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Schizophrenia—Time to Commit to Policy Change

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Care and outcomes for people with schizophrenia have improved in recent years, but further progress is needed to help more individuals achieve an independent and fulfilled life. This report sets out the current need, informs policy makers and all relevant stakeholders who influence care quality, and supports their commitment to creating a better future. The authors recommend the following policy actions, based on research evidence, stakeholder consultation, and examples of best practice worldwide. (1) Provide an evidence-based, integrated care package for people with schizophrenia that addresses their mental and physical health needs. (2) Provide support for people with schizophrenia to enter and to remain in their community, and develop mechanisms to help guide them through the complex benefit and employment systems. (3) Provide concrete support, information, and educational programs to families and carers on how to enhance care for an individual living with schizophrenia in a manner that entails minimal disruption to their lives. (4) All stakeholders, including organizations that support people living with schizophrenia, should be consulted to regularly revise, update, and improve policy on the management of schizophrenia. (5) Provide support, which is proportionate to the impact of the disease, for research and development of new treatments. (6) Establish adequately funded, ongoing, and regular awareness-raising campaigns that form an integral part of routine plans of action. Implementation of the above recommendations will require engagement by every stakeholder, but with commitment from all, change can be achieved.

Key words: schizophrenia/health policy/quality of life/antipsychotics/psychotherapy/recovery

A word on language

How best to refer to people with schizophrenia is an emotive, and sometimes controversial, question. The word "patient" is appropriate in a medical context but may be too clinical for a person living in the community. Terms such as "service user," "client," and "consumer" are used in some countries and settings, but they often do not translate well elsewhere. In this report, the authors have chosen to use the word "patient" when the setting is strictly clinical, but "person with schizophrenia" (or similar) is used in other contexts.

Introduction

At least 26 million people are living with schizophrenia worldwide,[1] and twice as many are indirectly affected by it. Owing to the chronic nature of the condition, it affects a person's wellbeing,[2] shortens life, and is among the top 10 causes of disability globally.[3]

Unusually, the protection and treatment of people with mental disorders is recognized by the United Nations (UN) as a fundamental human right.[4] We have come a long way toward achieving this in recent years, but more can still be done. In particular, achieving some degree of recovery should be the goal of treatment from the onset of the disorder. With appropriate care and support, people can recover and live fulfilled lives in the community, with up to 50% of individuals potentially having a good outcome.[5,6]

Antipsychotic medication is effective in treating acute psychotic episodes and improves symptoms of early schizophrenia in 85% of patients[7]; long-term therapy can reduce the risk of psychotic relapses by 60%,[8] and it has also been shown to reduce suicidal behavior.[9] Currently available drugs, however, have limited effects on the most disabling "negative" symptoms and on cognitive impairment, which are associated with decreased social function.[10] The authors strongly support the rationale for research and development of new treatments to address this unmet need.

Psychosocial interventions also promote recovery and are cost-effective[11]; relapses and hospitalizations can be reduced by 20% when families are included in the treatment.[12] Furthermore, the support and education provided by peer-led groups and advocacy groups substantially improve quality of life; 48% of people with schizophrenia identify self-management strategies as an important factor in their recovery.[13] The extent to which psychosocial therapies are funded by public health care systems varies across countries and, as a result, many patients are denied or are unable to access such treatment. These interventions should be made available to everybody in need.

In addition to the routine activities of health services, psychoeducation aimed at the general public can be effective in increasing awareness, changing negative perceptions of mental illness, and addressing prejudice and discrimination toward schizophrenia.[14] Therefore, educational and multimedia campaigns, including social marketing approaches, should be developed and sustained.

One of the most fundamental issues is that people with schizophrenia die 15–20 years earlier than the general population.[15,16] It is thus important not only to manage the symptoms of schizophrenia but also to treat coexisting physical illnesses. Underdiagnosis and undertreatment contribute to this high death rate. It should be a priority to develop and implement an evidence-based, integrated care package that addresses patients' mental and physical health needs. This should be underpinned with an integrated approach by health care professionals and supported by the health care system.

