reasons, the disorder would manifest itself only during early adult life, when some selected neuronal systems, maturing long after birth, become unable to cope with several types of psychosocial stress and life vicissitudes.

Although this view is still circumstantial (Cannon 1997), several types of evidence tend to support it. In particular, it has been shown that complications of pregnancy and delivery increase the risk for developing schizophrenia two to three times, probably because of damage to the developing brain (McNeil 1988; Geddes and Lawrie 1995; Goodman 1988; Kendell et al. 1996). Perinatal hypoxia (deprivation of oxygen to the fetus), which occurs in some 20%-30% of people suffering from schizophrenia as compared to a base rate of 5%-10% in the general population, appears to be an important factor (McNeil, 1988; Cannon 1998). The risk of schizophrenia increases with the number of perinatal complications (McNeil 1988; Kendell et al. 1996; Eagles et al. 1990; O'Callaghan et al. 1992; Günther-Genta et al. 1994).

The risk of intrauterine brain damage is increased if a pregnant woman contracts a viral illness. It has been observed that more people with schizophrenia are born in the late winter or spring than at other times of year (Torrey et al. 1988) and that the proportion of people with schizophrenia born at this time increases after epidemics of viral illnesses such as influenza, measles, and chickenpox (Mednick et al. 1987; O'Callaghan et al. 1991; Barr et al. 1990; Sham et al. 1992). However, maternal viral infections probably account for only a small fraction of the increased risk for schizophrenia (Adams et al. 1993; Wilcox and Nasrallah 1987).



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Are There Physical Abnormalities in the Brain Associated with Schizophrenia?

Structural Abnormalities

Physical changes in the brain have been identified in some patients with schizophrenia. Such changes in the structure and function of the brain have been identified by the analysis of brain tissue after death, as well as by new brain imaging techniques that can be used to examine the brain while the person is alive. Computerized Tomography (CT-Scan) and Magnetic Resonance Imaging (MRI) provide images of the structure of the brain. Functional MRI and techniques that use isotopes, such as Single Photon Emission Tomography (SPECT) and Positron Emission Tomography (PET), are able to demonstrate cerebral regional blood flow (rCBF) changes and modifications of the chemistry of the brain.

Early CT-Scan studies showed abnormalities in many patients with schizophrenia. These were mainly asymmetries of the brain and ventricular system, especially affecting the frontal lobes and the left hemisphere. This asymmetry is unrelated to the evolution or duration of illness or treatment and does not progress during the illness (Vita et al. 1997). It is therefore considered to reflect events that took place early during cerebral development. MRI studies have found similar results (Andreasen et al. 1986). The correlation with family history of the disease, season of birth, intrauterine viral exposure, obstetric complications (DeQuardo et al. 1996), and age of onset (Lim et al. 1996) remains unclear. Studies of sex differences (Cowell et al. 1996) have produced conflicting results. The abnormalities in the size of the brain and ventricular system, when present, are found during first episodes of the disease (Vita et al. 1997), reinforcing the interpretation that these abnormalities represent a long-standing vulnerability and are not a consequence of the evolution of the disease itself or of drug treatment.

The correlation of structural abnormalities with symptoms or symptom clusters is less well supported, although the asymmetries seem to correlate with negative symptoms (Messimy et al. 1984). Negative symptoms also appear to be correlated with left temporal lobe atrophy (Turetsky et al. 1995). The greater the observed changes, the greater the severity of the person's thought disorder and auditory hallucinations (Suddath et al. 1990).

In the baseline condition, SPECT shows a decrease in rCBF, especially in the frontal lobes, in more than 80% of patients (Steinberg et al. 1995).

PET provides a similar picture of abnormalities. SPECT and PET regional cerebral blood flow (rCBF) studies have looked at the correlation of specific symptoms or symptom patterns with abnormalities in the blood flow of different regions. In general, positive symptoms are associated with hyperfunctioning of some areas and hypofunctioning of others, while negative symptoms are always correlated with hypoperfusion (Sabri et al. 1997).

Electrophysiological brain recording using EEG tracings shows that most people with schizophrenia seem to be excessively responsive to repeated environmental stimuli (such as repeated clicking noises and flashing lights) and to have a limited ability to blot out irrelevant material (Freedman et al. 1997).

Postmortem examination of the brain tissue of individuals with schizophrenia has revealed problems in a certain type of brain cell—the inhibitor interneurons. Inhibitory interneurons damp down the action of the principal nerve cells, preventing them from responding to too many inputs. Thus, they prevent the brain from being overwhelmed by too much sensory information from the environment. These interneurons normally manufacture several neurotransmitters, including gamma-aminobutyric acid (GABA), which gives them their inhibitory function. All these neurotransmitters are diminished in the interneurons of people with schizophrenia (Benes et al. 1991; Akbarian et al. 1993).

Taken together, these findings suggest that, in schizophrenia, there is a deficit in the regulation of brain activity by interneurons, so that the brain over-responds to the many signals in the environment and lacks the ability to screen out unwanted stimuli. At the same time, there is a decrease in the size of the temporal lobes that process sensory inputs and make it possible for a person to develop new and appropriate behaviour.

While the techniques discussed in this section provide clues concerning how brain function is affected in schizophrenia, they cannot today be considered as essential for diagnosis or as part of the routine clinical evaluation of patients.

Neurochemical Abnormalities

The hypothesis that neurochemical abnormalities are involved in schizophrenia has a long history (Andreasen 1995). However, empirical evidence was provided only when the mode of action of antipsychotic drugs was shown to be related to catecholamine metabolism in the brain and more specifically to the blocking effect of these drugs on the catecholamine postsynaptic receptors (Carlsson and Lindkvist 1963). Subsequent research indicated that it was the capacity of antipsychotics to block the dopamine-2(D₂) receptors that was responsible for their clinical efficacy (Peroutka and Snyder 1980). Dopamine increases the sensitivity of brain cells to stimuli. Ordinarily, this heightened awareness is useful in increasing a person's awareness in times of stress or danger. However, for a person with schizophrenia, the addition of dopamine's effect to an already hyperactive brain state may tip that person into a psychosis.

Additional support for the role of dopaminergic hyperactivation in schizophrenia came from the observation that amphetamine, a drug that increases dopamine's effects, worsens and may even elicit schizophrenia-like symptoms (Meltzer and Stahl 1976). This increased dopaminergic activity in the central nervous system occurs through two mechanisms: 1) increased availability of dopamine in synaptic sites and 2) receptor hypersensitivity.

Both these mechanisms have been extensively investigated in schizophrenia, but conclusive evidence in favour of either of the two is thus far lacking. Studies of dopamine turn-over in patients' body fluids as well as direct determination of dopamine levels in postmortem brain tissue have yielded conflicting results (Heritch 1990; Hirsch and Weinberger 1995; Bloom and Kupfer 1995).

Neuroimaging techniques, such as PET, have recently been applied to determine dopamine receptor density in the brain. While the blocking effect of classical antipsychotics on dopamine receptors has been clearly demonstrated, findings concerning dopamine-receptor density in drug-free patients compared to controls vary considerably among researchers (Wong et al. 1986; Farde et al. 1990). Using techniques of molecular biology, an increased dopamine receptor density and sensitivity in post-mortem brain tissue of drug-free patients with schizophrenia have been demonstrated (Seeman 1987, 1995; Stefanis et al. 1998). When the atypical antipsychotics (clozapine, followed by risperidone, olanzapine, and others) were introduced, researchers began to question the assumption that the D₂ blocking effect of antipsychotics was the major factor accounting for their antipsychotic action. It has been demonstrated that the mode of action of the "atypical" antipsychotics involves a close affinity for several receptors besides the D₂ dopamine receptors, including serotonin (5-HT) receptors. (Meltzer et al 1996). Current research findings therefore suggest that many other receptor sites, such as D₁, D₃, D₄, 5-HT₂, and NMDA, are also likely to be involved in the pathogenesis of schizophrenia (Hirsch and Weinberger 1995; Seeman 1995; Kerwin et al. 1997).



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Schizophrenia is a serious public health problem.

The presence of schizophrenia is often hidden because of feelings of shame and stigma. Therefore, many people suffering from schizophrenia remain undetected and untreated, particularly early in the course of the illness.

Epidemiology of Schizophrenia

Public Health Issues

Schizophrenia is a serious public health problem. It occurs throughout the world. People suffering from schizophrenia experience significant disability, which causes them distress, reduces their productivity, and lowers their quality of life. Schizophrenia also places an emotional, and sometimes financial, burden on the families of those with the illness. The costs to society, both in terms of direct medical costs and the indirect costs associated with lost productivity, are also significant. These problems are all compounded by the stigma and discrimination associated with the illness, which often hinder the provision of effective treatment and the reintegration of people with schizophrenia into the community.

Incidence and Prevalence

The presence of schizophrenia is often hidden because of feelings of shame and stigma. Therefore, many people suffering from schizophrenia remain undetected and untreated, particularly early in the course of the illness.

Incidence refers to the number of persons who become ill with a specific disease during a specified period of time (e.g., the number of individuals who are newly diagnosed with schizophrenia in a year in developing countries). A World Health Organization (WHO) study found very little variation in the incidence of the illness in countries around the world, with incidence rates for schizophrenia very similar in both developed and developing countries. When a precise definition of schizophrenia was used, the incidence of schizophrenia was found to be between 7 and 14 per 100,000 in the sites investigated. When a less rigid definition is used, incidence figures are considerably higher. When other psychotic conditions related to schizophrenia are included, incidence rates are higher still and do show significant variation across countries (Jablensky et al. 1992; Jablensky 1995).

Prevalence refers to the number of individuals with an illness that exist in a given population at a specific period of time (e.g., the number of individuals currently diagnosed with schizophrenia in the population of the United States). Unlike incidence rates, the prevalence rates of schizophrenia vary substantially around the world, with prevalence figures for populations in developing countries consistently lower than those in developed countries. Age corrected 1-year prevalence rates of schizophrenia in developing countries average 3.4 per 1,000 (range 0.9-8.0, SD 2.09) compared with a mean prevalence rate of 6.3 per 1,000 (range 1.3-17.4, SD 4.32) in Europe and North America (Table 4 in Warner and de Girolamo 1995). This difference is likely the result of difficulties in identifying those with the illness, higher death rates (Mortensen and Juel 1990), and higher recovery rates in developing countries. Even in countries with lower prevalence rates, schizophrenia is often a major public health problem because of its severity, chronicity, and the impairment it causes.



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Disability and Suffering Caused by Schizophrenia

The discrimination because of schizophrenia increases the suffering of the person with the illness. Those close to the person also suffer because they are marked by the stigma of the disease.

Schizophrenia causes distress and suffering for those with the illness and for their families. Discrimination and stigma, which affect not only the person with the illness but also those close to him or her, significantly increase the suffering associated with the illness.

The symptoms of schizophrenia and the stigma associated with them make it difficult for people with schizophrenia to pursue their goals and be part of the community. According to the World Health Organization, schizophrenia ranks among the ten diseases that cause the most disability among those who are 15-44 years old (See Table 2) (Murray and Lopez 1996).

Table 2

Ten Leading Causes of Disability Adjusted Life Years (DALYs) at Ages 15-44 Years in the World, 1990

Rank	Disease or Injury
1	Unipolar major depression
2	Tuberculosis
3	Road traffic accidents
4	Alcohol use
5	Self-inflicted injuries
6	Bipolar disorder
7	War
8	Violence
9	Schizophrenia
10	Iron-deficiency anemia

Source: Murray CJL, Lopez AD. *The Global Burden of Disease*. Geneva: World Health Organization; 1996: 270.

The discrimination because of schizophrenia increases the suffering of the person with the illness. Those close to the person also suffer because they are marked by the stigma of the disease.

Schizophrenia is also costly to society, both in terms of increased medical costs and lost productivity. It has been estimated that, in 1991, schizophrenia cost the United States \$19 billion in direct expenditures and \$46 billion in lost productivity, for a total of almost \$65 billion. This illustrates the financial burden of this illness, which devastates the lives of millions of individuals and their families (Wyatt et al. 1995).

The suicide rate in schizophrenia is also high. The 5-year cumulative standard mortality rate among individuals with schizophrenia in Denmark increased from 5.3 (males) and 2.3 (females) in 1971-73 to 7.8 (males) and 5.2 (females) in 1980-82, an increase that in part parallels the increase in suicide rates in the general population in the same age groups in Denmark. The standard mortality rate for males in the first year following the diagnosis of schizophrenia was as high as 16.4 for men in this particular study (Munk-Jørgensen and Mortensen 1992).

Recent studies estimating the total burden of schizophrenia have found that the disease causes distress, loss of productivity, a lower quality of life, and secondary mental and medical problems for patients and their families (Thorncroft and Tansella 1996).



- [1] Munk-Jørgensen P, Mortensen PB. Incidence and other aspects of the epidemiology of schizophrenia in Denmark. *Br J Psychiatry* 1992;161:489-495.
- [2] Murray CJL, Lopez AD. *The Global Burden of Disease*. Geneva: World Health Organization; 1996: 270.
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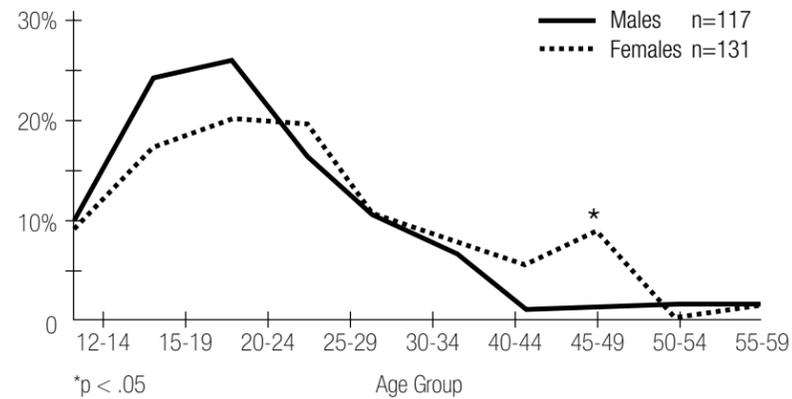
Onset

Schizophrenia typically begins in late adolescence or early adulthood. In some cases the onset of illness is very gradual, over the course of months or years; in other cases, it can begin very suddenly, within hours or days.

Figure 2 shows the age distribution of onsets of schizophrenia (Häfner et al. 1993; 1998b). Schizophrenia may have its onset before the age of 18, which is referred to as early-onset schizophrenia and, in rare cases, may begin before age 13, which is termed very-early-onset schizophrenia. Recent research, however, indicates that all, or almost all, children with very-early-onset-schizophrenia have already entered puberty. Early-onset schizophrenia appears to be much more common in males and to be associated with greater premorbid abnormalities, a more insidious onset, and a poorer response to antipsychotic medication (Robertson 1996). Women with schizophrenia tend to develop their first symptoms later than men and the course of their illness tends to be less severe.

Figure 2

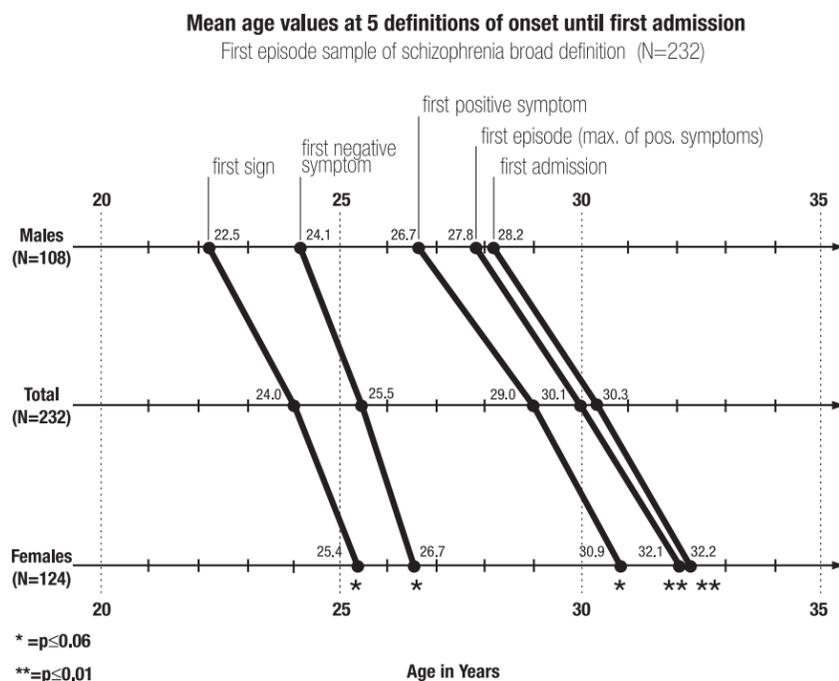
Age distribution of onsets of schizophrenia (first ever sign of mental disorder) for males and females (ICD-9 diagnoses: 295, 297, 296.3, 298.4)



Source: Reprinted by permission. From Häfner et al. *Is schizophrenia a disorder of all ages? A comparison of first episodes and early course over the life cycle. Psychol Med* 1998; 28 (351-365)

Figure 3 shows mean age values of the onset of schizophrenia in men and women, using different definitions of onset. These data are taken from a population-based first-episode sample of schizophrenia in Germany (Häfner 1996). The sequence of milestones within the early course (i.e., first sign of the illness, first negative and positive symptom, and climax of the first episode) is parallel for both sexes; however, in comparison to men, there is a significant delay in onset of 3-4 years in women. There is also a considerable delay before treatment begins for both men and women.

Figure 3



Source: Reprinted by permission. From Häfner H. *The epidemiology of onset and early course of schizophrenia*, in Häfner H. and Wolpert EM, eds. *New Research in Psychiatry*. Göttingen: Hogrefe and Huber, 1996: 33-61.

Late onset schizophrenia (beginning after age 40) is generally milder and less frequent than early onset schizophrenia. However, late onset schizophrenia is less mild and about twice as frequent in women as in men (Jeste et al. 1995; Häfner and an der Heiden 1997). This is presumably due to the menopausal decrease in oestrogen secretion since the female sex hormone appears to have a mild protective effect against schizophrenia (Häfner et al. 1998a).

In old age, the onset of schizophrenia-like delusional disorders, diagnosed as delusional or paranoid psychosis or late paraphrenia, becomes increasingly frequent (Riecher-Rössler et al. 1997; van Os et al. 1995). Generally, the symptomatology is milder but cannot be clearly separated from that of schizophrenia occurring at an earlier age; however, negative symptoms, schizophrenic thought disorders, and bizarre behaviour occur less frequently in delusional disorders at older ages (Häfner et al. 1998b). Risk factors for such late onset disorders are cognitive and sensory, particularly auditory, deficits (Riecher-Rössler et al. 1997). Severe dementia rules out the diagnosis of a schizophrenic-type disorder. The treatment for late onset psychosis is the same as for schizophrenic disorders in younger patients, taking into account differences in metabolism in the elderly (Eastham and Jeste 1997).

Course and Outcome

The Course of the Illness is Different in Different People

Wide variation occurs in the course of schizophrenia. Some people have episodes of illness lasting weeks or months with full remission of symptoms between each episode; others have a fluctuating course in which symptoms are continuous; others have very little variation in the symptoms of their illness over the course of years. At one end of the spectrum is a pattern in which the person has a single episode of schizophrenia followed by complete recovery; at the other end of the spectrum is a course in which the illness continues unabated. Negative symptoms appear to have a more stable course than positive symptoms and the presence of predominant negative symptoms appears to predict a more severe course of illness. The final outcome from the illness (even after several years duration) can be complete recovery, a mild level of disturbance, or severe disability (Bleuler 1978; Fenton 1997).

Figure 4 presents data from a methodologically sound study that examined the course of illness during the 5 years after the first admission and shows the four most common patterns of the course of schizophrenia (Shepherd et al. 1989). Recent longitudinal studies from developed countries show only slight variations in the overall course and outcome of schizophrenia (McGlashan 1988; Ram et al. 1992). Studies from developing countries report a tendency toward the more favourable types of course, particularly group 1 in **Figure 4** (See the discussion of acute and transient psychoses, p. 5). In assessing the course and outcome of schizophrenia, one must take into account both the different domains of the disease and factors related to the patients' lives (i.e., positive and negative symptomatology, functional

People can recover from schizophrenia. The misconception that people cannot recover from schizophrenia leads to hopelessness and despair, neglect, abandonment, and burn-out of family members.

The objective and subjective living conditions of people suffering from schizophrenia depend not only on the severity of their illness, but also on the degree of acceptance within the family, at work, and in society at large, which is often reduced because of the stigma associated with schizophrenia.

Over the course of time, the severity of symptoms, particularly positive symptoms, diminishes and the illness becomes less severe.

Although schizophrenia may follow a chronic and debilitating course, deterioration is not inevitable.

Schizophrenia is associated with an increased risk of suicide, particularly early in the course of the illness.

impairment and disability, work and living conditions, and subjective life satisfaction). Even after only a short duration of the disease, the objective and subjective living conditions of people suffering from schizophrenia depend not only on the severity of their illness, but also on the degree of acceptance within the family, at work, and in society at large, which is often reduced because of the stigma associated with schizophrenia. In many cases, quality of life is also impaired by a significantly increased vulnerability to depression.

Retrospective long-term clinical studies in the 1970s and early 1980s (e.g., Bleuler 1978; Ciompi 1980) had already showed some degree of social improvement after a course of 10 years or longer. Since that time, several prospective long-term longitudinal studies, which used the same instruments at the beginning and end of the relevant period, have been published. The results of the transnational WHO schizophrenia studies, which covered periods of 25 years (the IPSS) and 13-15 years (the Disability Study), are now available. They demonstrate that, wherever it has been studied, schizophrenia is not a progressively deteriorating disorder (Sartorius et al. 1996; Mason et al. 1995; Wiersma et al. 1996; an der Heiden et al. 1996), an incorrect hypothesis postulated by Kraepelin in 1896 which was held for many years afterwards. The wide variability of individual courses ranges from complete remission of all symptoms after a short psychotic episode with a full return to the previous level of functioning to frequently recurring psychotic episodes and/or a chronic course of negative symptomatology with considerable impairment and a need for long-term treatment and support. Despite recurring episodes and contrary to what one might expect, the indicators of the severity of the disease—frequency of relapse, need for treatment, degree of functional impairment, et al.—generally remain relatively stable over the whole course after remission of the first episode (an der Heiden et al. 1996).

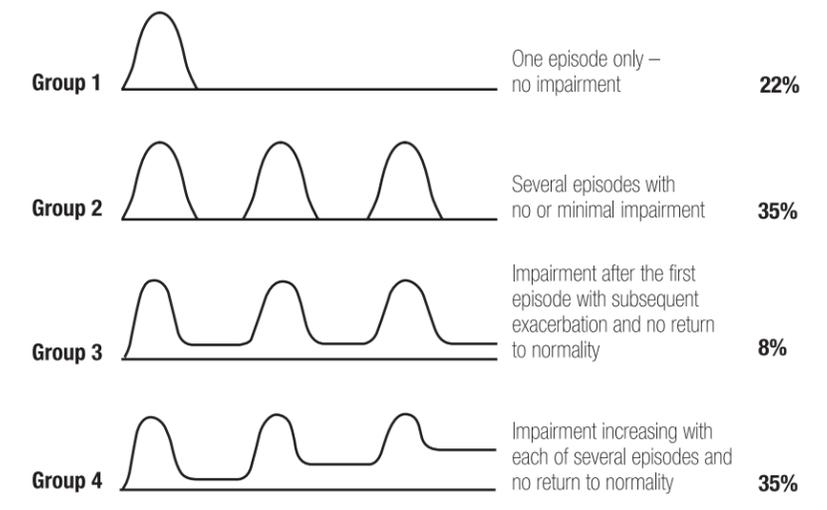
In early onset schizophrenia, the disease is generally more severe, particularly in men. Episodes are more acute and cause more serious social consequences, mainly because social development is more seriously impeded (Asarnow et al. 1995). With increasing age, the disease generally gets milder, particularly in men, and the course is less severe (Häfner et al. 1998b).

After a prolonged course, psychotic symptomatology frequently becomes more stable (WHO 1979). Even those patients who still suffer from recurring symptoms are often able to live satisfying and productive lives within society and to perform well in their jobs. Several studies investigating a course of up to 40 years found that one-third to two-thirds of patients had a good or at least moderate degree of social life. A large proportion of patients were able to live a satisfying and almost completely independent life within society (Harding et al. 1987; Harrison et al. 1996; an der Heiden 1996; an der Heiden et al. 1996; Mason et al. 1995; Wiersma et al. 1996; Ciompi 1980).

There is considerable variation among individuals and cultures in course and outcome.

Figure 4

Graded course of illness in first-admission schizophrenics as indicated by episodes of illness, symptomatology, and social impairment at assessments during 5 years (n=49)



Source: Reprinted with permission from Shepherd et al. *The natural history of schizophrenia: a five-year follow-up study of outcome and prediction in a representative sample of schizophrenics. Psychol Med Monograph Supplement 15. Cambridge: Cambridge University Press; 1989.*

Predictors of Outcome

Studies have examined factors associated with better or worse prognosis in schizophrenia, as well as predictors of short- and long-term outcome, including both the global (overall) outcome of the disorder as well as outcomes in single domains (e.g., symptomatic, clinical, social, and employment outcomes). Factors associated with a better short-term global outcome in schizophrenia are listed in Table 3, while factors associated with a poorer clinical prognosis are summarised in Table 4.

Table 3

Factors Associated with Better Short-term Outcome in Schizophrenia

- Short duration of initial episode of the disorder
- Fewer episodes of similar illness in the past
- Good premorbid adjustment in the areas of social relationships and employment
- Predominance of florid positive symptoms and absence of negative symptoms
- Being married
- Being female
- Short interval between onset of psychosis and initiation of treatment
- Acute onset
- Rural background and cohesive family ties
- Absence of criticism, hostility, or over-involvement in the home and family atmosphere
- Good adherence to drug treatment

Table 4

Factors Associated with Poorer Short-term Prognosis and Outcome in Schizophrenia

- Younger age at onset
- Chronic and insidious onset
- Unmarried
- Being male
- Poor premorbid adjustment
- Poor premorbid school or work history
- Family history of schizophrenia
- Long duration of illness
- Longer duration of untreated psychosis
- Substance abuse and other comorbid mental illnesses
- Abnormalities on brain imaging and presence of soft neurological signs at the beginning of the illness, particularly in first episode patients
- Excessive criticism, hostility or over-involvement in the home and family atmosphere

Many psychosocial and clinical factors can influence outcome.

Studies have shown that schizophrenia has a worse outcome in developed countries. This difference may in part be due to varying perceptions of the disease, its symptoms, and its origins. For example, the belief in some African countries that schizophrenia is caused by the unfriendly acts of other people or the anger of offended spirits may make people with schizophrenia more acceptable to their families and social group and increase others' willingness to help and work with them.

Research has found that relatives of patients with schizophrenia in India are less hostile and critical than relatives of patients in Denmark and the United Kingdom (Wig et al. 1987; Leff et al. 1987).

Despite the lack of inpatient care facilities, outcomes are better among patients in developing countries because of social variables.

Differences in Course and Outcome Between Developed and Developing Countries

Studies by the World Health Organization and other researchers have consistently shown that patients in developing countries have more favourable outcome and course and higher recovery rates (WHO 1979; ICMR 1988; Kulhara 1994). The first indication that the course of the disorder is different in non-white, non-European populations was provided by a study by Murphy and Raman (1971) in Mauritius. They found that the course of the disorder in indigenous blacks and people of Indian origin was more benign and outcomes were more favourable than in white Europeans. Kulhara and Wig (1978) published similar findings from India.

Two World Health Organization (WHO) studies have demonstrated that good outcome occurs in about twice as many patients diagnosed with schizophrenia in the developing world as in the developed world (WHO 1979; Jablensky et al. 1992). In the International Pilot Study of Schizophrenia (IPSS), a transcultural investigation of 1202 patients in nine countries (WHO 1973), investigators found that at 2-year follow-up, patients with an initial diagnosis of schizophrenia had a considerably better course and outcome in centres in developing countries than in developed countries (WHO 1979). At 5-year follow-up, clinical and social outcomes were also found to be better for patients in developing than in developed countries (Leff et al. 1990). The data on social impairment from this study are shown in **Table 5**.

In the second study (Jablensky et al. 1992), 1379 patients from ten countries were followed for 2 years. Again, better outcomes were found in developing than developed countries. The percentage of patients in developing and developed countries falling into selected categories of course and outcome variables are shown in **Table 6**. In this study, 62.7% of patients in developing countries showed a remitting course over the 2 years of follow-up versus 36.8% in developed countries; 38.3% of patients in developing countries were symptom-free (in complete remission) for more than three-quarters of the follow-up period compared to 22.3% in developed countries. More recent studies from India have confirmed these findings (Verghese et al. 1989; Thara et al. 1994).

Table 5

Social impairment of schizophrenic patients at 5-year follow-up

Centre	Severe impairment %	Moderate, mild or no impairment %
Aarhus (Denmark)	50%	50%
Agra (India)	13%	87%
Cali (Columbia)	17%	83%
Ibadan (Nigeria)	19%	81%
London (England)	27%	73%
Moscow (USSR)	23%	77%
Prague (Czech Republic)	30%	70%
Washington (US)	25%	75%
All centres	24%	76%

(n = 28.12, p < 0.001)

Source: Reprinted with permission from Leff et al. The international Pilot Study of Schizophrenia: Five-year follow-up findings, in Häfner H, Gattaz WF, eds. Search for the Causes of Schizophrenia, Vol. 2. Berlin: Springer-Verlag; 1990.

Table 6

Percentage of Patients in Developing Countries and in Developed Countries Falling into Selected Categories of Course and Outcome Variables

Course and outcome category	Developing countries	Developed countries
1. Remitting course with full remission	62.7%	36.8%
Continuous or episodic psychotic illness, without full remission	35.7%	60.9%
2. In psychotic episodes 25% of FU* period	18.4%	18.7%
In psychotic episodes 76-100% of FU period	15.1%	20.2%
3. In complete remission 0% of FU period	24.1%	57.2%
In complete remission 76-100% of FU period	38.3%	22.3%
4. No antipsychotic medication throughout FU	5.9%	2.5%
On antipsychotic medication 76-100% of FU period	15.9%	60.8%
5. Never hospitalized	55.5%	8.1%
Hospitalized for 76-100% of FU period	0.3%	2.3%
6. Impaired social functioning throughout FU period	15.7%	41.6%
Unimpaired social functioning for 76-100% of FU period	42.9%	31.6%

*FU=follow-up

Source: Reprinted with permission. From Jablensky et al. Schizophrenia: Manifestations, incidence and course in different cultures: A World Health Organization ten-country study. Psychol Med 1992;22 (suppl 20):1-97.

The reason for the better outcome in the developing world is not completely understood, but it may be due to the fact that many people with mental illness in villages in the developing world are better accepted, less stigmatised, and more likely to find work in the subsistence agricultural economy (Warner 1994; Kulhara 1994).

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IB. How Is Schizophrenia Treated?

Effective treatments are available for schizophrenia.

Treatment improves long-term outcome. Many people recover from schizophrenia if they receive effective and adequate treatment early in the course of the disorder.

There are three main components of treatment for schizophrenia:

- *Medications*
- *Education and psychosocial interventions*
- *Social rehabilitation*

The development of an array of medications and psychosocial interventions has greatly improved the outlook for patients with schizophrenia. Newer antipsychotics can help control the symptoms of the disorder while causing fewer stigmatising side effects. Education and other psychosocial interventions can help patients and families learn to manage the disorder more effectively, reduce social and occupational dysfunction, and enhance the social reintegration of those with schizophrenia. Research to find safer and more effective treatments is underway. In addition, continuing studies on the better prognosis for schizophrenia in developing as opposed to developed countries may suggest strategies that can be applied globally to improve the outcome for patients with schizophrenia everywhere.

There are three main components of treatment for schizophrenia:

- Medications to relieve symptoms and prevent relapse
- Education and psychosocial interventions to help patients and families solve problems, deal with stress, cope with the illness and its complications, and help prevent relapses
- Social rehabilitation to help patients reintegrate into the community and regain educational or occupational functioning

Clinicians should be aware of the principles outlined in the World Psychiatric Association's Declaration of Madrid, issued in 1996, which stressed the importance of keeping abreast of scientific developments, conveying updated knowledge to others, and accepting the patient as a partner by right in the therapeutic process. It is also important that the various treatment approaches be provided in an integrated manner, for example, using the principles of case management teams (Kanter 1989; American Psychiatric Association 1997). This ensures that all efforts are focused on the same goals and that the patient and family will understand the common therapeutic thread in the treatment plans. Finally, clinicians should encourage patients and families to become involved with patient/family support groups, which can provide valuable help and guidance in coping more effectively with the illness.

Medications

The medications that are currently used to treat schizophrenia generally fall into two groups:

- Standard antipsychotics (previously referred to as neuroleptics)
- Novel antipsychotics (also referred to as second generation or “atypical” antipsychotics)

The first standard antipsychotic medicines were introduced into clinical practice in the early to mid-1950s. The term “standard” (or “traditional” or “conventional”) antipsychotic is used to refer to all the antipsychotic drugs developed before the introduction of clozapine. These antipsychotics were formerly called neuroleptics because of their characteristic side effects on the extrapyramidal motor system, including dystonia, parkinsonism, dyskinesia, and akathisia (see **Table 7A**). These agents have proved useful in reducing, and sometimes eliminating, positive symptoms of schizophrenia such as thought disorder, hallucinations, and delusions. They can also decrease associated symptoms such as agitation, impulsiveness, and aggressiveness. Unfortunately, they do not appear to be as effective in reducing the negative symptoms of schizophrenia such as apathy, social withdrawal, and poverty of ideas. If these medicines are taken consistently, they can also reduce the risk of relapses. The introduction of effective antipsychotic medicines made it much more possible to treat patients with schizophrenia in the community, while avoiding readmission to the hospital. Antipsychotic medication can also help people with schizophrenia benefit from psychosocial forms of treatment.

Whereas the focus in the earlier years of drug development was mainly on reducing positive symptoms such as hallucinations and delusions, in recent years researchers have been working to develop antipsychotic drugs with improved efficacy and fewer side effects, that would be more effective against negative as well as positive symptoms and help improve quality of life, factors that are crucial in modern treatment and rehabilitation efforts. Clozapine was the first antipsychotic drug developed that caused very few extrapyramidal side effects (EPS). Clozapine has been followed by a number of other new drugs (see Appendix D) that share this advantage. The terms “novel,” “second generation,” or “atypical” antipsychotic are used to refer to this group of medications, novel being the preferred term because atypicality is difficult to delineate. A considerably lower risk of inducing EPS is the landmark characteristic of the novel antipsychotics. They also appear to have advantages over the traditional antipsychotics in improving negative symptoms and inducing lower or no relevant increase in prolactin levels.

The most common standard antipsychotic medications currently in use are listed in Appendix C.

Standard Antipsychotic Medications

The most common standard antipsychotic medications currently in use are listed in Appendix C. It is believed that they exert their antipsychotic effect by blocking receptors of the neurotransmitter dopamine in the limbic system of the brain. Some of these medications are available in “depot formulations” that can be given in long-acting injections at 1- to 4-week intervals. Such injections can be especially helpful for patients who find it hard to take pills every day (Davis et al. 1994).

The standard antipsychotic medications do not differ appreciably in their effectiveness, although there are differences in the most common side effects associated with different agents (Wirshing et al. 1995). Therefore, in selecting a standard antipsychotic, the clinician will usually consider its side effect profile, the patient’s treatment history (if he or she has responded well or poorly to a certain drug or has had problems with specific side effects in the past), and the availability of a depot formulation of the drug if it appears that adherence to the medication regimen may be a problem.

Side Effects of Standard Antipsychotic Drugs

For treatment to be effective, patients need to take their medication as prescribed. Patients are much more likely to stick with medications if they help quickly and have few visible side effects that may cause other people to react negatively. In selecting a treatment, it is important for clinicians to remember that certain treatments (e.g., electroconvulsive therapy) carry their own stigma. It is important to consider the effect of the treatment on others. If the treatment immediately reduces socially unacceptable symptoms, the family is far more likely to support it and be willing to have the person stay at home.

Side effects of medication prescribed for the treatment of schizophrenic disorders are often very unpleasant for the patient and are likely to decrease compliance with the doctor’s recommendations. Worse still, side effects are often the main and visible signs of the illness in the patient. While positive as well as negative symptoms may be significantly decreased or may even have disappeared, some of the extrapyramidal side effects mark the patient and cause those around him to perceive the person as mentally ill or brain damaged, which seriously impedes the chances that the patient will find a place in the community. Earlier treatment efforts focussed on the total removal of symptoms, even if this had to be achieved at the cost of the appearance of serious side effects. Modern treatment strategies, however, are directed toward prescribing treatment that minimises symptoms while avoiding side effects, while adding other therapeutic, non-pharmacological interventions to further reduce symptoms.

Common side effects of medications used to treat schizophrenia are summarised in **Table 7A** and **Table 7B**, along with the types of problems they can cause for individuals with schizophrenia.

The side effects of antipsychotic medication may be responsible for more stigma than the disorder itself. Treatment that improves acute symptoms quickly while minimising side effects helps other people believe the disorder is milder, thus reducing stigma.

Antipsychotic medications are not addictive.

If the side effects of standard antipsychotics or negative symptoms are stigmatising an individual with schizophrenia and making it difficult for the person to be accepted and function in society, the clinician should consider switching to one of the novel antipsychotics which have less risk of causing EPS and have been found to be more effective for the treatment of the negative symptoms of schizophrenia.