Without an environment that supports recovery, treatment may not be effective. In today's society, it is unacceptable that patients with schizophrenia are 6–7 times more likely to be unemployed than the general population, and only 10%–20% are in competitive employment.[17,18] Supported employment approaches are effective and should be encouraged, and better mechanisms are needed to guide people through the benefit and employment system. Furthermore, up to one-third of homeless people in the United States have schizophrenia, and 15% of people with schizophrenia in Europe have experienced homelessness,[19] which is a major barrier to recovery. Contact with the criminal justice system is also common[20] but can be prevented by high-quality, early intervention services, which also reduce hospitalizations and increase employment rates, producing significant savings in health care and societal costs.[20] More, therefore, needs to be done to identify schizophrenia earlier and to initiate appropriate treatment as soon as possible.

In conclusion, the care of people with schizophrenia can be vastly improved through political action, changes in health service organization and better use of integrated psychological, medical, and social interventions. This approach, combined with active engagement on the part of people with schizophrenia, their families, and their communities, could lead to better lives for all those affected.

Report Development

This report summarizes the evidence and consensus findings emerging from discussions among a group of international psychiatrists, researchers, advanced practice nurses, patients, and carers with expertise and experience in the field of schizophrenia. The group met several times and brought together knowledge of the clinical and scientific evidence base for schizophrenia, combined with first-hand insight into the practical reality of living daily with the condition.

This diverse group was united in reaching 3 clear, evidence-based conclusions.

- The likelihood of a good outcome for people with schizophrenia has improved in recent decades; with appropriate management, many people affected by the condition can now achieve an acceptable quality of life.
- A modern approach to schizophrenia management should aim to move patients along a pathway toward recovery of normal function, as well as to alleviate distressing symptoms.
- Driving further change toward a more positive outlook in schizophrenia requires fundamental policy change.

Protection and Treatment—Delivering Our Fundamental Human Right

Key points

- Schizophrenia is a mental disorder characterized by abnormal thinking, perceptual disturbances, and diminished or exaggerated emotional expression.
- The protection and treatment of people with mental disorders such as schizophrenia is recognized by the United Nations as a fundamental human right.
- Recent advances mean that people with schizophrenia can live productive and satisfying lives, but many still face discrimination, making it difficult for them to integrate into society.

- As well as the potential human cost, schizophrenia places substantial demands on health care resources and on society.
- Improving care for people with schizophrenia, their carers, and their families should be an urgent health care priority.

Living With Schizophrenia: What Does It Mean?

The term schizophrenia describes a mental disorder characterized by abnormal thinking, perceptual disturbances, and diminished or exaggerated emotional expression. It is estimated that schizophrenia directly affects at least 26 million people worldwide, and twice as many are indirectly affected by it (eg, as carers).[1] In the European Union (EU), psychotic illnesses such as schizophrenia affect about 5 million people,[21] while data from the United States indicate that approximately 2.4 million people have schizophrenia (about 1.1% of the US adult population).[22] It is also prevalent in Africa, The Americas, South-East Asia, and the Western Pacific region, where 2.1 million, 3.9 million, 6.2 million, and 7.9 million people, respectively, are directly affected by the condition.[1] Moreover, each year, about one person in 4000—around 1.5 million people worldwide—is diagnosed with schizophrenia.[23]

Schizophrenia is typically diagnosed in adolescence or early adulthood and may affect a person's wellbeing throughout life[2]; indeed, the World Health Organization (WHO) has identified schizophrenia as one of the 10 leading global causes of disability, and imposes a significant disease burden worldwide.[3,24]

The protection and treatment of people with mental disorders such as schizophrenia is now recognized by the UN as a fundamental human right.[4] This means that all affected individuals should be helped to live a life free from prejudice, discrimination, and hostility. They should be protected from abuse and from behavior, attitudes, and assumptions that lead to social exclusion; they also have a right to the best available treatments. These rights are enshrined in the WHO Global Mental Health Action Plan,[25] which emphasizes the use of evidence-based therapies and the empowerment of people with mental disorders. Mirroring these WHO aspirations, during the last 2 decades, the care of people with schizophrenia has seen positive advances in many countries, with improvements in medications and psychosocial therapies, and in societal attitudes toward those affected; mental health has well and truly arrived on the global health agenda.[26]

Views about the outcome of schizophrenia have also been evolving, and a growing movement now emphasizes a vision of recovery, with a shared hope and expectation of living a productive and satisfying life with mental illness.[6] Although schizophrenia is undeniably a potentially disabling and severe mental disorder, people with the illness can—with appropriate clinical assessment, support, and recognition of their needs—make remarkable progress.[5] Even with the tools available today, a significant proportion recover fully. Many more can achieve at least some degree of recovery, with an improvement in their symptoms and a reduction in the impact of schizophrenia on everyday life.[6,27]