Some of the most common side effects caused by standard antipsychotic agents are extrapyramidal symptoms (EPS), which are especially a problem in the early days of treatment (Casey 1996). EPS, which include dystonia, dyskinesia, akathisia, and parkinsonism, may cause stiffness, shakiness, restlessness, or acute muscle spasms. These symptoms can often be controlled by taking anticholinergic medications (e.g., biperiden or benztropine), an antihistamine (e.g., diphenhydramine), or a beta-blocker (Remington and Bezchlibnyk-Butler 1996; Fleischhacker et al. 1990). However, these agents need to be used carefully since they can cause their own side effects, have a potential for abuse, and may lead to a worsening of psychotic symptoms (Fleischhacker et al. 1987; Fayen et al. 1988; Smith 1980; Tandon et al. 1990).

Other adverse reactions that can occur with antipsychotic drugs are blurred vision, over-sedation, blunting of spontaneity, sexual impotence and failure of ejaculation, interruption of the normal menstrual cycle, and, rarely, epileptic seizures. There are no specific treatments for these side effects. Clinicians usually try decreasing the dose and/or switching to another antipsychotic drug.

A late side effect, called tardive dyskinesia (TD), may emerge after taking standard antipsychotic medication for several years, or more rarely, after several months. Tardive dyskinesia involves involuntary movements of the tongue, mouth, or other muscles that usually occur in short episodes. The cumulative incidence of tardive dyskinesia is approximately 5% per year (Kane et al. 1988b). In certain cases, tardive dyskinesia may become chronic or irreversible (see Long-term Management of Side Effects p. 45).

Neuroleptic malignant syndrome (NMS) is a rare life-threatening side effect that includes akinesia, fluctuating consciousness, profuse sweating, fever, rigidity, and an increase in liver enzymes. When NMS occurs, the drug needs to be discontinued immediately and intensive care management may be necessary.

In selectioning medications, clinicians should consider the side effect profile of the medication and possible effects on the patient’s life.

Novel Antipsychotic Medications

Recently a number of newer medications have been developed that have an effect on a broader range of brain receptors, including serotonin receptors and several different types of dopamine receptors. These newer agents, which are often referred to as second generation, novel, or “atypical” antipsychotics, may be effective when the standard antipsychotic medications are not.

The first novel antipsychotic drug to be introduced was clozapine. The introduction of clozapine challenged the previously held view that all antipsychotics have similar efficacy. Clozapine is the only antipsychotic that has so far been consistently found to be superior to other antipsychotics in comparative trials. Clozapine has also been shown to be superior to standard antipsychotics for patients who have failed to respond to

The novel antipsychotics that are currently available or are expected to be available in the near future are listed in Appendix D.

Studies to establish appropriate dose ranges of the novel antipsychotics should be performed in a variety of different patient populations.

the standard drugs. In addition, clozapine has consistently been shown to improve psychopathology and other psychosocial outcomes in patients with schizophrenia and to have a better effect on negative symptoms than standard antipsychotics (Kane et al. 1988a; Hagger et al. 1993; Meltzer et al. 1990). Unlike the standard antipsychotics, clozapine does not induce clinically significant EPS in most patients (Casey 1996; Kurz et al. 1995). Clozapine also has a much weaker dopamine antagonistic effect than the standard antipsychotics.

Unfortunately, clozapine has several other serious side effects. Most significantly, this drug has a risk of causing a fatal blood disorder called agranulocytosis, in which the patient's white blood cells are suddenly destroyed. Agranulocytosis occurs in about 1% of patients treated with the drug (Alvir et al. 1995) and occurs most often in the first 3 months of treatment. Since agranulocytosis is reversible if clozapine is stopped, in most countries, patients must have regular tests of their white blood cell count. For this reason, the indication for clozapine in most countries is restricted to those patients who are either resistant to treatment with other antipsychotics or are unable to tolerate other antipsychotics because of side effects. Dose recommendations for clozapine vary among different countries.

Since the introduction of clozapine, researchers have been trying to develop other new antipsychotics that would have an effectiveness similar to clozapine's but without the risk of agranulocytosis. A number of new antipsychotic medicines that do not have the risk of destroying white blood cells have recently been introduced or are expected to be available in the near future (see Appendix D for a list of these medications).

Drugs that are already available in many countries include olanzapine, quetiapine, risperidone, sertindole, and zotepine. All these drugs have been reported to be comparable or even superior to standard antipsychotics for the treatment of the positive symptoms of schizophrenia. They have also been found to improve negative symptoms to a greater extent than the standard drugs.

Since these medications have either only recently been released or are still being tested in clinical trials, it is not yet clear how useful they will be, but it seems likely that they will offer a safer alternative to clozapine for the person with schizophrenia who does not respond to the standard medicines.

Side Effects of the Novel Antipsychotics

As mentioned above, clozapine causes agranulocytosis, a potentially fatal blood disorder, in about 1% of all patients treated with the drug, making regular blood testing a necessity as long as the person continues to take clozapine. Other important side effects of clozapine include weight gain, sedation, drooling, constipation, and epileptic seizures (Physician's Desk Reference 1998).

Side effects of the other novel antipsychotics include weight gain, constipation, and sedation. Some novel antipsychotics have also been found to cause EPS if given at higher doses. Refer to **Tables 7A and 7B** for more details concerning these side effects.

Table 7A

Common Side Effects of Antipsychotic Medications

Side Effect	Standard Description
Akathisia	Inner unrest and an urge to move (inability to remain seated, pacing, shifting from foot to foot, marching in one spot, hands in and out of pockets)
Akinesia	Slowed down; lack of normal spontaneity; lack of energy
Anticholinergic	Dry mouth effects Constipation Blurry vision Trouble urinating Memory difficulties Confusion
Dyskinesia	Writhing movements of the mouth, tongue, or sometimes hands. Can become chronic or irreversible (tardive dyskinesia).
Dystonia	Briefly sustained or fixed abnormal postures of eyes, tongue, face, neck, limbs, or trunk
Parkinsonism	Akinesia, bradykinesia, tremor, rigidity, flexed posture, shuffling gait, postural instability, "mask" face
Sedation	Sleepiness
Sexual and menstrual difficulties	Sexual impotence; failure of ejaculation; menstrual irregularities; loss of menses difficulties
Tremor	Regular shaking of the hands and/or other parts of the body
Weight gain	

Table 7B

Consequences of Side Effects of Antipsychotic Medications

Side Effect	Consequences
Cognitive	
Anticholinergic effects	Decreased cognitive performance: less able to study and learn new tasks. Difficulty reading. Can diminish employment prospects.
Akathisia	
Dyskinesia	
Sedation	
Social Relationships	
Akathisia	Person has difficulty participating normally in social intercourse.
Akinesia	
Sedation	
Anticholinergic effects	Dry mouth impairs speech.
Sexual and menstrual difficulties	Interferes with normal sexual life and reduces self-esteem.
Weight gain	Loss of attractiveness to others; reduces self-esteem
Appearance to Others	
Akathisia	Generates social rejection and reduces chances of integration into the community. Reduces chances for employment requiring motor skills.
Akinesia	
Dyskinesia	
Dystonia	
Parkinsonism	
Tremor	
Weight gain	

Improving Adherence to Medication

Side effects often cause patients to discontinue medications. Certain side effects may also be unacceptable to family members and others close to the patient and may cause these individuals to withdraw support for the treatment. Therefore, in order to improve the patient's willingness to stick with treatment, clinicians need to educate patients and families about what adverse effects to expect, instruct them to report side effects quickly, take necessary measures to reduce side effects that are likely to derail treatment (e.g., reducing the dose of the medication, prescribing medications such as benztropine to reduce certain side effects, considering switching to another antipsychotic medication with a more acceptable side effect profile for the particular patient).

Helping individuals with schizophrenia continue to take their medication as prescribed is very important in reducing relapses. If people with schizophrenia can avoid relapses, this helps them to continue to make progress in rehabilitation, keep their jobs and housing, and maintain social relationships, and consequently helps reduce the stigma associated with the disorder.

The terms "compliance" and "adherence" have both been used to indicate that a patient is taking medications as prescribed. In this document, the term adherence is generally used.

Adherence to treatment is also a problem in many other long-term medical disorders (e.g., hypertension, diabetes).

A good relationship (alliance) between doctor and patient increases the patient's willingness to take medication as prescribed.

Other factors that can also interfere with a person's willingness to take antipsychotic medications include the complexity of the treatment regimen (e.g., b.i.d. versus once-a-day dosing, multiple medications), the personality of the patient, his or her insight into the need for medications, the type of symptoms, the doctor-patient relationship, the therapeutic environment, and various demographic variables (Fleischhacker et al. 1994). The clinician should evaluate these factors and try to take necessary steps to reduce problems that might cause the patient to discontinue medication.

There has recently been a shift away from an emphasis on compliance alone toward a focus on treatment alliance as a means of improving adherence to treatment. Frank et al. (1995) described a method for forming a strong treatment alliance between clinician and patient. They found that this method greatly reduced rates of patient drop-out and increased rates of adherence to treatment among patients with mood disorders and suggest that their method would be similarly effective in general clinical practice. The cornerstones of the method involves providing the patient with as much education and information about the disorder, its treatment, and its side effects as possible at the particular stage of the disorder. Frank et al (1995). suggest involving the patient as a "coinvestigator" in the treatment process, so that the clinician is the expert on the disorder and its treatment in general, while the patient is the expert on his or her own disorder and experience with treatment. They also try to involve family members as "adjunct members of the treatment team" by educating them about the disorder and its treatment and keeping them informed throughout the treatment process. Finally, the method involves using objective measures to monitor adherence to treatment (e.g., serum level measures for medication treatment, "homework" between psychotherapy sessions).

Treatment Adjustments When the Current Medication Is Not Effective

Ten to twenty percent of patients show no or only limited responses to a treatment trial with a presumably adequate dosage of an antipsychotic (Hogarty and Ulrich 1997). In selecting a next step for these patients, the clinician first needs to be sure that the medication trial was long enough and that the dosage was really adequate. Suggestions for an adequate trial range from 1-2 weeks up to several months, especially for clozapine (Meltzer 1989). Some studies have found that patients who subsequently respond to a medication tend to show improvement in non-specific symptoms such as sleep disturbances and agitation as well as some improvement in positive symptoms during the first 2 weeks of treatment (Levinson et al. 1992). This suggests that patients who show no response at all during the first 2-3 weeks of treatment may need a treatment adjustment. Whether clozapine is different from other drugs in this respect needs further evaluation (Meltzer 1989).

When a patient is showing no or minimal response to treatment after an adequate (duration and dosage) trial, clinicians may try increasing the dosage, changing drugs, or combining more than one drug (e.g., using more than one antipsychotic or combining the antipsychotic with a different type of drug such as a benzodiazepine, lithium, or an anticonvulsant (see below) (Zarate and Cole 1994). Although commonly used, such combination strategies have not been investigated in large-scale, controlled clinical trials and should therefore be considered last resort treatment options for patients who have failed to respond to all other strategies. Electroconvulsive therapy is a possibility for patients with severe treatment-resistant schizophrenia (Salzman 1980); however, this treatment is associated with considerable stigma in the minds of the public.

Long-term Medication

Who Should Receive Long-term Treatment?

There is increasing evidence that the outcome of schizophrenia depends on early pharmacologic treatment and successful prevention of psychotic relapses (Crow et al. 1986; Loebel et al. 1995; Wyatt 1992). The best way to prevent relapse is to continue long-term treatment with antipsychotic drugs (Davis 1988; Kane and Lieberman 1987), which has been shown to reduce 1-year relapse rates by about two-thirds (Kissling 1991; Hogarty et al. 1974; Hogarty and Ulrich 1997). Long-term medication should also be complemented by psychosocial treatment (see p. 50). It is important to remember, however, that about 30% of patients with schizophrenia relapse in the course of a year despite taking antipsychotic medication; during these relapses, these patients seem to be unresponsive to dosage increases (Steingard et al. 1994). Another 20% of patients with schizophrenia experience only a single episode of the illness without any recurrence (Möller and Van Zerssen 1995). Unfortunately, there is currently no way to predict which patients will belong to this group and might not need continuing medication (Gaebel and Pietzcker 1983).

Studies that have been done to investigate the necessary duration of drug treatment to prevent relapse have unanimously shown a high risk of relapse when antipsychotic medication is discontinued (Crow et al. 1986; Kane and Lieberman 1987; Müller 1982; Hogarty et al. 1974; Gilbert et al. 1995). It should be noted, however, that no studies of this kind have been done in developing countries in which the outcome of schizophrenia is demonstrably better than in developed countries. It is suggested that patients whose illness meets criteria for schizophrenia receive treatment for at least 1-2 years. Patients with multiple episodes should be in remission for about 5 years before discontinuing medication is considered (Kissling et al. 1991). If a patient has had repeated episodes, long-term or even lifelong treatment may be needed. It is also very helpful to maintain supervision of patients who have had multiple episodes. Note that it is important, in making the diagnosis, to rule out acute psychosis.

In determining the most appropriate duration of treatment, clinicians should consider the type of symptoms present, the person's history of treatment response, and culture and psychosocial factors.

More research is needed to establish the most appropriate duration of treatment for acute transient psychoses, which are particularly common in developing countries.

Depot formulations of antipsychotics represent a special option in the maintenance treatment of schizophrenia, especially for patients who have difficulty taking their oral medications as prescribed (Davis et al. 1994).

Dosage

Once a person's illness is stable, the person can be maintained on the dosages that were used successfully during acute treatment and stabilisation. The clinician should try to establish the lowest dose of medication that will keep the worst aspects of the illness at bay without causing intolerable side effects. This can be done by cautiously adjusting the dosage. Since it has been reported that relapses caused by insufficient dosages may have a lag time of several months (Kane and Lieberman 1987; Johnson 1979), dosages should be kept stable for 3-6 months before additional adjustments are made.

Long-term Management of Side Effects

Since schizophrenia is often a chronic disorder, maintaining adherence over the long-term is one of the most difficult aspects of treatment. Rates of adherence decline, the longer treatment continues (Kane and Borenstein 1985) and side effects may be a major reason patients discontinue medication. While EPS are often the main problem during the early acute phase of treatment, in long-term treatment other side effects such as weight gain or sexual dysfunction may become increasingly important.

Most of the adverse effects of antipsychotics that occur in the early acute phase of treatment can theoretically become chronic problems. Although clinicians try to prevent this, in some cases compromises are necessary when the benefits of long-term treatment clearly outweigh the relevance of certain side effects. The clinician and patient should regularly evaluate the situation together.

Tardive dyskinesia (TD) is an extrapyramidal motor disorder that may occur after long-term treatment with antipsychotic drugs (Kane et al. 1992). (see page 41) Clinicians should therefore regularly monitor for signs of TD, which consists of involuntary muscle movements, usually stereotyped, repetitive pursing, chewing, and smacking movements of the tongue, lips, and muscles around the mouth. Intermittent brief tongue protrusion may occur. Sometimes, in uncommon, severe cases, the condition progresses to writhing movements of the shoulders, limbs, and trunk. TD needs to be managed by a specialist. Although the condition can sometimes be progressive, at least half the cases are reversible (Gardos et al. 1994). It is usually reversible if the antipsychotic medication is discontinued soon after the appearance of symptoms. If TD emerges and continuous treatment with an antipsychotic is necessary, a dosage reduction

may be helpful. If the symptoms continue to progress despite a dosage reduction, the clinician should seriously consider switching the patient to clozapine, since this is the only drug so far introduced with a negligible risk of TD (Casey 1996; Kurz et al. 1995; Lieberman et al. 1991; Dave 1994). Preliminary evidence suggests that the other novel antipsychotics also have considerably less risk of inducing TD.

Fortunately, only very few patients experience the more severe, irreversible manifestations of TD. Many patients also have no subjective awareness of the symptoms of TD, although the symptoms can contribute to stigma.

The long-term management of other chronic antipsychotic-induced side effects generally follows the same principles that are used in managing these side effects during acute treatment (see above).

Antidepressant Drugs in Schizophrenia

Diagnosing depression in individuals with schizophrenia can be difficult because it is often hard to distinguish true depressive symptoms from the primary negative symptoms that are part of the schizophrenia and from certain side effects of antipsychotic medication such as akinesia (Carpenter 1996). However, depression can be part of the schizophrenic illness or can be a psychological reaction to the illness, which occurs most often while the person is in remission (Siris 1995; Liddle et al. 1993).

The suicide rate in schizophrenia is also high and one of the reasons for this high suicide rate is the depressive symptoms that frequently occur in schizophrenia, especially early in the course of the illness (Roy 1990). It is therefore extremely important to treat depression when it is present, and antidepressant medication can be helpful in such cases. Both imipramine (Rifkin and Siris 1987) and selective serotonin reuptake inhibitors (Goff et al. 1990) have been shown to be effective for the treatment of depression in patients with schizophrenia. The selective serotonin reuptake inhibitors may also be helpful in treating negative symptoms (Goff et al. 1995). However, a mood stabiliser may be more appropriate, since antidepressant drugs can trigger a manic episode and may exacerbate the symptoms of schizophrenia.

Mood Stabilisers in Schizophrenia

In instances in which schizophrenia is accompanied by significant mood symptoms (i.e., depression, mania), it may be helpful to add a mood stabiliser to the antipsychotic medication. Lithium carbonate is a mood stabiliser which has been used for decades in the treatment of bipolar disorder (manic-depressive illness). In recent years, anticonvulsant drugs, such as carbamazepine and valproate, have also been found to be effective in treating bipolar disorder. These medications are also used for the treatment of people with a form of schizophrenia, called schizoaffective disorder, in which the person exhibits cyclical fluctuations in mood and drive

Suicide is frequent in schizophrenia, in part due to the depressive symptoms that often occur, especially early in the course of the illness. Interventions focused on suicide prevention early in the course of treatment help improve outcomes.

Schizophrenia is often accompanied by significant mood symptoms (i.e., depression, mania). When this is the case, it may be helpful to add a mood stabilizer to the antipsychotic medication.

or other features that are commonly seen in bipolar disorder. In addition, these medications can be used on a trial basis for patients for whom treatment with any antipsychotic medication alone is not adequately effective.

Adjunctive Use of Benzodiazepines in Schizophrenia

When people with schizophrenia are acutely disturbed (e.g., overactive, excited, at risk of hurting others, attempting suicide, or running away from treatment), they may often be helped in the short-term by the use of benzodiazepines in addition to an antipsychotic medicine. It used to be widely believed that benzodiazepine drugs (e.g., diazepam and lorazepam) were worthless in psychosis. However, it has since been found that benzodiazepines are often effective in calming people with an agitated psychosis (Taylor et al. 1982; Haefely 1978; Nestoros 1980; Bunney and Aghajanian 1976).

An advantage of the benzodiazepine medications as an adjunct to antipsychotic medications is that they have fewer side effects than antipsychotics. A disadvantage is that people may become dependent on the use of these drugs, so that, in most cases, they are suitable only for short-term use.