Social Consequences for People Living With Schizophrenia

Despite the improvements in societal attitudes, many people with schizophrenia still face social isolation, prejudice, and discrimination, making it difficult for them to live a productive life in society. This discrimination can prevent them from seeking help for their condition and can also disrupt their personal relationships and employment: people with schizophrenia are more likely to be unemployed than those without the condition, and they are also particularly likely to come into contact with the criminal justice system, either as perpetrators or more likely as victims.[13] A recent national study in Sweden found that people with schizophrenia are 1.8 times more likely to be victims of homicidal death than those without mental illness.[28]

Schizophrenia also imposes a heavy toll on families and friends, who bear much of the day-to-day burden of care (figure 1). Mental illness affects the entire family; a recent survey found that 68% of carers are parents or step-parents of the person living with schizophrenia, 12% are siblings, and 7% are spouses/significant others.[29] Many carers experience challenging emotions such as grief, exhaustion, anger, and fear for the future.[13] Some carers may find the burden of care so excessive that they cannot continue in their role; we need to prevent this happening through appropriate care for patients and support for carers.

Compared with the general population, carers of people with schizophrenia are at an increased risk of developing stress-related disorders and physical health problems. In 1 survey in the United States, 41% of carers had provided care for more than 10 years, and over half found it challenging to take care of their own health when caring for somebody with a mental illness (figure 2).[29]

Family member account

"I became involved in mental health advocacy because of my son, Thomas. He is now 40 years old and has been suffering from schizophrenia for 15 years. Even today I am still trying to cope with the effects that his mental illness has had on me.

"I have already spent many years struggling with the illness and with the professionals, as well as with my personal difficulties as a carer. It looks as if there are many more years to come. When Thomas fell ill, my dreams disappeared. It is very hard for me to accept that my son cannot use his gifts and potential. ... This is not an occupation, it is a lifetime challenge."

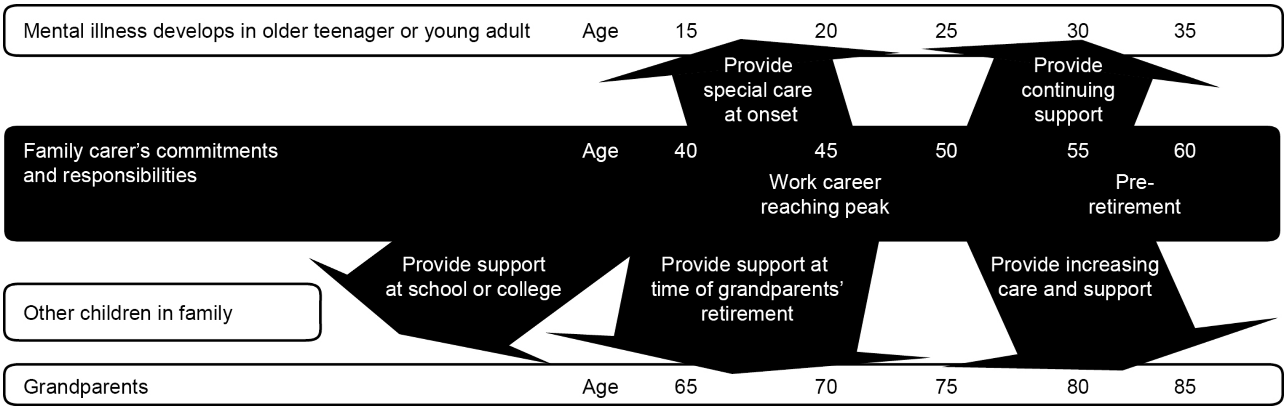

Fig. 1. Burden on family carers: what is the bigger picture? At the age of onset of a child's mental illness, the age of family carers (40–60 years) and the possibility of separation or divorce mean that they are at a time of great family stress and pressure. Reproduced with permission from EUFAMI.

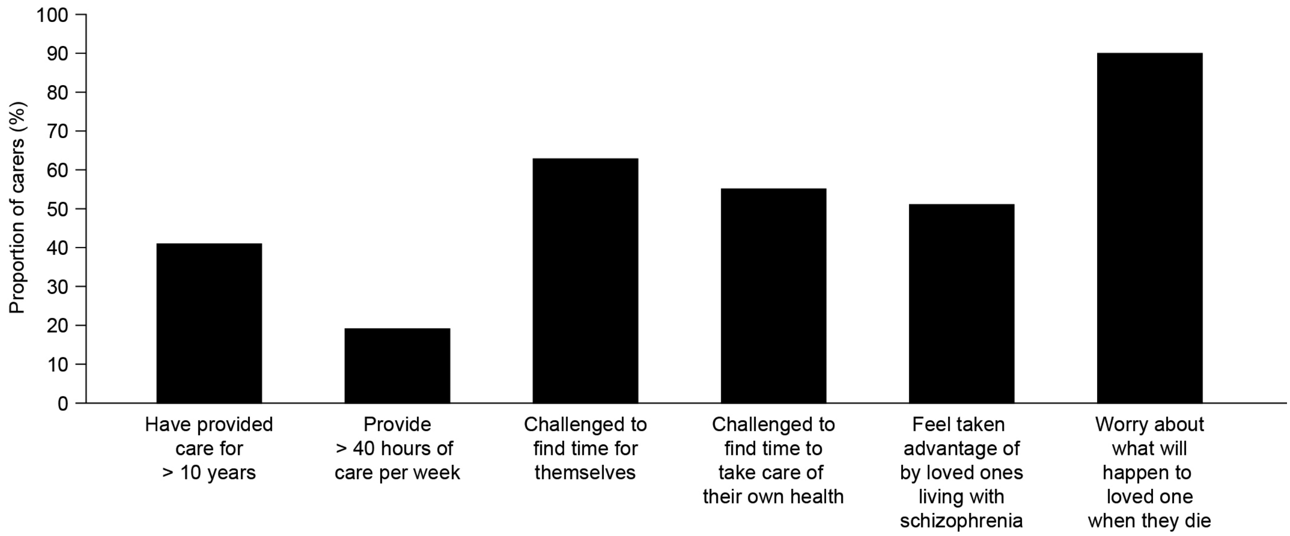

Fig. 2. Caring for somebody with a mental illness can take its toll on the carer. The figure shows issues faced by carers in a survey by the US National Alliance on Mental Illness.[29]

Consider the increased risks of homelessness or a jail sentence associated with schizophrenia. Consider too that people with schizophrenia are at an increased risk of dying prematurely from conditions such as heart disease or infectious diseases, or from suicide or homicide.[15,16,28,30] Add to this the burden that this illness places on carers … and it becomes clear that better support is needed on all fronts. Improving the care of people with schizophrenia should thus be a priority in health care policy.

Economic Consequences of Schizophrenia for Society

In addition to the potential human cost, inappropriately managed schizophrenia can have significant implications for health care resources and society. The total cost of schizophrenia to society comprises the following:

- **direct** costs of treating the condition, which may need to increase (initially at least) to enable better treatment to be offered to more patients and
- **indirect** costs, which are likely to decrease with improved treatment.

Indirect costs include lost productivity (both by the person affected and their carers) and decreased earning potential due to lost schooling during adolescence, social housing expenses, the unpaid time of family and other carers, and costs of interactions with the criminal justice system.

In 2012, the estimated total cost of psychotic disorders such as schizophrenia in Europe (the 27 members of the EU, plus Iceland, Norway, and Switzerland) amounted to €29.0 billion—equivalent to €5805 per patient per year.[31] The cost of care per year, however, varies considerably among (and within) European countries, and budgets for mental health care are extremely low in many countries.[31]

In the United States, the total annual cost of schizophrenia has been estimated to be $62 billion, of which direct costs account for $22.7 billion.[32] A comparison of the total costs of schizophrenia with diabetes mellitus shows that indirect costs account for a higher proportion of the total for schizophrenia (62%) than for diabetes mellitus (30%; figure 3).[32,33] Hence, there is considerable potential for reducing these indirect costs for schizophrenia by reducing the morbidity (the frequency at which the disease is seen in the population) and mortality (the death rate) associated with it.[20] A similar picture can be seen in Japan, where the total cost has been estimated at JPY 2.77 trillion ($2.8 billion), with indirect costs accounting for 72% of this figure.[34]