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Psychosocial Treatments

Because the impact of schizophrenia is felt in so many areas of life, effective treatment must address multiple problems, including:

- *early recognition of relapse*
- *relapse prevention*
- *improved insight and adherence to treatment*
- *psychoeducation*
- *family living*
- *community care and care in other special settings*
- *social and coping skills and rehabilitation.*

It has long been realised that psychosocial factors affect the treatment, prognosis, course and outcome of schizophrenia. Even though drug therapies have revolutionised the treatment of schizophrenia, recent years have also witnessed a growing awareness supported by research evidence that psychosocial interventions have considerable impact on treatment outcomes in schizophrenia. Psychosocial interventions involve using psychological or social management strategies and techniques to reduce or eliminate cognitive, psychological, and social impairments, disabilities, dysfunctions, and handicaps in order to facilitate social reintegration and psychosocial rehabilitation. In practical terms, psychosocial interventions aim to reduce both positive and negative symptoms, enhance insight and adherence to treatment, prevent relapse, improve social and communications skills, and provide coping skills and strategies to patients and relatives so that they can better deal with stresses (Mueser et al. 1990; Tomaras et al. 1998). Psychosocial intervention is an ideal complement to drug therapies.

The problems in living experienced by people with schizophrenia are social, personal, clinical, and sometimes political (e.g., discrimination). Because the impact of schizophrenia is felt in so many areas of life, effective treatment must address multiple problems, including early recognition of relapse, relapse prevention, improved insight and adherence to treatment, psychoeducation, family living, community care and care in other special settings, and social and coping skills and rehabilitation.

Virtually every rigorous comparison of medical approaches and social rehabilitation has shown that medication combined with social rehabilitation leads to a better outcome than either approach alone. Medications are often a necessary but never a sufficient treatment, while social rehabilitation is almost always augmented by the use of carefully prescribed medications.

People with schizophrenia benefit when an array of treatment methods are provided by teams of professionals who remain in contact with them over time. Continuity of care and caregivers is very important for the person being treated. Patients are also best served when they have a voice in choosing among a range of treatment options, locales, and services. Special types of services that provide both medication and social rehabilitation may be needed for people who are particularly vulnerable (e.g., elderly people, women, children and adolescents, people with multiple disabilities, and those who do not speak the major language of the country).

Education

It is important that people with schizophrenia and their families or caregivers be given information about the nature of schizophrenia, its causes, symptoms, and treatment. Instruction should be given concerning the

Education in the treatment of schizophrenia, often referred to as psychoeducation, involves providing information about the disorder, treatment options, side effects, relapse prevention, and coping strategies.

An effective treatment alliance between patient and clinician is an important key to successful treatment.

Many symptoms of schizophrenia occur on a continuum with normal beliefs and experience. This fact can be used to reduce stigma and is one of the reasons for using cognitive therapies in schizophrenia.

benefits and disadvantages of different medications, the most common side effects to expect with each type of medication, the warning signs of relapse, and the particular risks of substance abuse for those with schizophrenia. This information will help patients and families take a more active role in treatment planning and will help to improve the patient's adherence to treatment and the family's or caregiver's support for treatment.

Psychotherapies

Psychotherapies play an important role in the treatment of schizophrenia. It should be recognized that an individual's psychotic experiences are not meaningless, but represent, in a distorted form, major issues and preoccupations in the person's emotional life. Mental health professionals have long recognised the role of family in the course and outcome of schizophrenia (Brown et al. 1972). Research suggests that involving family members in the psychotherapeutic process is beneficial for both patient and family (Falloon et al. 1988). See pp. 53-54 for a more detailed discussion of family interventions. A wide variety of psychotherapy approaches have been investigated for the treatment of schizophrenia.

Individual supportive psychotherapy combined with drug maintenance has been widely recommended. Supportive psychotherapy emphasises empathic listening and emotional support. It focuses on exploring the patient's ability to cope with social and other difficulties, while helping and encouraging the patient to find ways to adjust to the complexities of living in the community.

Cognitive behavioural therapies play an increasingly important role in modifying behaviour by the application of various techniques of symptom management, (e.g. anxiety management), control of persistent hallucinations, reduction of delusional speech, and enhancing cognitive functioning (Lieberman et al. 1995; Perris 1989, 1992; Brenner et al. 1993). Cognitive behaviour therapy appears to be an effective treatment for both individuals and groups of patients with schizophrenia (Bellack 1992; Kingdon and Turkington 1994). Individual and group psychoeducation is usually included as part of cognitive behavioural therapy. The therapist deals with issues such as acceptance of illness, adaptation to functional deficits and the chronic nature of the illness, self management of medication, and early recognition of symptoms of relapse. Interventions include supportive instruction, role playing, and modelling (Hogarty et al. 1995).

Group psychotherapy is a form of psychological treatment that is most often used after the positive symptoms have been stabilised by medication. The purpose is to help the members of the group experience a therapeutic and socialising atmosphere that supports reality and encourages each member to relate to the others by means of a variety of techniques (Yalom 1985). Some comparative research has found that group psychotherapy may be more effective than individual psychotherapy (May 1968).

Combination Approaches. A variety of multidimensional psychosocial treatment models for patients with schizophrenia have been proposed that combine individual and family therapy with educational components, vocational rehabilitation, and drug maintenance (Bellack and Mueser 1993; Ciompi 1987; Keith and Docherty 1990).

Psychodynamic psychotherapy consists of interpreting to the patient his or her past and current life. Psychodynamic psychotherapy is not considered a psychological treatment of choice for schizophrenia since controlled studies on psychodynamic psychotherapeutic interventions among patients with schizophrenia have failed to provide evidence for its efficacy (May 1968; Grinspoon et al. 1972; Gunderson et al. 1984).



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The process of recovery from schizophrenia is enhanced if people with the illness are involved with health professionals in discussing and making decisions about their own treatment.

Participation of the Person with Schizophrenia in Treatment

The process of recovery from schizophrenia is enhanced if people with the illness are involved with health professionals in discussing and making decisions about their own treatment. People with schizophrenia and their family members can help with the planning of services and, in some cases, with the delivery of treatment services. When appropriate information and education is given to patients and their families and they are given a chance to participate in making decisions, this also increases the likelihood that patients will adhere to their treatment. In addition, when family members and people with schizophrenia are involved in the training of professionals, there are demonstrable improvements in professional attitudes and treatment outcomes (National Community Advisory Group on Mental Health 1994).



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The Role of the Family in the Treatment Process

Participation of Families in Treatment

Many people with schizophrenia are limited in their capacity to find work, make friends, find a spouse, and care for themselves. Most people with schizophrenia can function in society if they have concerned and knowledgeable caregivers to help them adapt to these limitations. The caregiver can be an important ally in ensuring that patients follow the treatment that has been prescribed. Caregivers often also need to provide financial assistance and housing; assist the ill person with daily activities, such as shopping, cooking, and washing clothes; supervise the person's medication; monitor their symptoms; negotiate with employers and social agencies; and provide emotional support.

Family members are often the most important caregivers for people with schizophrenia. The types of support they provide depend on the needs of the ill relative, the availability of mental health and community support services, and the culturally defined role of families in caring for relatives. In Western, individually-centred societies, the primary goal of family members (and the mental health care system) is to help the ill person function independently, manage his or her illness, and lead life on his or her own.

Cultures differ in the emphasis they place on self-reliance and independence of the individual. In some cultures, interdependence is considered the best form of social relationship and a moral mode of existence. In such circumstances, individuals who actively or passively avoid the interdependent relationship will be considered as transgressing against good behaviour and social norms. In settings in which large households are frequent and families maintain strong ties throughout life, people who remain dependent on others (or become dependent because of illness or aging) will be well tolerated, provided that they do not consistently bring

Many people with schizophrenia are limited in their capacity to find work, make friends, find a spouse, and care for themselves. Most people with schizophrenia can function in society if they have concerned and knowledgeable caregivers to help them adapt to these limitations.

Family members are often the most important caregivers for people with schizophrenia.

Cultures differ in the emphasis they place on self-reliance and independent of the individual.

shame to the family or household. Societies vary significantly in their evaluation of the symptoms of schizophrenia that are considered most disturbing (Katz et al. 1988).

The proportion of people with schizophrenia who live with their family varies. In developing countries, there are limited social welfare services, so that individuals are even more likely to live with family members. In some family-centred cultures (such as China), the family as a whole, not the individual, makes most of the health care and social decisions for ill family members. In these societies, it is assumed that people with long-standing illnesses such as schizophrenia are dependent on family support, so there is little attempt to promote independence. The family goal is to cure the illness if possible or, if the symptoms of the illness persist, to develop a sustainable family-based support system (Phillips 1993; Xiong et al. 1994; Zhang et al. 1994).

Family support groups are an important means of reintegrating families into the community.

Supporting a relative with schizophrenia is a difficult, life-long effort that can be very stressful. The presence of someone with schizophrenia in the home can result in financial burden, affect the work and social life of other family members, and be emotionally draining—particularly when the ill person has a relapse. In some cases, the emotional response of family members to the illness and the method family members use to manage the illness prove counterproductive. Attempts to control the ill person's behaviour by excessive criticism or being overprotective may result in more frequent relapses (Kavanagh 1992 a and b). Family members often benefit from education about the illness and its treatment and family counselling that provides emotional support and practical advice about how to manage the ill person's behaviour. Patient and family support groups can also be a good source of education for patients and families and are especially helpful in improving communication skills and teaching coping strategies. Improving the coping skills of family members can decrease the burden on the family and reduce the ill person's symptoms and disability (Birchwood and Cochrane 1990; Lam 1991; Leff et al. 1990; Rea et al. 1991; Torrey 1988; Vaughan et al. 1992).



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Families can become effective partners in treatment and can help enhance the effectiveness of treatment in a number of ways. Family support for treatment also helps improve patients' adherence to treatment.

Support for families can be provided in a number of different settings, including individual counseling and groups that involve only family members or both family members and patients.

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Professional Work with Families

After a diagnosis of schizophrenia has been made, it is important for those treating the patient to educate the family (and patient, unless the severity of the illness makes this impossible) about the illness and the benefits and risks of medication treatment. It is important for patients and families to understand the importance of taking medications as they are prescribed, to learn to recognise and report side effects as they occur, and to learn to recognise the early symptoms of a relapse. It has been demonstrated that, when patients and families are given adequate information, this can improve adherence to the treatment regimen considerably (Bäumel et al. 1993). These early contacts are crucial in establishing a **therapeutic alliance** between clinician and patient, an alliance on which all future treatment efforts will be based. Psychoeducational workshops have been shown to be very helpful in establishing such alliances, improving medication adherence, and preventing relapses (Bäumel et al. 1993; Goldstein 1994).

However, there is more to family interventions than education alone. Work with the families of those with schizophrenia has been given many different titles including crisis management (Goldstein et al. 1978), behavioural family intervention (Falloon et al. 1982), and psychoeducation (Hogarty et al. 1986). The latter has proved most popular with relatives' organisations because it suggests that the major component of these interventions consists of giving information about schizophrenia to family members. Some professionals have also chosen to interpret the research in this fashion since it appears to offer a quick, cheap, and easy way of increasing the satisfaction of relatives and improving the outcome for patients. However this is a serious misrepresentation of the findings of a substantial body of research, which has demonstrated which interventions are effective and which are not. Education sessions alone make very little impact (Berkowitz et al. 1984; Tarrrier et al. 1988). This is partly because relatives often have high levels of anxiety that prevent them from absorbing information when it is first presented. It takes time and professional skill to alleviate the anxiety sufficiently for relatives to be able to take in the factual information and make use of it. In addition to information, families also need help in developing coping skills for the difficult behaviour they face day and night.

Many families with a seriously ill member need help in developing coping skills for the difficult behavior they face day and night.

There is an increasing trend to train mental health professionals in family work. For example, two centres for training psychiatric professionals in family work have been established in London and Manchester. The Thorn Courses include both didactic and experiential learning, and have already trained over 100 practitioners (Midence et al. 1995).

Family psychoeducation and support are probably the most underused of the empirically validated psychosocial strategies for the treatment of schizophrenia

Brief interventions, though superficially attractive, are illusory. A time limited course of ten sessions proved ineffective in altering the course of the disorder (Vaughan et al. 1992). Family intervention by therapists who have not acquired the necessary skills is also ineffective (McCreadie et al. 1991). The requisite therapeutic skills and techniques have been set out by a number of authors (Anderson et al. 1986; Falloon et al. 1984; Kuipers et al. 1992). They include:

- imparting education about schizophrenia
- helping families learn problem-solving techniques
- improving communication
- dealing with conflict
- reducing criticism and over-involvement
- lowering expectations
- increasing social networks

Eight controlled trials have established the value of family work (Goldstein et al. 1978; Falloon et al. 1982; Leff et al. 1982; Anderson et al. 1986; Tarrier et al. 1988; Xiong et al. 1994; Zhang et al. 1994; Randolph et al. 1996) and the efficacy of this type of intervention has been endorsed by the Cochrane collaboration on evidence-based medicine (Anderson and Adams 1996). The National Institute of Mental Health (NIMH) Treatment Strategies Study has shown that even a monthly family support group is associated with a lower relapse rate and better adjustment in patients (Schooler et al. 1997).

Unfortunately, despite the evidence for the efficacy of family work, family psychoeducation and support are probably the most underused of the empirically validated psychosocial strategies for the treatment of schizophrenia (Kane and McGlashan 1995). This is partly because it is necessary to learn the skills from an experienced teacher, few of whom are available.



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Social Rehabilitation

Improving Quality of Life

Improving the quality of life of the individual with schizophrenia is the primary goal of social rehabilitation.

An essential goal of mental health programmes is to ensure that appropriate treatment is received and impairment and social handicaps are reduced.

Rehabilitation of individuals with schizophrenia has two main objectives: 1) to improve functioning and 2) to reduce handicaps, stigma, and social disabilities. Although such services are not needed by all patients with schizophrenia, they are important for those with continuing impairment and disability.

In recent years, there have been changes in the strategies of rehabilitation of psychiatric patients. While, in the past, primary emphasis was placed on returning the individual to work, it has now been accepted that there are many other equally important goals of the rehabilitative process. It has also been accepted that, for many individuals with schizophrenia, returning the individual to his or her previous position is not realistic. Because the illness often begins early in life, the person may never have achieved a desirable position. Improving the quality of life of the individual with schizophrenia—both during the illness and after—has emerged as the primary concern of many programmes, which has changed the types of interventions, settings, and other characteristics of management of the disease (Sartorius 1995).

The intermediate objectives of the psychosocial rehabilitation process are:

- to reduce the symptoms of the patient through medication and psychological and psychosocial interventions
- to reduce adverse physical and behavioural consequences of the illness
- to improve the individual's social competence
- to increase family and social support in the areas of employment, housing, and socialisation.

Several psychosocial interventions have been considered effective in rehabilitating individuals with schizophrenia, including group supportive therapy, patient self-help groups, community support and outreach programs, case management, and social reinforcement (token economy).

Group supportive psychotherapy plays an especially important role after the acute symptoms of the illness have been stabilised. Such therapy helps members of the group experience a therapeutic and socialising atmosphere that supports reality and encourages each member to relate to the others.

Patient self-help groups also provide an opportunity for socialisation and emotional support and give patients an opportunity to learn coping strategies that have worked for others with schizophrenia.

The goals of **community support and outreach programs** are to reduce readmission rates to psychiatric inpatient facilities and improve skills needed to live independently in the community. Community

Psychiatrists and other mental health professionals should be aware of social and legal barriers to the reintegration of individuals with schizophrenia into the community and should work to reduce these obstacles.

support systems try to help manage the various problems that face individuals with schizophrenia and their families, such as controlling symptoms, securing continuity of care, preventing relapses, reducing social stigma and isolation, and obtaining necessary financial resources (Caplan and Killilea 1976; Killilea 1982). Community support systems involve both mental health professionals and a variety of community resources to help the patient and the family cope with problems caused by the illness and improve the quality of life for the affected individual. Such programs usually involve developing a community support system and setting up a case management program (Bachrach 1992).

Case management helps to ensure that patients get all the help and services they need to lead as full a life as possible in the community. Case managers may co-ordinate the provision of services by others or may provide many of the services themselves. In the latter case, the case manager may help the client find an apartment, obtain monetary benefits, budget money, modify drug use, and keep doctors' appointments (Goering et al. 1988). Case management may be especially important in complex systems of services to ensure continuity of treatment and co-ordination of services.

A number of other strategies are important in the reintegration process:

Training in independent living skills aims to improve the individual's ability to perform basic daily living activities (Stein and Test 1978). The goal is to educate the person to pay attention to proper dress and appearance. Other skills for independent living may include meal preparation, security measures, and obtaining and maintaining housing.

Social skills training is widely used in the treatment of patients with chronic schizophrenia. Individuals are trained in interpersonal communication skills, such as maintaining appropriate eye contact and voice volume, using learning processes such as modelling, role playing, reinforcement, and *in vivo* exercises (Lieberman 1992; Lieberman et al. 1986, 1989). Several studies have demonstrated the positive effects of social skills training on symptoms, relapse reduction, and social adjustment of patients with schizophrenia, especially in younger patients (Bellack et al. 1984; Lieberman et al. 1986; Hogarty et al. 1987; Marder et al. 1996).

Vocational rehabilitation involves vocational training activities related to real work environments and experiences. Its goal is to facilitate the job placement of the trainee.

Job placement (permanent or transitional) is the final stage of the vocational rehabilitation process for those individuals who are eligible to work. When individuals with schizophrenia are able to work, this enhances their self-esteem, provides economic benefits or income, and gives them opportunity for socialisation and interpersonal communication (Anthony et al. 1990). (See below for a more detailed discussion of issues related to working.)

Skills for independent living include attention to proper dress and appearance, meal preparation, security measures, and obtaining and maintaining housing.

Deficits in social skills (e.g., lack of smiling in response to social approaches) mark out the person with schizophrenia as different from others. Improving social skills increases the likelihood that the person will be accepted in society.

When individuals with schizophrenia are able to work, this enhances their self-esteem, provides economic benefits or income, and gives them opportunity for socialisation and interpersonal communication.

Individuals working with people with schizophrenia in residential treatment settings can experience some of the same stresses as family members and may benefit from similar education and supportive interventions (see p. 54).

Residential alternative accommodation is a basic component of community-based psychosocial rehabilitation for those individuals who need a residential alternative either to a long-term stay in a psychiatric hospital or with their family (Stein and Test 1978). More severely disabled patients need staff to be present in the accommodation during the day and, in some cases, throughout the night as well. In these situations, staff and patients in some respects come to resemble family groups. Studies have shown that staff in these homes can develop critical attitudes toward patients, just as happens in some families (Ball et al. 1992; Snyder et al. 1994). A training programme for staff based on family interventions has been quite successful in improving staff attitudes toward patients (Willetts and Leff 1997).



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Work and Schizophrenia

Most People with Schizophrenia Can Work Even If They Have Symptoms

Several studies have shown that people with major mental illness fare better if they are working but that the ability to hold a job is scarcely related to the severity of the person's illness. British and American studies have shown that people with schizophrenia are more likely to stay out of hospital if they are employed. It has also been shown that seriously disturbed patients can hold jobs on a long-term basis (Freeman and Simmons 1963; Fairweather et al. 1969). While many people with schizophrenia are able to work successfully in competitive employment, for others long-term sheltered work is a necessity.