Although there are substantial economic impacts associated with schizophrenia, public spending on interventions to improve mental health may nevertheless be cost-effective (even in the current economic climate), owing to the potential benefits of reducing lost productivity and decreasing health care costs.[35] Hospitalization accounts for the majority of direct costs for schizophrenia: medication costs make up a relatively small percentage (about 2%–4%),[36,37] and it is likely that this percentage will decrease further as the use of inexpensive generic products (as opposed to branded agents) increases. In an analysis of medication costs in the United States, the average cost of new drugs acting on the central nervous system (including antipsychotics, which treat the symptoms of schizophrenia) was the lowest of all 12 therapeutic classes studied.[38]

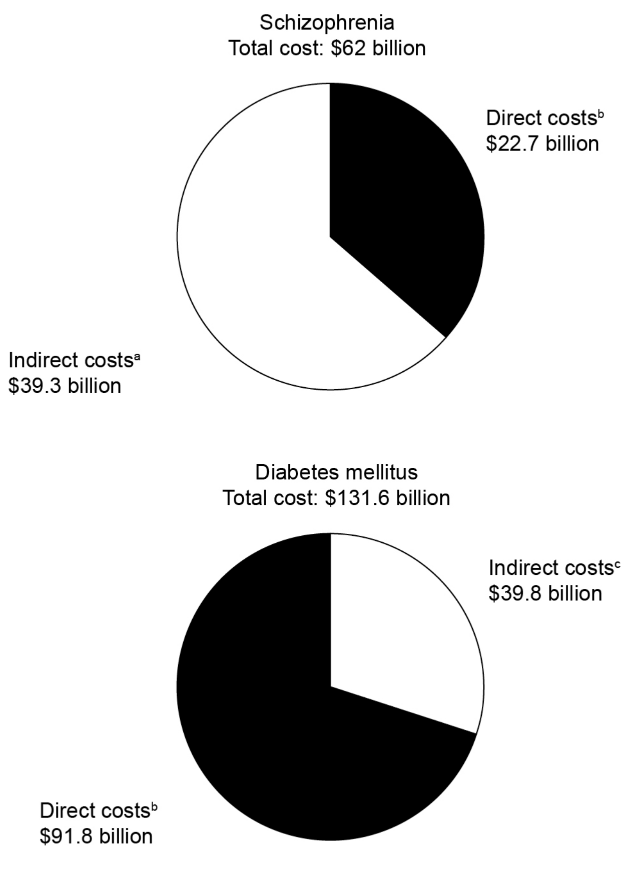

Fig. 3. Total costs of schizophrenia[32] and diabetes mellitus[33] in the United States in 2002 (US dollars). Indirect costs account for a higher proportion of the total costs of schizophrenia compared with some common (and expensive) conditions such as diabetes mellitus. [a]Indirect costs comprised absence from work, caregiver burden, premature mortality, and reduced productivity at work. [b]Direct costs comprised outpatient care, medication, inpatient care, and long-term care. [c]Indirect costs comprised disability, reduced productivity, premature mortality, and absence from work.

Interventions that reduce the risk of hospitalization may thus produce valuable savings in health care costs, in addition to a better quality of life for the patient. Increased spending on treatment and direct health care costs of schizophrenia may result in lower total costs because productivity by patients and their carers increases and other associated indirect costs fall; timely treatment with evidence-based approaches can also reduce future health care expenditure. This is highly relevant in the current economic environment, in which continuing care services are under threat in many countries, but a large number of patients with schizophrenia need long-term support.

Importantly, spending on schizophrenia (and other mental health problems) should not be seen as a competitor for spending on physical illnesses. As we shall see later in this report, physical and mental ill-health often coexist: many people with schizophrenia also have a physical illness, such as heart disease or diabetes mellitus. Conversely, mental health problems such as depression or anxiety are frequently seen in people with physical illnesses. Furthermore, it is enshrined in UK law that mental health and physical health should be treated equally in terms of research and funding.[39]

Making Best Practice Standard: Investment Is Needed

The limitations of current care are such that the UK Schizophrenia Commission has labeled schizophrenia "the abandoned illness."[13] It is therefore imperative that our existing (and effective) tools are available to all those with schizophrenia who need them; our *best* practices should become *standard*. There is good evidence that high-quality, early intervention services increase the likelihood of a good outcome and are cost-effective.[10,40–43] More, therefore, needs to be done to identify schizophrenia earlier and to initiate appropriate treatment as soon as possible, to improve the lives of patients, families, and carers. Such aims will require investment in the following:

- expansion of existing services for people with schizophrenia,
- research into the causes and mechanisms of the disorder,

- research into new and more effective treatments,
- research aimed at improving standards of care in specific domains.