In a recent study, Bond et al. (1997) reviewed a number of studies and surveys concerning employment and schizophrenia, all of which suggested significant gains in supported employment programs. In the experimental studies they examined, 58% of clients in supported employment programs achieved competitive employment compared to 21% of those who received traditional vocational services. Two features of supported employment programs appear to be particularly important in achieving these better results: the integration of mental health and vocational services within a single team and avoidance of prevocational training, or the "train then place" model (i.e., programs that place people and then provide on the job training appear to achieve better results than the more traditional approach of pre-employment training).



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Work Helps People Recover from Schizophrenia

Engaging in productive and meaningful activity is basic to an individual's sense of social and personal identity and to his or her sense of self worth. Work benefits not only the individual but also his or her social group. Schizophrenia can impair a person's ability to work during an acute attack. However, research has shown that, with the proper encouragement, training, treatment, and support, most people with schizophrenia can work inside or outside the home (Cook and Pickett, 1994).

Work helps the person with schizophrenia in a number of ways:

- it enhances self-esteem
- it contributes to household income and elevates the sick person's standing in the family
- it provides a focus of attention that can decrease the person's preoccupation with hallucinations and delusions, when they are present (Wing et al. 1964)

Work brings people with schizophrenia into contact with a healthy group of people and increases their chances of forming relationships with others.

While many people with schizophrenia are able to work successfully in competitive employment, for others long-term sheltered work is a necessity.

The integration of mental health and vocational services within a single team is important.

In developed countries, being unemployed carries with it its own stigma and most people with schizophrenia are unemployed. Not having a job in a developing country is not associated with a similar stigma because only a small proportion of the population holds a paying job.

- it provides a daily structure and order to life and reduces boredom
- it provides a new set of relationships and social interactions with co-workers and generates a sense of community
- it brings the sick person into the society of healthy people.

Unfortunately, in many industrialised countries, fewer than 20% of people with serious mental illness are in full-time or part-time work (Anthony and Blanch 1987; Farkas et al. 1987; Anthony et al. 1988). This low level of employment is as much the result of the nature of the economy (e.g., high levels of unemployment) and the disability support system in industrial countries as of the mental disability itself. When competition for jobs is fierce, applicants with a history of severe mental illness tend to be rejected in favour of those without such a history. In addition, individuals with severe mental illness encounter economic disincentives to work because increasing work hours results in loss of income from the person's disability pension, rent subsidy, and other forms of income support (Bond et al. 1997). These disincentives could be alleviated by a more gradual reduction of disability benefits for beginning workers (Warner and Polak 1995b). Unemployment adversely affects the course of serious mental illness. Hospital admissions for schizophrenia increase during economic downturns (e.g., the outcome for schizophrenia worsened during the Great Depression) (Warner 1994), while efforts to rehabilitate those with mental illness improve under full-employment conditions (Brenner 1973). It is, of course, important, as it is for everyone, that the kind of work be appropriate for the individual. The most suitable types of employment for those with schizophrenia are generally well-structured situations that are not too stressful. Part-time work may be a useful option for some individuals.

In several European countries, where economic disincentives to work are less severe, model vocational programs have demonstrated that a much larger proportion of people with serious mental illness can gain employment. European social enterprises successfully employ a mixed workforce of mentally disabled and healthy workers in manufacturing and service enterprises (Warner and Polak 1995a). Similar ventures may be viable in other industrialised countries, especially if attention is paid to the issue of reducing individual economic disincentives to work.

In contrast, in developing countries, work prospects for people with schizophrenia are less affected by fluctuations in the economy because many individuals can be employed in subsistence agriculture and family enterprises.



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Changing Approaches to Employment

In traditional mental hospitals, many patients were employed on the farms, which supplied the hospitals with produce, and in services such as the laundry. They were not paid for this work, which eventually came to be seen as exploitation and was discontinued, although it may have benefited some for the reasons given above. It was replaced by occupational therapy, with the functions of recreation and self expression, and industrial therapy (IT), which provided work-like activities through which very small sums of money could be earned. The work consisted predominantly of assembly and packing tasks, which were contracted out to the hospital IT department by local businesses and factories. The repetitive work was within the capacities of many of the patients, but was boring for those with a higher level of competence and frustrating for those who had been in higher education or in positions of some responsibility before becoming ill. Furthermore, very little social interaction took place among those who participated (Dunn et al. 1990).

With the advent of community care, IT activities began to be provided outside mental hospitals in facilities such as day hospitals, day centres, and sheltered workshops. The major disadvantages of these arrangements were that the work was still largely repetitive and boring and that the attendees were all mentally ill. Hence, they came into social contact only with other users or with providers of the service, so that the work, instead of aiding their reintegration into society, perpetuated their segregation.

A number of different approaches to these problems have proved successful. Some services have developed work projects that generate jobs of differing levels of responsibility and involve a variety of tasks, thereby avoiding boredom. Examples are a cafe, a picture framing shop, and a bakery. Projects like these that provide services to the general public help to break down the barriers of social isolation which grow from stigma. The Clubhouse model enables people who are quite severely affected by mental illness to participate in a work force and to provide services to the public (Fairweather et al. 1969). Worker co-operatives and social enterprises have been established in a number of European countries and often

Sheltered work facilities established in the community have major disadvantages: the work is often repetitive and boring and attendees only come into contact with other users or providers of the service.

Work projects that generate jobs of differing levels of responsibility and involve a variety of tasks help to avoid boredom.

Projects that provide services to the general public help to break down the barriers of social isolation.

Programs that use on-the-job training approaches produce better results than the more traditional “train then place” approach.

The chances of success are probably increased if local business people of goodwill can be persuaded to contribute their expertise and guidance.

employ a mixed workforce of mentally disabled and healthy workers (Grove et al. 1997). They are able to compete with local businesses and pay standard wages to those mentally ill employees who work full time (Warner and Polak 1995). As mentioned above, recent research suggests that programs that use on-the-job training approaches produce better results than the more traditional “train then place” approach (Bond et al. 1997).

These relatively new approaches to employing those with mental illness offer much more attractive opportunities than the traditional IT units, but require ingenuity and enthusiasm to succeed in establishing and maintaining viable enterprises. The chances of success are probably increased if local business people of goodwill can be persuaded to contribute their expertise and guidance.



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For centuries, the public has viewed people with severe mental illness with fear, based on a stereotype of the mentally ill as difficult to understand, dirty, unkempt, unpredictable, and violent.

Isolation of those with mental illness from the rest of society reinforces the public image of the mentally ill as alien and dangerous and contributes to stigma.

Providing a more stimulating environment, both inside and outside the mental hospital, leads to a decrease in the negative symptoms of schizophrenia.

Treatment Settings

Individuals with schizophrenia may be treated by general and mental health practitioners in a variety of settings as described below.

Inclusion in the Community

For centuries, the public has viewed people with severe mental illness with fear, based on a stereotype of the mentally ill as difficult to understand, dirty, unkempt, unpredictable, and violent. In developed countries, the response to these attitudes during the nineteenth century was a massive program of building psychiatric hospitals—self-contained worlds with their own farms and water supplies—on isolated sites far from the towns. Most of the wards were locked and patients rarely passed out of the gates. Relatives were discouraged from visiting by the distance and the grim atmosphere that pervaded these institutions. A recent study of two London psychiatric hospitals found that 75% of long-stay patients had no contact with relatives (Leff 1997).

Although it was felt at the time that such peaceful surroundings and green spaces would be helpful to patients, it became clear that such isolation of the mentally ill from the rest of society adversely affected both the patients and the public. The public image of the mentally ill as alien and dangerous was reinforced, as well as the belief that mental illness was incurable. It appeared that, once a person entered the hospital, they stayed for life. The hospitals themselves became objects of fear and stigma, reflected in slang terms such as “loony bins,” “nut houses,” and “funny farms.” The patients’ mental state was made worse by the combination of social isolation and inactivity, which resulted in an increase in apathy, inertia, lack of speech, and restricted emotional responsiveness—the so-called secondary negative symptoms of schizophrenia.

The concept of the large isolated institution for the mentally ill was also exported to a number of developing countries, especially those that were colonies of Western countries. Such institutions proved even more inappropriate and isolating in these cultures.

After World War II, progressive attitudes led to a policy of early discharge and, beginning in the late 1940s, the number of inpatients began to fall in northern Europe. With the introduction of effective antipsychotic medication in 1954, patients began to be discharged in larger numbers. Improvements in the social environment within the hospitals led to a decrease in negative symptoms (Wing and Brown 1970), which diminished even further as patients moved from hospital to more stimulating environments in the community (Leff 1997). However, while discharging patients to homes in the community can improve negative symptoms, it does not automatically lead to social integration. Many patients were hastily released in the 1970s and 1980s without adequate preparation or support for living in the community, which caused problems for them and their communities, and increased the stigma because of schizophrenia.

Currently in many parts of the world, the largest part of the care provided to those with schizophrenia is community based.

It is essential that primary care physicians receive adequate education and information about the symptoms and treatment of severe mental illness.

Surveys of public attitudes reveal a substantial amount of goodwill towards discharged patients with mental illness. This goodwill can be mobilised by focussed educational campaign.

Patient and family advocacy groups, churches, and research foundations can often offer valuable assistance in improving community attitudes and initiating outreach programs.

Specific treatment settings can also carry a stigma. For example, anyone who has spent time in a psychiatric hospital may be stigmatized. Treatment in a general hospital may therefore be preferable to treatment in a specialised facility.

Stigma is often also associated with the dilapidated conditions and dehumanising treatment of psychiatric wards.

The current trend towards fragmentation of treatment services by population group (e.g., adolescents, the elderly) often contributes to a lack of continuity of care.

Currently in many parts of the world, the largest part of the care provided to those with schizophrenia is community based. Often a primary care physician acts as gatekeeper and arranges referrals for more specific mental health services. It is therefore essential that primary care physicians receive adequate education and information about the symptoms and treatments of severe mental illness.

Integration of mental health care into general health care has special advantages for developing countries. A number of nations, such as India, Iran, and Pakistan, have used this approach to provide essential care to rural populations.

Surveys of public attitudes still reveal negative attitudes towards the mentally ill, but also a substantial amount of goodwill towards discharged patients (Wolff 1997; Reda 1995). This goodwill can be mobilised by focussed education campaigns to encourage neighbours of patients to initiate social contact (Wolff 1997). Patient and family advocacy groups, churches, and research foundations can often offer valuable assistance in improving community attitudes and initiating outreach programs. Patients can also be offered a social skills training program (see p. 59) that improves their ability to initiate and sustain relationships (Lieberman et al. 1986). Tackling the issue from both sides in this way offers the possibility of true social integration of people with schizophrenia into the community of citizens where they belong.



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Inpatient and Outpatient Care

Recent studies have shown that a variety of settings, ranging from innovative alternatives to the hospital to comprehensive community programs, can be effective in treating people with schizophrenia. In general, when inpatient and comprehensive outpatient programs are compared, people in the community-based programs show better outcome for longer periods of time than those treated in the hospital. Even people who are acutely psychotic can be treated effectively in carefully monitored community settings where supervision is continuous, where the setting is quiet and comforting, and where lay and professional staff are available.

Inpatient care that is as brief as feasible and combines a variety of treatment approaches, including comprehensive discharge planning and post-hospital reintegration services, is effective. Although compulsory treatment is sometimes necessary to ensure the patient's safety, the treat-

The treatment of choice is the one that puts the fewest restrictions on the patient's choices, causes the least disruption in the person's daily life and social relations, and is the most focused on social and vocational rehabilitation.

Patients who are treated with the least restriction and coercion can better integrate into the everyday life of the family and community

Confinement in a jail or prison conveys a double stigma, that of being insane and a criminal. In some societies, however, the stigma attached to imprisonment is incomparably less serious than that of being mentally ill, and particularly being diagnosed with schizophrenia.

The supreme court in India recently ruled that it is unconstitutional to keep any person in jail only for the reason of mental illness (see p. 89).

ment of choice is the one that puts the fewest restrictions on the patient's choices, causes the least disruption in the person's daily life and social relations, and is the most focused on social and vocational rehabilitation.

The growth of different kinds of services for specific populations or needs (e.g., the acutely disturbed, adolescents) increases the risk of losing the long-term approach which is needed in schizophrenia. Case management, therefore, has become increasingly important (see page 59).

People with Schizophrenia Can Get Worse If Treated Punitively or Confined Unnecessarily

People with schizophrenia are likely to get worse if treated punitively or confined unnecessarily. The history of psychiatry reveals that patients who are treated with the least restriction and coercion can better integrate into the everyday life of the family and community. For many people with schizophrenia, their most unpleasant memory of treatment is the experience of being detained in seclusion or held down with physical restraints. Treatment facilities should establish guidelines to minimise the use of such measures.

Schizophrenia changes some aspects of a person's thinking and feeling while other aspects of the personality can remain intact and undamaged. People with schizophrenia generally want to live their own lives, surrounded by friends, eating decently and free from abuse or confinement. For these reasons, international standards, national laws, and modern treatment approaches all promote voluntary treatment and the avoidance of confinement. Jails are considered especially harmful to the person with schizophrenia and are not suitable places for treatment (see below).

Illogical thinking may lead a person with schizophrenia to break the law or the accepted codes of behaviour. In such cases when the behaviour is the result of the person's illness, the offender may fail to understand cause and effect in the usual way and will be unlikely to learn from punishment.

People with Schizophrenia Should Not Be Put in Jail or Prison

About 25% of people involved in police encounters in North America are considered to be displaying abnormal behaviour due to substance abuse or mental illness (Arboleda-Florez and Holley 1988). Many of these people end up in jail or prison. In Ontario, the largest province in Canada, 15%-20% of inmates have a psychiatric illness and 5%-7% are considered to be seriously mentally ill (Government of Ontario 1995). In North America and other parts of the developed world, prisons and, even more so, local jails, have become the modern asylum and a substitute for the mental hospital (Torrey 1995; Warner 1995).

A large number of the people with mental illness in prisons and jails have severe mental disorders, including schizophrenia. Lacking proper resources, and geared, not for treatment, but for containment and control, jails and prisons merely warehouse the mentally ill. Most inmates with mental illness do not receive appropriate treatment. If they are given med-

icine in the form of pills, other inmates tend to steal it. They are, therefore, more likely to be given long-acting injections with little regard for side effects. If the inmates with mental illness are kept with the general jail population their behaviour soon becomes disturbing to other prisoners, so that jail authorities usually have to segregate them in order to prevent them from being beaten or otherwise abused. This segregation is like a double imprisonment and the isolation simply worsens the person's symptoms.

The supreme court in India recently ruled that it is unconstitutional to keep any person in jail only for the reason of mental illness. (see p. 89 and Appendix E, Volume I)



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Sources of Support Exist Outside the Health Care System

People in distress seek help from a variety of individuals or institutions in the community. When distress is caused by illness they approach priests or institutions such as temples or mosques, organisations of patients, other non-governmental organisations, practitioners of alternative medicine, traditional healers, and others they think might help them. Often, patients approach more than one such source of potential help as well as health care services, in succession or simultaneously. There is relatively little evidence about the benefit that people derive from these contacts, although anecdotal reports indicate that there may be considerable benefit.

In some countries, traditional healers are trained in accordance with a well-organised doctrine (e.g., Ayurveda, Unani, Chinese traditional medicine), while, in other locations, training takes place through apprenticeship or other means. In some countries, no collaboration exists between traditional healers and the official health care system and the work of traditional healers is not recognised by the official health care system. In other parts of the world, traditional healers have established collaboration with the health care system and have proven to be useful in recognising psychoses and referring people suffering from them to health services. On the other hand, the exclusive use of indigenous healing methods for the treatment of schizophrenia can delay the start of effective treatment, and some traditional healing practices are known to harm patients.

Information is available about the practice of traditional healers in a number of countries, while little is known about the way in which they operate in other locations. The types of institutions mentioned above, traditional and religious healers, and community leaders all serve as a point of first contact for a large number of people with mental illness and often provide help to them and their families.

In developing mental health programmes, it is important to explore the pathways people use, who are seeking help and to learn about the practices of those whom people approach for help in order to optimise their action and ensure that patients receive appropriate and co-ordinated support from the health care services and others in the community.

II. Decreasing Stigma

What are Stigma, Prejudice, and Discrimination?

Stigma is currently used especially to indicate that certain diagnoses (e.g., tuberculosis, cancer, mental illness) and the characteristics and behaviours associated with them awaken prejudice against persons so diagnosed.

Prejudice is an attitude reflecting the readiness of people to act in a positive or negative way toward the object of the prejudice without examining whether there is any justification for such behaviour.

Discrimination is a particularly negative consequence of stigma and prejudice. It means that individuals or groups in a society deprive others of rights or benefits because of stigma and prejudice. (see Figure 5, p.76)

The word “stigma” is of Greek origin and means “to pierce, to make a hole.” The word was also used, however, to mean branding a criminal with a hot iron to mark infamy. In the *Anatomy of Melancholy*, Burton spoke of being “stigmatized with hot iron.” It was in the late middle ages that the word came to mean the public defaming and branding of a criminal so that all could recognise him. Other meanings of the word, in particular with reference to stigmata (wounds similar to those of Christ indicating that a person has lived a life of extraordinary sanctity), have gradually disappeared. In more recent years, stigma has been used especially to indicate that certain diagnoses (e.g., tuberculosis, cancer, mental illness) awaken prejudice against persons so diagnosed.

Prejudice is an attitude reflecting the readiness of people to act in a positive or negative way toward the object of the prejudice without examining whether there is any justification for such behaviour. There are numerous prerequisites for prejudice to develop. Several of the most important are:

- Recognition of the object of prejudice: for example, prejudice is awakened once the individual admits that he has a mental disorder or when extrapyramidal side effects make it clear to others that he has been receiving antipsychotic medication.
- Social acceptance of the prejudice: there is an absence of any strong reaction by others to the prejudice.
- Lack of personal knowledge about the object of prejudice: for example, serving in the same military unit with people from a different race can help reduce prejudice against those belonging to that racial group.

The literature concerning breaking down prejudice indicates that there are numerous methods of eliminating or weakening prejudice, but that none of them is easy or quick.

Discrimination is a particularly negative consequence of stigma and prejudice. It means that individuals or groups in a society deprive others of rights or benefits because of stigma and prejudice. For example, those given a diagnosis of schizophrenia are often denied the rights or benefits they would have if they were not given such a diagnosis. Discrimination because of schizophrenia is expressed in numerous ways, including lack of parity in reimbursement for care, injustice in legislation, unwillingness to employ people with schizophrenia, and refusal to allow someone with a mental disorder entry into a social group (e.g., by way of marriage). In terms of priorities, there is no doubt that discrimination should be the first target of action—not only because it is the most direct form of harm inflicted on those with mental illness, but also because reducing discrimination (e.g., in the laws) in turn helps reduce stigma and consequent prejudice.