Addressing the challenges

Policy makers and payers

- Ensure that equal weight is given to investment in mental health services and physical health services.

All relevant stakeholders

- Ensure that enough medical professionals are expertly trained to perform detailed assessment and diagnosis in patients with suspected schizophrenia. To achieve this, teaching of mental illness should be proportional to its global public health burden.

Expanding the Focus on Recovery

Key points

- Up to 50% of people with schizophrenia may eventually have a good outcome if they receive appropriate treatment, which in turn depends on an accurate and thorough clinical assessment.
- For the person with schizophrenia, recovery can be viewed as a process of personal growth despite the presence of mental illness.
- Empowerment is a significant factor in achieving recovery.
- Mental health professionals should recognize that most people with schizophrenia can achieve some degree of functional recovery, ultimately achieving a productive and fulfilled life in the community.
- The potential for recovery should be the first consideration in treatment decisions.

The past 4 decades have seen a growing movement in schizophrenia that emphasizes the importance of recovery, in addition to symptomatic improvement, as the aim of schizophrenia treatment. This development, coupled with a growing body of clinical evidence, has led to widespread acceptance that some degree of recovery of normal function is possible, despite the presence of residual symptoms, and that some people with schizophrenia may achieve full recovery.[6,27,44–47] Long-term studies have shown that up to 50% of people with schizophrenia may eventually have a good outcome.[6] This relatively optimistic view stands in stark contrast to reports describing schizophrenia as a chronic disorder with little hope of a positive outcome.[48,49]

The Concept of Recovery

Importantly, the recovery movement has been led by people with schizophrenia. From their perspective, recovery can be viewed as a process of personal growth despite the presence of mental illness[17]; thus, recovery focuses on attainment of a fulfilled and valued life, rather than on elimination of symptoms alone.[17,50] Affected individuals therefore consider themselves to be "in recovery" and learning to live with their disorder, rather than having "recovered from" it.[44] Their resilience plays an important role in recovery: each individual uses their strengths to establish compensatory mechanisms, thus helping to develop coping strategies to adapt to residual symptoms and focus on where they want their life to go. A huge amount of psychological adaptation occurs in the recovery process, which can be measured using clinical tools, such as the 50-item Stages of Recovery Instrument.[51]

Central to recovery is empowerment; a number of studies have shown that interventions designed to involve people with schizophrenia in decisions about their treatment result in a better outcome than those that do not.[27,52,53] There is some evidence from England of improved well-being when people with mental illness are given the power to decide how personal social care budgets should be spent[54]; however, this approach has not been studied widely elsewhere. In this report, recovery is considered from the perspective of the person with schizophrenia—as a process of *adaptation to mental illness*.

First-person account

"The stress of graduate school, along with other factors, triggered the beginning of my illness. I began fearing for my life because I thought that people wanted to harm or kill me. I believed that my house was bugged, that people could read my mind, and that people were trying to insert evil/destructive thoughts in my mind. The television and radio began to send me secret messages and were referring directly to me in their broadcasts.

"... I felt incapacitated and depressed. I could do nothing, and I lost all hope in myself and in life. For several years, I lived in darkness and despair.

"Fortunately, I had people in my life, like my mum, who genuinely loved me and who believed in me and never lost hope in me. With her steadfast support, along with that of my psychiatrist and the rest of my family, and along with my faith that guided me through the darkest hours of my life, I very, very slowly began to recover. Recovery was not some magic wave that swept over me. I had to learn to live life all over again, and it occurred in painstakingly small, tiny steps over long periods of time."

From Scotti P. *Schizophr Bull* 2009;35:844–846.[55]

How Is Recovery Defined?

Recovery in schizophrenia is defined in various ways. The US Substance Abuse and Mental Health Services Administration defines recovery as "a process of change through which individuals improve their health and wellness, live a self-directed life, and strive to reach their full potential."[56] Importantly, this process can occur even in the presence of residual symptoms.[44] By contrast, medical criteria for improvement or recovery generally rely on changes in symptoms and measures of functioning, assessed using various objective rating scales; hence, recovery is often defined scientifically as complete absence of symptoms and achievement of normal functioning.[6,44] For the person with schizophrenia, definitions of recovery focus on progression beyond the psychological effects of schizophrenia toward a meaningful life in the community.[44]