The stigma associated with schizophrenia is attached not only to the individual with the illness, but also to everything and everyone associated with the person, the illness, and its treatment (e.g., medications, other treatments such as electroconvulsive therapy, family members, caregivers, health care professionals who work with those with schizophrenia, and institutions where individuals with schizophrenia are treated).

The stigma associated with mental illness has a long historical tradition. It is pervasive and difficult to overcome.

What Is the Stigma Because of Schizophrenia?

The general public and even health professionals tend to hold a stereotyped image of those with schizophrenia. This image usually involves some or all of the following misconceptions:

- Nobody recovers from schizophrenia.
- Schizophrenia is an untreatable disease.
- People with schizophrenia are usually violent and dangerous.
- People with schizophrenia are likely to infect others with their madness.
- People with schizophrenia are lazy and unreliable.
- Schizophrenia is the result of a deliberate weakness of will and character (“the person could snap out of it if he would”).
- Everything people with schizophrenia say is nonsense.
- People with schizophrenia cannot reliably report the effects of treatment or other things that happen to them.
- People with schizophrenia are completely unable to make rational decisions about their own lives (e.g., where to live).
- People with schizophrenia are unpredictable.
- People with schizophrenia cannot work.
- People with schizophrenia get progressively sicker all their lives.
- Schizophrenia is the parents’ fault.

The stigma that attaches to schizophrenia extends beyond the individual with the illness to encompass everything and everyone associated with him or her. This includes the medications and other treatments that may be used to control symptoms, family members (who are often wrongly considered to have caused the illness), other caregivers, health professionals who care for those with schizophrenia, and even the hospitals and other institutions in which those with schizophrenia are treated.

Extent of the Stigma

It is clear that people with mental illness are highly stigmatised in the West. Branded as “psychos” in popular parlance, they encounter discrimination in housing and employment (Miller and Dawson 1965) and generate fear that they are dangerous. Citizens fight to exclude treatment facilities and living quarters for the mentally ill from residential neighbourhoods. According to a 1990 survey of the American public, the “not in my backyard” phenomenon is a widespread obstacle to the community integration of people with mental illness (Robert Wood Johnson Foundation 1990). The status afforded the mentally ill is the very lowest—lower than that of ex-convicts or the developmentally disabled (Tringo 1970). According to one U.S. survey, even after 5 years of normal living and hard work, an ex-mental patient is rated as less acceptable than an ex-convict (Lamy 1966).

Tragically, people with mental illness themselves accept the stereotype of their own condition.

The agencies serving the mentally ill are tainted by association and mental health professionals themselves sometimes hold attitudes towards mental patients that are similar to those of the general public; they may even be more rejecting. In one study, mental hospital staff were considerably less likely than members of the public to take the trouble to mail a sealed, addressed letter which they believed to have been accidentally lost by a mental hospital patient (Page 1980).

Tragically, people with mental illness themselves accept the stereotype of their own condition. Young patients in rural Ireland viewed “spending time in the ‘madhouse’... as a permanent ‘fall from grace’ similar to a loss of virginity” (Scheper-Hughes 1979, p. 89). A number of studies have shown that mental patients are as negative in their opinions of mental illness as the general public (Giovannoni and Ullman 1963; Manis et al. 1963; Crumpton et al. 1967). Some reports, indeed, indicate that mental patients are more rejecting of the mentally ill than are family members or hospital staff (Bentinck 1967; Swanson and Spitzer 1970).

In a comparison of attitudes toward the mentally ill at sites in four European countries, people in Athens, Greece, and Naples, Italy, were more rejecting than those in Britain and Sweden. Most of the respondents in Greece and Italy felt that “lack of will power” was a primary cause of mental illness and believed that the mentally ill were “far more dangerous than most suppose” (Hall et al.).

Some individual factors are known to moderate stigma and improve public tolerance of the mentally ill. Younger and better educated people are usually more tolerant (Brockington et al. 1993; Wolff 1997; Rabkin 1980). Prior contact with someone who suffers from mental illness decreases stigma and fear of dangerousness, as does knowledge of the person’s living situation (Penn et al. 1994). Those who do not perceive the mentally ill as violent are relatively tolerant (Penn et al. 1994; Link et al. 1987). Residential facilities for the mentally ill are better accepted in downtown, transient districts with low social cohesion, while they are less well accepted in single-family neighbourhoods (Trute and Segal 1976).

A survey in England, Scotland, and Wales (Mori 1997) seemed to indicate an improvement in public attitudes toward schizophrenia, at least with regard to treatment possibilities and integration into the community. In this study, 59% of those surveyed felt that schizophrenia can be treated effectively while only 10% disagreed; only 18% said that they would not be willing to work alongside someone with schizophrenia while 54% disagreed; 12% felt that people with schizophrenia should live in institutions for the mentally ill, not in neighbourhood areas, while 64% disagreed; and, finally, 72% felt that, with careful support and appropriate treatment with modern medicines, people with schizophrenia can live successfully in the community. However, when questions about more personal issues were posed, the public’s tolerance appears to change to a more neutral or negative feeling, with only 13% saying they would be happy if their son or daughter was going out with someone with schizophrenia, while 47% disagreed.

72% felt that, with careful support and appropriate treatment with modern medicines, people with schizophrenia can live successfully in the community.

The perception of people with schizophrenia is to a great extent influenced by the culture of the community. When the culture is strongly family-based, there tends to be much greater tolerance for those with serious mental illness.

In general, there tends to be more tolerance for mental illness in developing countries. This is partly because mental illness is generally not considered the fault of the person who is ill and because families tend to be more tolerant and cohesive. However, with increasing urbanisation, attitudes are changing.

People with Schizophrenia Are Often Viewed Differently in Developing Countries

A number of factors in developing countries result in greater tolerance and continued family and community support for those with serious mental illness. In developing countries, persons with mental illness and schizophrenia have traditionally lived in the community and with their own families. In addition, large scale institutionalisation has not been part of the mental health care system in these countries. Other factors contributing to greater tolerance and support are

- the rural agrarian nature of the society
- strong family system with filial affiliation
- models for explaining the cause of the illness that are external (e.g., spirits) and are shared by community members
- reversibility of behaviour including symptoms

However, this situation could change with increasing urbanisation, the influence of mass media, and the breakdown of family structure.

A number of studies in the 1970s and earlier found that a lower level of stigma was attached to mental disorder in developing countries and that those with mental illness were often better tolerated by families and were the object of less criticism and hostility. Among the Formosan tribesmen studied by Rin and Lin (1962), mental illness was free of stigma. Sinhalese families freely refer to their psychotic family members as pissu (crazy) and show no shame about it; tuberculosis in Sri Lanka was more stigmatising than mental illness (Waxler 1977).

The lower level of stigma in parts of the developing world may be a result of different folk-diagnostic practices. Throughout the non-industrial world, the features of psychosis are likely to be given a supernatural explanation (e.g., people with these symptoms may be considered the victims of witchcraft, shamans, or spiritualists [Warner 1974]). When urban and rural Yoruba with no formal education from Abeokuta in Nigeria were asked their opinions about profiles of mentally ill people, only 40% of those questioned thought the person described with symptoms of paranoid schizophrenia was mentally ill (Erinosho and Ayonrinde 1981), whereas nearly all Americans labelled the subject of this vignette as mentally ill (D’Arcy and Brockman 1976). Only a fifth of uneducated Yorubans considered the person described with symptoms of simple schizophrenia to be mentally ill, versus three-quarters of American respondents (D’Arcy and Brockman 1976). A third of the uneducated Yoruba would have been willing to marry the person with paranoid schizophrenia and more than half would have married the person with simple schizophrenia. However, when skilled workers from the area of Benin in mid-western Nigeria were asked their opinions about someone specifically labelled a “nervous or mad person,” 16% thought that all such people should be shot and 31% believed that they should be expelled from the country. These educated Nigerians conceived of mad people as “senseless, unkempt, aggressive and irresponsible” (Binitie 1970).

A survey of Indian professionals (Sathyavathi et al. 1971) found that they were willing to interact with the mentally ill in various aspects of life and would not feel the need to conceal the illness of someone in their own family.

The authors of a WHO follow-up study of schizophrenia suggest that one of the factors contributing to the good outcome from schizophrenia in Cali, Colombia, is the "high level of tolerance of relatives and friends for symptoms of mental disorder," a factor that can help the "readjustment to family life and work after discharge" (WHO 1979).

It is clear that attitudes to the mentally ill vary from culture to culture and are influenced by the label that is applied to the person with psychosis.

The WHO multicentre study in four developing countries studied community attitudes using seven case vignettes in Columbia, India, Philippines, and Sudan. This study found that the community differentiated the different disorders in terms of severity, treatability, marriagiability, and desirability as neighbours (Wig et al. 1980). The respondents placed greater emphasis on external behaviour rather than internal symptoms experienced by the individual.

Indian mental health professionals have conducted many studies on the attitude of the general public toward mental illness. Again, earlier studies found higher levels of tolerance than in developed countries. A survey of Indian professionals (Sathyavathi et al. 1971) found that they were willing to interact with the mentally ill in various aspects of life and would not feel the need to conceal the illness of someone in their own family. Similarly, most adults in Vellore, India, when interviewed, were sympathetic toward mental patients and accepted modern treatment methods available in hospital (Verghese and Beig 1974). The respondents expressed optimism about the outcome of treatment, especially if provided early in the course of the illness. However, nearly two-thirds of the respondents felt that the cure could be only partial and also opposed marital alliances with families in which there is a history of mental illness.

The authors of a WHO follow-up study of schizophrenia suggest that one of the factors contributing to the good outcome from schizophrenia in Cali, Colombia, is the "high level of tolerance of relatives and friends for symptoms of mental disorder," a factor that can help the "readjustment to family life and work after discharge" (WHO 1979). In an Indian 5-year follow-up study of persons with schizophrenia, 80% of families preferred that the person continue to stay with the family (ICMR 1988). Another study found home care treatment for persons with schizophrenia was more accepted and less disruptive for families than hospital care (Pai and Kapur 1983).

More recent findings, however, have shown that with increasing urbanisation and the breakdown of traditional values and social structures, there has been a decline in tolerance for the mentally ill in industrialising parts of the developing world. In a review of public attitudes toward mental illness in New Delhi, India, Prabhu et al (1984) concluded that "the lay public, including the educated urban groups, are largely uninformed about the various aspects of mental health. The mentally ill are perceived as aggressive, violent and dangerous. There is a lack of awareness about the available facilities to treat the mentally ill and a pervasive defeatism exists about the possible outcome after therapy. There is a tendency to maintain social distance from the mentally ill and to reject them."

It is clear that attitudes to the mentally ill vary from culture to culture and are influenced by the label that is applied to the person with psychosis.



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Discrimination adds to the difficulty people with schizophrenia have in regaining the ability to function in society.

Cultural practices and norms will, of course, influence the types of attitudes that develop. If negative attitudes are adopted, negative actions may follow.

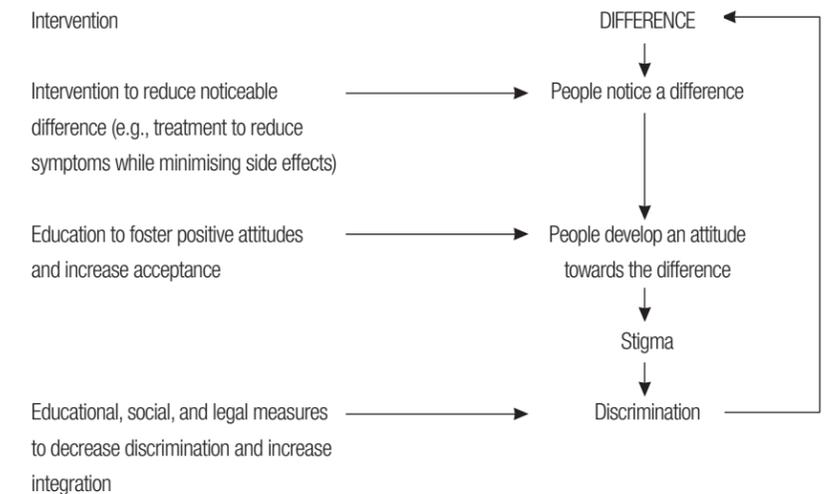
Origins of Stigma

Discrimination adds to the difficulty people with schizophrenia have in regaining the ability to function in society. Such discrimination is the result of a process (see **Figure 5**) that begins when someone is labelled as different (see discussion of labelling theory below). The public at large will develop an attitude toward those who are different. Cultural practices and norms will, of course, influence the types of attitudes that develop. If negative attitudes are adopted, negative actions may follow. Discrimination — which is an expression of negative attitudes — can take many forms. People may refuse to rent to someone with schizophrenia, may refuse to hire the person or not be willing to pay a reasonable amount for his or her work, or may be reluctant to spend time with the person or let him or her associate with their family. Such actions place a great additional burden on those with schizophrenia who are already struggling to overcome their illness and regain a more normal life. Public health authorities will invest less in mental health care than in other areas. Post-graduate students may avoid entering psychiatric training.

As shown in **Figure 5**, interventions to reduce stigma and discrimination can be targeted toward each step of the stigma/discrimination process. Treatment that effectively reduces symptoms without causing stigmatising side effects (e.g., tremors, sluggishness, diminished spontaneity) makes it less likely that people will notice a difference in the person. Education about what schizophrenia is and is not can help change people's attitudes from negative to positive. Finally, social and legal measures targeted at discriminatory practices can reduce the discrimination people with schizophrenia encounter.

FIGURE 5

This figure illustrates how stigma and discrimination develop. Note that one can intervene at any point in the process



Labelling Theory

In the early post-war period, research on the stigma of mental illness was fuelled by interest in labelling theory (Hastings and Remington 1993). Once a deviant person has been labelled “mentally ill,” argued Scheff, society responds in accordance with a pre-determined stereotype and the individual is launched on a career of chronic mental illness from which there is little opportunity for escape (Scheff 1966). There is evidence to support Scheff’s position. Phillips’ study of the attitudes of residents of a small New England town showed that a normal person of an “ideal type” who was described as having been in a mental hospital was socially rejected to a much greater degree than was a person with schizophrenia who sought no help or who instead consulted a clergyman (Phillips 1966).

Critics of labelling theory argue that the approach understates the importance of the initial deviance and of the inherent pathology of mental illness in causing a label to be attached, and that it minimises the capacity of mental patients to shake off the harmful effects of stigma (Gove 1975). A dozen studies conducted after 1963 assessed the relative importance of the mental illness label versus the person’s behaviour in determining public attitudes. Most of these studies found that the effect of labelling was significant but nearly all found that the person’s behaviour was more potent (Link et al. 1987). Similarly, in a more recent study, knowledge of the symptoms of a person’s acute schizophrenic episode created more stigma than the label “schizophrenia” (Penn et al. 1994).

Public Attitudes

With the growth of interest in community psychiatry in the 1950s and 1960s, attention in the industrial world was focused on the question of the stigma of mental illness. Star, using vignettes depicting people with psychotic symptoms, conducted a nation-wide survey of members of the American public in 1950 and found the general reaction to the mentally ill to be negative and poorly informed (Star 1955). Using the same techniques in 1951, Cumming and Cumming uncovered similar attitudes among residents of a rural town (which they called Blackfoot) in Saskatchewan, Canada, and found that the negative attitudes were untouched after a 6-month educational campaign (Cumming and Cumming 1957). Following a survey of residents of the Champaign-Urbana area of Illinois in the 1950s, Nunally concluded that the mentally ill were viewed by the general public with “fear, distrust, and dislike.” “Old people and young people,” reported Nunally, “highly educated people and people with little formal training—all tend to regard the mentally ill as relatively dangerous, dirty, unpredictable and worthless.” They were considered, in short, “all things bad” (Nunally 1961, p.46).

In the following years, a dispute has arisen over whether the initial impressions of high levels of stigma attached to mental illness continue to hold true. A number of researchers in the 1960s concluded that public tolerance for the mentally ill had improved (Lemkau and Crocetti 1962; Meyer 1964; Bentz et al. 1969; Crocetti et al. 1971). In the late 1970s, 20

Commonly held misconceptions about schizophrenia include the following:

- *People with schizophrenia are usually violent and dangerous.*
- *People with schizophrenia are likely to infect others with their madness.*
- *People with schizophrenia are lazy and unreliable.*
- *People with schizophrenia cannot reliably report the effects of treatment or other things that happen to them.*
- *People with schizophrenia are completely unable to make rational decisions about their own lives (e.g., where to live).*
- *People with schizophrenia are unpredictable.*
- *People with schizophrenia cannot work.*
- *People with schizophrenia get progressively sicker all their lives.*

Misconceptions about the nature of schizophrenia and the most appropriate treatments for the disorder exist even among mental health professionals.

It is important to increase the knowledge of mental illness and appropriate treatments and to improve the attitudes of the medical profession in order to achieve further progress in fighting the stigma and discrimination because of schizophrenia.

years after Nunally’s original survey, Cockerham again analysed public attitudes towards the mentally ill in Champaign-Urbana and found that the public was somewhat more tolerant (Cockerham 1981). Rabkin argued in 1980 that attitudes had improved but had subsequently reached a plateau (Rabkin 1980). Other researchers found no improvement in popular mental health attitudes between the 1960s and 1970s (Olmsted and Durham 1976). A second survey of public tolerance of the mentally ill in Blackfoot, Saskatchewan, 23 years after Cummings’ original study, revealed that virtually no change had occurred (D’Arcy and Brockman 1976). As recently as 1993, surveys conducted in two English communities found that respondents failed to identify mental illness much as they had in Star’s U.S. study in 1950; the authors argued that there was a public reluctance to label someone mentally ill because of the negative associations of the term (Hall et al. 1993). The same study revealed that public tolerance of the mentally ill was scarcely better in a district that had been served for 10 years by a model community psychiatry program than in an area that had no such service (Hall et al. 1993; Brockington et al. 1993).

Misconceptions about schizophrenia are still common. For example, a British survey reported in 1996 revealed that 50% of the people surveyed believed that setting fire to public buildings was a “very likely” consequence of mental illness (O’Grady 1996). Similarly, although many Americans correctly attribute the cause of mental illness to inheritance and chemical imbalance, 93% also blame drug and alcohol abuse and 58% blame “lack of discipline” (Borenstein 1992).

Misconceptions about the nature of schizophrenia and the most appropriate treatments for the disorder exist even among mental health professionals. Angermeyer and Matschinger (1996a and b, 1997) investigated the attitudes of medical students toward the treatment of schizophrenia with antipsychotic drugs during the beginning, middle, and end of their studies, and compared them with corresponding attitudes among the general public in Germany. While 50% of the general population favoured treatment of schizophrenia with natural rather than “chemical” remedies, only 10% of the medical students shared this view. In their last terms of study, 25% of the medical students were undecided about medication, indicating that during the course of their studies the students had slightly modified their attitudes in favour of a more rational treatment of schizophrenia. In comparison with the beginning of their studies, when the students’ attitudes were far more in line with the negative attitudes of the general public, this represents significant progress. However, at the end of their studies, 30% of students were still in favour of a qualified prohibition of treatment with neuroleptics with a risk of severe side effects. There are presumably national, age, and speciality-dependent differences in the attitudes of physicians toward mental illnesses in general and schizophrenia and its treatment in particular. Nevertheless, it is important to increase the knowledge of mental illness and appropriate treatments and to improve the attitudes of the medical profession in order to achieve further progress in fighting the stigma and discrimination because of schizophrenia.