The Potential for Long-Term Recovery

Studies lasting up to 25 years show that many people with schizophrenia can achieve a good long-term outcome.[5,6,47,57,58] However, comparatively few participants in these studies experienced continuous recovery: most had periods of recovery interrupted by symptomatic episodes.[6,59,60]

There is some evidence that not all people with schizophrenia require long-term medication[59]; identifying patients who no longer need treatment is very difficult, though, and important to get right, especially in the light of recent research that has found relapse rates over a few years to be substantial when antipsychotic medication is stopped.[61,62] Discontinuation of medication can lead to serious consequences for the patient; hence, accurate, detailed clinical assessment is crucial in all cases. Individuals who respond well to medication may be those who benefit the most from continuing treatment and subsequent psychosocial therapy.[10,63] Most guidelines suggest that antipsychotic medication for people with a first episode of schizophrenia should be maintained for at least 6 months to 2 years.[10,11,64]

What More Can Be Done?

Mental health professionals, people with schizophrenia and their carers should align in recognizing that most people with schizophrenia can achieve some degree of functional recovery.[47] The goal of treatment from the outset should be recovery, so that mental health professionals and people with schizophrenia focus on optimal outcomes from treatment, as well as reducing the symptoms.

Addressing the challenges

Clinicians and all relevant stakeholders

- Recognize that many people with schizophrenia can ultimately achieve a productive and fulfilled life in the community.
- Consider the potential for recovery as a first principle in treatment recommendations; such recommendations should be agreed jointly by health care providers and people with schizophrenia (or their representative if appropriate).

Advocacy groups/peer support, policy makers, and payers

- Develop appropriate communication campaigns to present current views of recovery in schizophrenia to a wide audience.

Integrating Current Approaches to Schizophrenia Treatment

Key points

- An integrated approach, delivered by a multidisciplinary team working with the patients and their families, can significantly improve the outcome of schizophrenia treatment and coexisting physical illness.
- *Antipsychotic medication* is effective in reducing the disabling psychotic symptoms of schizophrenia and the risk of relapse; however,
  - available medications have troublesome side effects,
  - efficacy against persistent negative symptoms and cognitive impairment is limited, and
  - adherence to antipsychotic medication is often low.
- New therapeutic approaches are under investigation, aimed at improving treatment of negative symptoms and cognitive impairment, and reducing the risk of suicide. Funding should be made available to support research into the causes of negative symptoms, to develop more effective treatments, thereby facilitating rational prescribing.
- *Psychosocial therapies* aimed at improving patients' functioning in the community are essential. These interventions are often available only to a small proportion of people, usually in specialized centers. They should be made accessible to as many people as possible, which may require a change in perceptions about psychosocial therapies by service commissioners/payers.
- *Coexisting physical illness* is an important issue in people with schizophrenia. On average, death occurs 15–20 years earlier than in the general population, and poor health behaviors are common. All people with schizophrenia should have access to adequate health care, both for physical and for mental health.
- Interventions to stop smoking and to reduce alcohol and substance abuse are a priority and should involve a combination of medical, psychological, and behavioral therapies.
- Better provision of information about schizophrenia (psychoeducation) is essential for all stakeholders; however, psychoeducation is often poorly defined.

- Campaigns to increase awareness and tackle prejudice and discrimination toward people with schizophrenia can be effective in diminishing negative attitudes.
- Advocacy and peer-led "self-help" groups have an increasingly important influence on schizophrenia care and should be available to everybody with schizophrenia.
- The provision of adequate measures to decrease the burden of illness requires effective coordination of services, and continuity of health and social care.

Schizophrenia is caused by a complex interaction of biological, genetic, and environmental factors; hence, the illness should generally be treated with a combination of medication and psychosocial therapies, alongside careful attention to physical health and treatment of comorbidities. Even if some of the elements are missing, much can be achieved: it is not a case of all or nothing but an additive situation—the more we do (of the right thing), the better. Typically, medication is given early in the course of schizophrenia, when symptoms bring an individual to the attention of psychiatric services. Psychosocial therapies are not always initiated until symptoms are controlled. This pattern may change, however, once early detection and intervention become more common and nonpharmacological treatments are started earlier. In addition, coexisting physical illnesses (comorbidities) are common in schizophrenia and need to be managed alongside the psychiatric symptoms.