In the media, individuals with mental illness are very frequently portrayed in a negative light—as violent criminals, murderers, or rapists, or at best, as objects of mockery.

The report found that mentally ill characters are mostly cast in the role of deviants who are “feared, shunned, shamed and punished.”

Fearmongering by tabloids continues to be common.

Media Representations

Media representations of people with mental illness have shown little change since World War II. In the late 1970s and early 1980s, U.S. media were still projecting a sensational image of those with mental illness (Steadman and Coccozza 1978); much of the time TV dramas represented the mentally ill as violent or homicidal (Gerbner et al. 1981). A U.S. media survey in 1983 (Shain and Phillips 1991) found the same misconceptions of mental illness as Nunally had found in 1961. In the following years, the U.S. advocacy group, the National Alliance for the Mentally Ill, grew in influence and confronted the issue of media coverage, so that, by 1988, press reporting had improved somewhat. There was less focus on crime, and more on causes of illness and treatment, but dangerousness was still a dominant theme (Shain and Phillips 1991).

As part of the Annenberg School for Communication Cultural Indicators Project, a recent study analysed nearly 20,000 speaking parts in 1,371 television programs over 10 seasons of major network television, including cartoons and soap operas, as well as other network and cable programs (Rovner 1993). George Gerbner, dean emeritus of the Annenberg School of Communication at the University of Pennsylvania and author of the report, said he was “frankly appalled” by the results. “The most negatively valued characters, with actually more villains than heroes, are the mentally ill who are at the bottom of fate’s ‘pecking order,’ perpetuating stigma of the most damaging kind.” The report found that mentally ill characters are mostly cast in the role of deviants who are “feared, shunned, shamed and punished,” that mentally ill characters are the most violent and the most victimised single group on television and that “violence and retribution are shown as inherent in the illness itself and thus inescapable.” In the analysis of prime time programming, the study found that 42% of “normal” individuals, but 70% of characters labelled as mentally ill are portrayed as violent. Although approximately 6 out of 10 characters are depicted in a positive way, only 2 out of 10 characters with mental illness are depicted as “good.” Concerning the study, Gerbner wrote “The majority of mentally ill characters on television are not only dangerous but are also touched with a sense of evil that justifies mistrust and eventual failure and victimization.”

A 1993 review of British news coverage revealed that individuals with mental illness were almost always portrayed in a negative light—as violent criminals, murderers, or rapists, or, at best, as figures of fun (Barnes 1993). A 1994 study of British media coverage of mental illness found that accounts of violence outweighed sympathetic reports by four to one (Philo 1994). Fearmongering by tabloids continues to be common. A recent British headline trumpeted, “Hospital Bungle Released Beast for Sex Spree” (Wolff 1997). Another headline vilified health services as “Setting Patients Free to Kill and Rape” (Wolff 1997).

In order to explore the relationship between psychiatry and the media, Matas et al. (1985) administered an attitudinal questionnaire to reporters, psychiatrists, medical outpatients with no psychiatric history, and psychiatric inpatients. The results showed that the media reporters were not less accepting of mental illness than the other groups. However, all groups sampled gave the media low scores for their coverage of mental illness, with psychiatrists tending to be the most critical. Reasons for the negative portrayals of mental illness offered by the reporters included “sensationalism sells” along with cost and time factors.



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One of the chief obstacles to the successful treatment and management of schizophrenia is the stigma often associated with the disorder.

Stigma because of schizophrenia affects not only those with the illness but also their families, caregivers, and healthcare providers.

In 1992, the United Nations adopted resolution 119, which stated that receiving health care for mental illness is a human right. (see page 90)

Neighbourhoods often block mental health residences despite the fact that such residences have not been shown to have adverse effects on communities

Consequences of Stigma

One of the chief obstacles to the successful treatment and management of schizophrenia is the stigma often associated with the disorder. This stigma can lead to severe discrimination that needlessly exacerbates the problems of individuals with schizophrenia. Such discrimination limits the amount of resources for the treatment of schizophrenia, availability of housing, employment opportunities, and social interaction, problems that in turn further increase the stigma associated with the illness. The stigma associated with schizophrenia leads to frequent misrepresentations in the media which help to perpetuate negative stereotypes. The stigma associated with having schizophrenia can also have a negative impact on the course and outcome of the illness itself. Finally, stigma because of schizophrenia affects not only those with the illness but also their families, caregivers, and healthcare providers.

Scarcity of Resources for the Development of Mental Health Services

In most countries of the world, mental health programmes function under conditions of severe financial scarcity. Even in highly developed countries, funds necessary to introduce changes in the treatment and rehabilitation of patients suffering from schizophrenia and its consequences are difficult to obtain. There is a severe disproportion between the seriousness of problems raised by schizophrenia and other mental disorders and the resources reserved to deal with them. It is highly probable that the fact that it is more difficult to obtain funds for services to people with mental illness than for services to people suffering from other diseases can, at least in part, be linked to the stigma attached to mental illness. In 1992, the United Nations adopted resolution 119, which stated that receiving health care for mental illness is a human right (see p. 90).

Housing Problems

Landlords often refuse to rent to individuals with psychiatric problems. In a recent study, it was found that over 40% of landlords immediately rejected qualified applicants who had a known psychiatric disorder (Alisky & Iczkowski 1990). In addition, neighbourhoods often block mental health residences despite the fact that such residences have not been shown to have adverse effects on communities (Boydall et al. 1989). Consequently, many individuals with severe psychiatric illness find themselves homeless or living in very substandard housing. In developing countries, people with schizophrenia and their families may also find themselves ostracised (Wig et al. 1980).

Employment Opportunities

Even though most mentally ill people have a significant capacity for work, fewer than 15% of the mentally ill in the United States are employed (Anthony and Blanch 1987; Farkas et al. 1987; Anthony et al. 1988). Figures from developing countries are difficult to obtain.

Social Isolation

In developed countries, people with schizophrenia are often socially isolated, partly due to stigma and partly as a consequence of the negative symptoms associated with their illness. They have far fewer social contacts than other members of the community, perhaps only a third to a fifth of the number individuals without mental illness possess. A third of the chronically ill have no friends at all. Although family relationships deteriorate less than contact with friends, a considerable disintegration of family ties does occur (Pattison et al. 1975; Cohen and Sokolovsky 1978; Pattison and Pattison 1981; Lipton et al. 1981). The social isolation of the person with schizophrenia in the West stands in contrast to the more effective social reintegration of people with psychosis in the developing world. Although disruptive and violent individuals living in villages who have been designated “mad” do have restricted social networks (Westermeyer and Pattison 1981), the problem does not apply to the same extent to less chronically and severely disturbed people with psychosis in the developing world (Strauss and Carpenter 1981).

In both the developed and developing world, however, social isolation has been repeatedly shown to be associated with poor outcome (WHO 1979; Strauss and Carpenter 1981; Brugha et al. 1993). For example, regardless of symptom severity, people with schizophrenia who have broader and more complex social networks are less likely to be readmitted to hospital (Cohen and Sokolovsky 1978).

Negative Effects on the Course of Illness

How does the stigma of mental illness affect symptoms of schizophrenia and shape the course of the illness? Warner suggests that patients who accept the diagnosis of mental illness feel internal pressure to conform to the stereotype of incapacity and worthlessness, becoming more socially withdrawn and adopting a disabled role. As a result, their symptoms persist and they become dependent on treatment and on the assistance of others. Thus, insight into one’s illness may be rewarded with poor outcome (Warner 1974).

Warner’s view is confirmed by Doherty’s study of self-labelling by psychiatric inpatients. Hospitalised patients who accepted that they were mentally ill were rated as showing the least improvement, while those who denied that they were mentally ill did better (Doherty 1975). A study by Warner and colleagues supported this finding. Patients who accepted that they were mentally ill had lower self-esteem and lacked a sense of control over their lives. Those who found mental illness most stigmatising had the worst self-esteem and the weakest sense of mastery. The study suggested

Patients and families continue to report that stigma is a significant obstacle to community integration (Penn et al. 1994), and it seems likely that being labelled as mentally ill has a significant effect in shaping the self-concept, behaviour, and symptoms of the person with mental illness.

The stigma that attaches to mental illness also taints relatives.

that patients could only benefit from accepting that they were ill if they also had a sense of control over their lives. Such patients were few and far between, however, since a consequence of accepting the illness label was loss of a sense of mastery (Warner et al. 1989). Thus, stigma creates a vicious cycle for people with schizophrenia—accepting the illness can mean losing the capacity to cope with it.

Patients and families continue to report that stigma is a significant obstacle to community integration (Penn et al. 1994), and it seems likely that being labelled as mentally ill has a significant effect in shaping the self-concept, behaviour, and symptoms of the person with mental illness.

The stigma associated with antipsychotic treatment may also be aggravated by psychiatrists who have been shown to be ill-informed about the necessity of long-term antipsychotic maintenance treatment (Meise et al. 1994) and the potential of antipsychotics to induce irreversible tardive dyskinesia (Kissling 1994), which is highly overestimated.

Negative Effects on the Families of People with Schizophrenia

The stigma that attaches to mental illness also taints relatives. Some react by talking to no one, not even close friends, about the illness for years. Those who do discuss the matter openly may find themselves snubbed by acquaintances. “Some old friends quit talking to us,” said the mother of a person with schizophrenia. “They absolutely dropped us.” Other families respond by withdrawing socially. “We haven’t done much entertaining because of this,” commented the parent of another youth with schizophrenia. “I’m never quite sure—he’s so up and down.” In a study in the United States, one-third of wives of those with schizophrenia actively concealed their husband’s illness, dropping and avoiding friends or even moving to a new residence. Another third of the wives discussed their husbands’ illness with only a few selected friends (Yarrow et al. 1955). Although there is a tendency for family members to deny the stigma, their concealment and withdrawal point to an underlying sense of shame and lead them into social isolation (Kreisman and Joy 1974).

In a survey of relatives of people with schizophrenia in Washington, D.C., Hatfield (1978) observed “a picture of unremittingly disturbed family life marked by almost constant stress” as the consequence of caring for a patient at home. She noted that marital disruption, blame, grief, and helplessness were common results. In a study of British families in which someone with schizophrenia was living at home, half the family members reported severe or very severe impairment of their own health as a consequence of their relative’s psychiatric condition (Creer 1975).

All of the parents of people with mental illness in a Massachusetts discussion group “to a greater or lesser extent saw themselves and the others as ogres responsible for the misfortune that befell their children” (Grinspoon et al. 1961). The burden of guilt such relatives carry is the result of the popular misconception that mental illness is a product of faulty upbringing. Mental health professionals, adopting this same

Social isolation is often associated with poor outcome.

attitude, may see the family members as adversaries and add to their estrangement. Isolated and guilt-ridden as they are, it is not surprising that the families of people with schizophrenia sometimes become over-involved with their sick relatives (Brown et al. 1972; Vaughn and Leff 1976). Seeing this interaction, mental health professionals may try to separate them, encouraging the patient to move away from home and minimize contact with relatives. This step completes a process of social disintegration: the patient may become separated from almost everyone except other stigmatised patients; the family members are socially isolated and feel banished not only from the social mainstream but also from their affected relatives (Schene et al. 1996).



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What Can be Done to Reduce Stigma and Discrimination?

In order to reduce the stigma and discrimination because of schizophrenia, it is necessary 1) to improve treatments, 2) to change people's attitudes through education and outreach programs, and 3) and to change public policy and laws to reduce discrimination and increase legal protection for those with mental illness (see Figure 5, p.76). Some specific strategies that can help reduce stigma and improve the quality of life for individuals with schizophrenia are listed in **Table 8**.

Table 8

Strategies for Reducing Stigma and Improving Quality of Life for Individuals with Schizophrenia

- Increase development and use of medications that control symptoms while minimising stigmatising side effects.
- Initiate community educational activities aimed at changing attitudes.
- Include anti-stigma education in the training of teachers and health care providers.
- Improve psychoeducation of patients and families about ways of living with the disease.
- Involve patients and families in identifying discriminatory practices.
- Promote social and legal action to reduce discrimination.

Educational and Outreach Initiatives

Educational campaigns on the local level have been shown to be effective in reducing stigma and discrimination because of schizophrenia. Surveys of public attitudes reveal negative attitudes but also a substantial amount of goodwill toward the mentally ill. When neighbours of a new group home for people with mental illness in south London were surveyed, two-thirds expressed a willingness to help the new facility and showed interest in learning more about mental illness. Organisers found that this goodwill could be mobilised by a focussed education campaign which encouraged neighbours to initiate social contact with mentally ill residents (Wolff 1997). During the campaign, informational packets (videotapes and written materials) were distributed, and social events and informal discussion sessions were organised. The campaign decreased fearful and rejecting attitudes and increased contacts between group-home residents and their new neighbours. Thirteen percent of the neighbours made friends with patients or invited them into their homes, whereas no neighbours did so in an area which was not exposed to the educational program (Wolff 1997). Campaigns that increase contact with patients can be expected to improve attitudes, since personal knowledge of someone with mental illness is associated with greater tolerance (Penn et al. 1994).

Carefully designed campaigns can have substantial effects on behaviour.

See Appendix E for a list of common misconceptions about schizophrenia and information that can be used to dispel these myths.

Such projects suggest that local action campaigns are feasible and effective. Can broader societal campaigns achieve a similar impact? To answer this question, we should study advances in modern communication technology.

Since the unsuccessful anti-stigma campaigns of the post-war period, public education methods and techniques for health promotion have improved dramatically. Such “social marketing” campaigns, as they are known in the communication field, have been used successfully around the world in reducing infant mortality, AIDS prevention, family planning, improving nutrition, smoking cessation, and a variety of other causes (Rogers 1995). Carefully designed campaigns can have substantial effects on behaviour (Rogers et al. 1995). Effectiveness is increased by “audience segmentation”—partitioning a mass audience into sub-audiences that are relatively homogeneous and devising promotional strategies and messages that are more relevant and acceptable to those target groups (Rogers et al. 1995; Rogers 1996).

In developing such campaigns, it is important to conduct a needs assessment to gather information about cultural beliefs, myths and misapprehensions, and the media through which people would learn about the topic. The needs assessment may incorporate focus groups, telephone surveys, and information from opinion leaders. A pre-testing mechanism is then established that allows the promotional strategy to be continuously refined (Rogers 1995) (see Volume 1). Initially, specific objectives, audiences, messages, and media are selected, and an action plan is drawn up. These messages and materials are pre-tested with specific audiences and revised. The plan is implemented and, with continuous monitoring of impact, a new campaign plan is developed and constantly refined. A number of common misconceptions about schizophrenia along with information that can be used to dispel these misconceptions are listed in Appendix E to this volume.

Health promotion campaigns aim to heighten awareness and to provide information. Awareness campaigns need to be supported by an infrastructure that can link people to sources of information and support—for example, a telephone number to call where trained people respond to the caller. Ideally, the infrastructure should be a central organisation with a local network.

Entertainment media, such as popular songs and soap operas, can heighten awareness and provide information and are especially useful for socially taboo topics such as mental illness. Soap operas have been successful in advancing social messages in several countries. For example, a television soap opera in China called *Ordinary People*, which promotes smaller family size and AIDS education, began broadcasting in 1995 and will, in due course, reach 16% of the world's population (Rogers et al. 1995). A radio soap opera encouraging AIDS awareness and family planning gained a wide audience in Tanzania and was effective in changing attitudes and sexual behaviour. Similarly, a television program centred on a character named Maria and aired in Mexico for 40 years, has promoted adult education among other things (Rogers et al. 1995).

In developing campaigns to increase awareness and knowledge of mental illness, it is very helpful to collaborate with local social advocacy groups.

Campaigns that increase contact with patients can be expected to improve attitudes, since personal knowledge of someone with mental illness is associated with greater tolerance.

Focus groups of local experts and representatives of interest groups help generate the “moral messages” for such serial dramas.

The approach embraces social-learning theory and the concept that people model their behaviour on others.

A character with schizophrenia was recently introduced into the most widely watched program in Britain, EastEnders. The National Schizophrenia Fellowship reports that this story line has attracted unprecedented attention and done more to reduce stigma than any number of worthy media appeals.

Focus groups of local experts and representatives of interest groups help generate the “moral messages” for such serial dramas. Scriptwriters develop positive, negative, and transitional characters. Transitional characters switch from positive to negative behaviour, or vice versa, to illustrate the rewards and consequences of their decisions. Characters are devised to reflect a variety of age ranges of both genders so that listeners can find someone with whom to identify. The approach embraces social-learning theory and the concept that people model their behaviour on others.

Pure entertainment soap operas can also be adapted to incorporate characters with a social message. In the United States, a group calling itself the “Soap Summit” analyses the content of soap operas (looking at such topics as teenage sexual behaviour), lobbies scriptwriters to change the content of their programs to create positive social messages, and measures the impact of their lobbying on soap-opera content. A character with schizophrenia was recently introduced into the most widely watched program in Britain, *EastEnders*. The National Schizophrenia Fellowship reports that this story line has attracted unprecedented attention and done more to reduce stigma than any number of worthy media appeals. The program has humanised the illness and exploded the myths that schizophrenia means someone has a split personality and or that it is likely to make someone violent (Frean 1997).

Films can also help to heighten awareness and to communicate information. After the film *Rain Man* was released in 1988, the National Alliance for the Mentally Ill (NAMI) and other associations reported that the general public became more accepting and sympathetic to autistic children and adults with schizophrenia. A recent film, *Le Huitième Jour*, which received a prize at the Cannes Film Festival in 1996, concerns a boy with Down’s Syndrome and can be expected to increase understanding and tolerance for individuals with this condition. The Oscar-winning Australian movie *Shine* conveyed several anti-stigma messages about serious mental illness.

Legislative and Policy Initiatives

To reduce discrimination because of schizophrenia, it is also important to lobby for better legal protections for those with mental illness. In some countries, legislative measures and judgements by the courts have greatly helped to reduce discrimination against people with mental illness.

For many years, mental health professionals in India have been protesting against the pitiable condition of the mentally ill languishing in the country’s jails. Recently, a group of social workers started a campaign to improve the lot of women prisoners in jails in West Bengal. It soon turned out that a large number of these women were mentally ill and were being kept in jails without any criminal record. A public interest litigation in the Supreme Court of India, the highest court in the land, resulted in a swift enquiry by a commission of the court and a far reaching judgement by the Chief Justice of India that it is unconstitutional to keep any person in jail in India only for the reason of mental illness. This single judicial intervention has forced many states in India to think of the human rights of those with mental illness and to provide better facilities for their care (Times of India, August 19, 1993).

A number of countries have also taken legislative steps to end discrimination against those with physical and mental disabilities.

The Americans with Disabilities Act was signed into law in the United States in July, 1990. This Act prohibits discrimination on the basis of disability in employment, programmes, and services provided by state and local governments, goods and services provided by private companies, and in commercial facilities. This step marked a large step forward in reducing discriminatory practices against all those with disabilities, including individuals with serious mental illness.

Similar legislation was passed in Australia in 1992 (the Australian Disability Discrimination Act), in the United Kingdom in 1995 (the U.K. Disability Discrimination Act), in Hong Kong in 1995 (the Disability Discrimination Ordinance), and in India in 1995 (The Persons with Disabilities [Equal Opportunities, Protection of Rights, and Full Participation] Act). These legislative initiatives cover a wide range of physical and mental disabilities and address discrimination and harassment in areas such as employment, education, access to premises, provision of goods, facilities, and services, and design of and alterations to buildings (Cheung 1997).

On February 18, 1992, the United Nations adopted resolution 119. This resolution provided for the adoption and dissemination of the “Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care.” The principles are outlined in an annex to the resolution and indicate the awareness of the United Nations that

- Mental illness is a major public health problem
- People with mental illness often do not receive appropriate mental health care
- Receiving health care for mental illness is a human right
- Care should be provided in the least restrictive facilities possible.

Numerous professional associations, including the World Medical Association and the World Psychiatric Association, have set out guidelines for providing ethical and high quality care for the mentally ill. In 1977, the World Psychiatric Association adopted the Declaration of Hawaii, which was subsequently amended in 1983 (World Psychiatric Association 1977, 1983). This document set out ethical guidelines for the practice of psychiatry. In 1989, the World Psychiatric Association adopted a Statement on the Rights and Legal Safeguards of the Mentally Ill at the General Assembly at the Athens (World Psychiatric Association Bulletin 1990).

Reflecting the impact of changing social attitudes and new medical developments in the psychiatric profession, in August, 1996, the World Psychiatric Association General Assembly adopted the Declaration of Madrid. This Declaration deals with the ethical principles that should govern the work of psychiatrists and the organisation of psychiatric services. The dominant theme in the Declaration is the need for the psychiatrist to respect the patient and arrive at a treatment decision in collaboration with the patient rather than to impose treatment upon him. (The text of the Declaration of Madrid is given in Appendix F)



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Appendices to Volume 2

Appendix A

The ICD-10 Diagnostic Criteria for Schizophrenia

The ICD-10 diagnostic criteria for schizophrenia organise the symptoms into nine groups, a certain number of which are required to make a diagnosis (usually one very clear symptom or two or more if they are less clear-cut). The symptoms must have been present for at least 1 month in order to diagnose schizophrenia. The nine groups of symptoms are listed and described below:

(a) Thought echo, thought insertion or withdrawal, and thought broadcasting

Thought echo is hearing one's thoughts aloud. Thought insertion and withdrawal mean that the person believes that thoughts are either being put into or taken out of his or her head by an external agency. Thought broadcasting means that the person believes that everybody knows his or her thoughts because they are being broadcast in some way that is different from voluntary communication. These symptoms reflect the person's alienation from the content of his or her own thoughts.

(b) Delusions of control, influence, or passivity, clearly referred to body or limb movements or specific thoughts, actions, or sensations; delusional perception

In this type of delusion, people believe that their thoughts, actions, and perceptions are being controlled by someone or something outside them, again reflecting a dissociation of the individual's mental processes from the experience of the self.

(c) Hallucinatory voices giving a running commentary on the patient's behaviour, or discussing the patient among themselves, or other types of hallucinatory voices coming from some part of the body

Many people with schizophrenia report that voices keep commenting on their behaviour. These voices usually make very negative judgements about the person.

(d) Persistent delusions of other kinds that are culturally inappropriate and completely impossible, such as religious or political identity, or superhuman powers and abilities (e.g., being able to control the weather or being in communication with aliens from another world)

For example, people may believe that they can live for ever and repeatedly survive experiences that would kill others, that they can heal others by "clean thinking," that they are a king or renowned leader, or that they are married to someone from another planet.

Symptoms a-d are considered especially typical of schizophrenia. Therefore, if one of these symptoms is present for at least 1 month, the diagnosis of schizophrenia can be established.

The following four groups of symptoms (e-h) are also important, but two of them must have been present for 1 month to make the diagnosis.

(e) Persistent hallucinations in any modality, when accompanied either by fleeting or half-formed delusions without clear affective content, or by persistent overvalued ideas, or when occurring every day for weeks or months on end

As mentioned above (see criterion c), the most common hallucinations are auditory, but tactile, olfactory, visual, and other misperceptions and false perceptions may also be present. People with schizophrenia may smell “poisonous” odours, experience the sensation of flying through the air, feel a stranger in their own bodies, or have the feeling that an insect is crawling on their skin. They may see people that are not really there or complex scenes that are not real.

(f) Breaks or interpolations in the train of thought, resulting in incoherence or irrelevant speech, or neologisms

Oddities in the thought processes of persons with schizophrenia may lead to the fragmentation and disintegration of logical thinking. The person may be unable to organise a group of unrelated thoughts. Neologisms are words that people with schizophrenia may make up to replace standard words (e.g., using the word “rementification” to mean building a new personality).

(g) Catatonic behaviour, such as excitement, posturing, or waxy flexibility, negativism, mutism, and stupor

These symptoms include a wide variety of strange, purposeless motor behaviour. In stupor, the person loses the ability to react to the environment so that movements and spontaneous activity disappear. In mutism, the person does not communicate orally. The opposite of stupor is excitement and agitation in which motor activity increases in a way that is not related to external stimuli and appears to have no goal or purpose. In some cases, when individuals with schizophrenia are placed in a position by someone else, they will maintain this position (called “waxy flexibility”). They may also assume and maintain inappropriate postures for long periods of time. For example, the person may assume an unnatural head position as if lying on a pillow (“a psychological pillow”). Other catatonic symptoms include muscular rigidity, conspicuous jerking movements, mimicking the words and movements of others, and a loss of “natural grace” in movements.

(h) “Negative” symptoms such as marked apathy, paucity of speech, and blunting or incongruity of emotional responses, usually resulting in social withdrawal and lowering of social performance; it must be clear that these are not due to depression or to neuroleptic medication.

This is an important group of symptoms that may help predict the outcome of the disorder (See Course and Outcome of Schizophrenia p. 24). Negative

symptoms may be considered a manifestation of an overall decrease in energy level. People may show a restricted range and depth of emotions and may be less able to participate emotionally in certain situations. This loss of emotional depth and range may increase and become more general so that the person becomes completely apathetic. Scarcity and impoverishment of thoughts is reflected in a poverty of speech. The person may lose motivation (a symptom called avolition). These symptoms may cause the person to withdraw socially or become uneasy and clumsy in social situations because of a fear of failure. It can be difficult to distinguish negative symptoms from the depression that may accompany schizophrenia. However, it is important for clinicians to try to make this distinction since proper treatment of depressive symptoms may significantly improve the person’s ability to function.

The final group of symptoms (i) may be one of the main causes of the social and occupational problems people with schizophrenia face.

(i) A significant and consistent change in the overall quality of some aspects of personal behaviour, manifest as loss of interest, aimlessness, idleness, a self-absorbed attitude, and social withdrawal.

Appendix B

ICD-10 Subtypes of Schizophrenia

Four Main Subtypes of Schizophrenia

Subtype	Target systems	Typical Symptoms	Comments
Paranoid	Thinking, perception	Delusions (mostly of persecution), hallucinations	Commonest type
Hebephrenic (disorganised)	Emotions, volition	Inappropriate affect, silliness, formal thought disorder, mental fragmentation	Typically begins in adolescence
Catatonic	Volition, motor activity	Stupor, agitation, posturing, mannerism, negativism	Becoming rare
Simple	Volition, personality	Social withdrawal, flat emotions, poverty of ideas, decreased drive and motivation	Insidious onset of behavioural problems

Undifferentiated schizophrenia combines features of two of the following types: paranoid, hebephrenic, and catatonic. The person's symptoms meet the diagnostic criteria for schizophrenia but do not fully conform to any one of the main subtypes.

Residual schizophrenia describes a stage in the disorder in which there has been a clear-cut episode of schizophrenia in the past and prominent negative symptoms are still present. However, the intensity or frequency of other psychotic symptoms, such as delusions, hallucinations, or catatonic symptoms, is reduced.

Post-schizophrenic depression describes the common situation in which a person develops mainly depressive symptoms following an acute psychotic episode, although negative or positive symptoms may still also be present.

Appendix C

Common Standard Antipsychotic Medications

Common Standard (Traditional) Antipsychotic Medications*

Benperidol	Levomepromazine
Bromperidol	Oxypertine
Butaperazine	Penfluridol
Chlorpromazine	Perazine
Chlorpromazine	Periciazine
Cloperithixol	Perphenazine
Clotiapine	Pimozide
Droperidol	Pipamperone
Fluanisone	Promazine
Flupentixol	Promethazine
Fluphenazine	Sulpiride
Fluspiriline	Thioridazine
Haloperidol	Trifluoperazine

*Product names vary from country to country and more than one product name may be used for the same drug within one country. When participating in this program, it will be helpful to obtain a list of the common product names in use in the country where the project is being undertaken.

Appendix D

Novel Antipsychotic Drugs That Are Currently Available in Selected Countries

Amisulpiride	Risperidone
Clozapine	Sertindole
Olanzapine	Zotepine
Quetiapine	

Appendix E

Dispelling Popular Misconceptions About Schizophrenia

The information provided in this appendix can be used in educational and public awareness programs to correct misinformation about schizophrenia. In each case, we first present the popular misconception about schizophrenia and then give information that can be used to dispel the myth and cross-references to the sections in Volume 2 where these issues are discussed in more detail.

Misconception: Schizophrenia is Split Personality or Multiple Personality Disorder.

Fact: Schizophrenia is not multiple personality disorder, which is an hysterical or dissociative condition. Nor is it “split personality,” a term that has sprung up from the Greek origins of the name “schizophrenia”—“split mind.” The term “schizophrenia” was coined by the Swiss psychiatrist, Eugen Bleuler, in the early years of the twentieth century to describe the fragmentation of the person’s thinking and feeling processes which he saw occurring in the illness. Neither the term “split mind” nor “split personality” clarify what schizophrenia really is—a serious brain illness. Moreover, the popular use of the word “schizophrenic” to mean a mixture of contradictory qualities is completely different from the psychiatric use of the term or the characteristics of people who suffer from schizophrenia.

Misconception: People Never Recover from Schizophrenia

Fact: Schizophrenia does not invariably have a downhill course. The misconception that schizophrenia is always an incurable disease leads to hopelessness and despair, neglect, abandonment, and burn-out of family members. (See the discussion on the course and outcome of schizophrenia, pp. 29-33, for a detailed discussion of these issues.)

Misconception: Poor Parenting Causes Schizophrenia

Fact: Psychiatrists since Sigmund Freud have regarded the family as crucial to the development of human personality and mental disorder and many have looked to the family for dynamic forces capable of creating schizophrenia. Despite this concerted effort, no evidence has been found that the family environment or poor parenting cause schizophrenia.

As early as 1948, psychoanalysts proposed that mothers fostered schizophrenia in their offspring through cold and distant parenting (Fromm-Reichmann 1948). Others have pointed to parental schisms and confusing patterns of communication within the family as important in causing the illness (Lidz et al. 1965; Laing and Esterton 1970). The double-bind theory, put forward by anthropologist Gregory Bateson and his colleagues, argued that schizophrenia is promoted by contradictory parental messages from which the child is unable to escape (Bateson et al. 1956).

While enjoying broad public recognition, such theories have seldom been adequately tested. Research that claimed to find abnormalities in the communication patterns of families of people with schizophrenia (Wynne and Singer 1963) was not confirmed by later research (Hirsch and Leff 1975; Woodward and Goldstein 1977). None of the work in this area, furthermore, satisfactorily resolves the question of whether the patterns of deviance alluded to in the families of people with schizophrenia are the cause or the effect of psychological abnormalities in the family member with mental illness.

Thousands, if not millions, of family members of people with schizophrenia have suffered shame, guilt, and stigma as a consequence of the widespread acceptance of such theorising. Parents not only witness their child’s personality change and his or her ambitions being destroyed by illness, they sometimes feel blamed for causing the condition. Family members often carry the burden of living with someone whose actions may be distressing and whose emotional responses may be unrewarding. They need empathy and support from therapists, not censure and distrust.



- [1] Bateson G, Jackson D, Haley J. Towards a theory of schizophrenia. *Behavioral Science* 1956;1:251-64.
- [2] Fromm-Reichmann F. Notes on the development of treatment of schizophrenia by psychoanalytic psychotherapy. *Psychiatry* 1948;11:263-273.
- [3] Hirsch S, Leff J. *Abnormality in Parents of Schizophrenics*. London: Oxford University Press; 1975.
- [4] Laing RD, Esterton A. *Sanity, Madness and the Family: Families of Schizophrenics*. Baltimore: Penguin Books; 1970.
- [5] Lidz T, Fleck S, Cornelison A. *Schizophrenia and the Family*. New York: International Universities Press; 1965.
- [6] Woodward J, Goldstein M. Communication deviance in the families of schizophrenics: A comment on the misuse of analysis of covariance. *Science* 1977;197:1096-1097.
- [7] Wynne LC, Singer M. Thought disorder and family relations. *Arch Gen Psychiatry* 1963;9:199-206.

The belief that schizophrenia is contagious has greatly contributed to the stigma that is attached to all those who are in contact with people with schizophrenia (e.g., family members, caregivers, therapists).

Misconception: Schizophrenia Is Contagious

Fact: Schizophrenia is not contagious. However, the belief that schizophrenia is contagious is widespread around the world and is the basis for much prejudice against people with mental illness. Fear of contagion results in people avoiding social contacts with those who have schizophrenia and excluding them from living or working near others in the community. Fear of contagion may also lead to the stigmatisation of family members, mental health professionals, and places of treatment.

Misconception: Schizophrenia Is Caused by Evil Spirits or Witchcraft

Fact: Although this is untrue, in a large part of the world many people believe that schizophrenia is caused by the actions of ancestral spirits or the use of witchcraft. There are a multitude of other misconceptions about schizophrenia. For example, we know that:

- Schizophrenia is not caused by a curse or “evil eye.”
- Schizophrenia is not God’s punishment for family sins.
- Schizophrenia is not caused by a lack of faith in God.
- Schizophrenia is not a form of demonic possession.
- Schizophrenia is not a result of frustrated love.
- Schizophrenia is not caused by reading too many books.
- Schizophrenia is not caused by eating poisoned food when asleep or awake.
- Schizophrenia is not transmitted by breast feeding.
- Schizophrenia is not caused by masturbation.

Diverse traditional beliefs about the nature and cause of mental illness may lead people with symptoms of schizophrenia and their families to seek care from a broad array of practitioners, and the use of indigenous healing practices in conjunction with medical treatment is widespread. For a discussion of the role of the traditional healer in the treatment of schizophrenia, see p. 60.

Misconception: People with Schizophrenia Are Mentally Retarded

Fact: Although, people with schizophrenia are sometimes confused with people who have mental retardation, schizophrenia and mental retardation are two very different conditions. This can be seen from the age of onset of the two disorders. Mental retardation is usually identified in early childhood, whereas, in the majority of cases, schizophrenia has its onset in adolescence or young adulthood.

The belief that schizophrenia is caused by evil spirits or witchcraft may reduce the provision of appropriate treatment. At the same time, however, such beliefs may have the effect of freeing the person with the illness from stigma, since he or she is viewed as the innocent victim of others’ hostility.

Misconception: People with Schizophrenia Have to Be Kept in the Hospital

Fact: Recent studies have shown that a variety of settings, ranging from innovative alternatives to the hospital to comprehensive community programs, can be effective in treating people with schizophrenia. (See the discussion of treatment settings, pp. 64-68, for a discussion of these issues.)

Misconception: Jail is an Appropriate Place for People with Schizophrenia

Fact: People with schizophrenia should not be kept in jail. People with schizophrenia are likely to get worse if treated punitively or confined unnecessarily. (See p. 67 for a detailed discussion.)

Misconception: People with Schizophrenia Are Not Able to Make Decisions About Their Own Treatment

Fact: People with schizophrenia can be involved in their treatment. (See p. 53)

Misconception: People with Schizophrenia Are Likely to Be Violent

Fact: People with schizophrenia are not likely to be violent. (See pp. 15-16 for a detailed discussion of this issue.)

Misconception: Most People with Schizophrenia Can’t Work

Fact: People with schizophrenia can work even if they have symptoms. Work helps people recover from schizophrenia. (See pp. 61-64 for a discussion of employment issues and schizophrenia.)

Appendix F

Declaration of Madrid

Psychiatry is a medical discipline concerned with the provision of the best treatment for mental disorders; with the rehabilitation of individuals suffering from mental illness and with the promotion of mental health. Psychiatrists serve patients by providing the best therapy available consistent with accepted scientific knowledge and ethical principles. Psychiatrists should devise therapeutic interventions that are least restrictive to the freedom of the patient and seek advice in areas of their work about which they do not have primary expertise. While doing so, psychiatrists should be aware of and concerned with the equitable allocation of health resources.

It is the duty of psychiatrists to keep abreast scientific developments of the specialty and to convey updated knowledge to others. Psychiatrists trained in research should seek to advance the scientific frontiers of psychiatry.

The patient should be accepted as a partner by right in therapeutic process. The therapist-patient relationship must be based on mutual trust and respect to allow the patient to make free and informed decisions. It is the duty of psychiatrists to provide the patient with relevant information so as to empower the patient to come to a rational decision according to his or her personal values and preferences.

When the patient is incapacitated and/or unable to exercise proper judgement because of a mental disorder, the psychiatrists should consult with the family and, if appropriate, seek legal counsel, to safeguard the human dignity and the legal rights of the patient. No treatment should be provided against the patient's will, unless withholding treatment would endanger the life of the patient and/or those who surround him or her. Treatment must always be in the best interest of the patient.

When psychiatrists are requested to assess a person, it is their duty first to inform and advise the person being assessed about the purpose of the intervention, the use of the findings, and the possible repercussions of the assessment. This is particularly important when the psychiatrists are involved in third party situations.

Information obtained in the therapeutic relationship would be kept in confidence and used, only and exclusively, for the purpose of improving the mental health of the patient. Psychiatrists are prohibited from making use of such information for personal reasons, or financial or academic benefits. Breach of confidentiality may only be appropriate when serious physical or mental harm to the patient or to a third person could ensue if confidentiality were maintained; in these circumstances, psychiatrists should whenever possible, first advise the patient about the action to be taken.

Research that is not conducted in accordance with the canons of science is unethical. Research activities should be approved by an appropriately constituted ethical committee. Psychiatrists should follow national and international rules for the conduct of research. Only individuals properly trained for research should undertake or direct it. Because psychiatric patients are particularly vulnerable research subjects, extra caution should be taken to safeguard their autonomy as well as their mental and physical integrity. Ethical standards should also be applied in the selection of population groups, in all types of research including epidemiological and sociological studies and in collaborative research involving other disciplines or several investigating centers.