An integrated and multifaceted approach that involves medication, psychosocial interventions, and attention to environmental circumstances is likely to improve the outcome of schizophrenia treatment. Thus, the psychiatrist should be part of a multidisciplinary team, consisting of mental health and other medical professionals, social service providers, and other relevant agencies (eg, housing authorities and employment agencies).

Antipsychotic Medication in Schizophrenia

Drugs that treat the symptoms of schizophrenia (known as antipsychotic medication) form a cornerstone of schizophrenia care.[65] Those currently available primarily act by blocking the effects of a chemical called dopamine in the brain although other approaches are under investigation[66]; however, medication does not work in isolation to improve symptoms. Other factors, such as facilitating the removal of an individual from a stressful environment to one in which they feel safe, also play a key role in allowing further recovery.[67]

Antipsychotic medication is unquestionably highly effective in reducing the disabling positive symptoms of schizophrenia. Currently available drugs also have significant limitations, however (table 1); notably, they do not adequately treat negative symptoms or cognitive impairment, and many patients continue to experience persistent psychotic symptoms. Furthermore, the lack of insight (the patient's unawareness of their illness) that accompanies schizophrenia also presents challenges.

Potential Benefits of Antipsychotic Medication.

Reduction of Positive Symptoms Clinical trials have consistently shown that antipsychotic medication reduces positive symptoms, such as delusions and hallucinations.[66,68] Large-scale studies have not provided unequivocal evidence that newer drugs are more effective than older drugs in this respect; however, some patients find them more acceptable.[66,69–71] The side-effect profiles of the older and newer drugs are, however, significantly different.[69]

First-person account

"I personally feel like my medication has worked miracles for me. I notice that I am about 10 times better with my medication than without it. It is not perfect, but it has been really effective."

From Brady M. *Schizophr Bull* 2008;34:204–211.[72]

Treatment of Acute Episodes Antipsychotic medication has been shown to be effective in the treatment of acute psychotic episodes.[10,11,73] These medicines are generally effective in relatively low doses in the treatment of first-episode or early schizophrenia.[44] About 85% of previously untreated patients show an improvement in symptoms, and 60% remain in remission at 3 years.[7] Effective,

Table 1. Potential Benefits and Limitations of Current Antipsychotic Medication

Benefits	Limitations
• Reduction of positive symptoms	• Limited efficacy against negative symptoms
• Treatment of acute episodes	• Inadequate treatment of cognitive impairment
• Reduced risk of relapse	• Troubling side effects or tolerability issues
• Provision of stability and a platform for other treatments	• Low acceptability to some patients
• Reduction of aggression and hostility	− Poor adherence
• Reduced suicidal behavior	− Negative perceptions

prompt treatment of psychosis in the early stages may avoid a long duration of untreated psychosis, which is associated with a worse clinical and social outcome.[74–76]

Reduced Risk of Relapse Long-term medication (maintenance therapy) reduces the risk of relapse in people with schizophrenia. In an early study, patients who did not receive antipsychotic medication relapsed at a rate of about 10% per month; this rate was reduced up to 10-fold in treated patients.[77] More recently, an analysis of results from clinical trials involving more than 6000 patients showed that maintenance treatment reduces relapse rates and hospitalization rates by about 60% (figure 4).[8] Importantly, this analysis also showed that treating just 3 patients for 7–12 months will prevent 1 relapse, and treating 5 patients will prevent 1 hospitalization,[8] when medication is supported by appropriate psychosocial therapy (see below).

Provision of Stability and a Platform for Other Treatments Prevention of relapses may, in some patients, postpone or prevent a deterioration in the illness.[78] In addition, by preventing relapses and restoring insight, antipsychotic medication can provide a period of stability, facilitating the introduction of and improved engagement with further treatments, such as psychosocial therapies.[63] There is evidence that the greater the improvement in symptoms following medication, the greater the likelihood of a good response to psychosocial therapies.[63,79]

Reduction of Aggression and Hostility Behavioral symptoms such as hostility and aggression are common in schizophrenia, and there is evidence that these symptoms are amenable to antipsychotic medication.[10,80] Violent behavior is most common before antipsychotic medication is initiated. In general, good adherence to treatment appears to be associated with lower levels of aggression,[10,80,81] and people with schizophrenia who adhere to their treatment and are clinically stable appear to be no more violent than the general population.[81] Antipsychotic medication is often combined with other drugs, such as anticonvulsants or mood stabilizers, in an effort to control aggression, but there is little evidence to support this approach.[10]

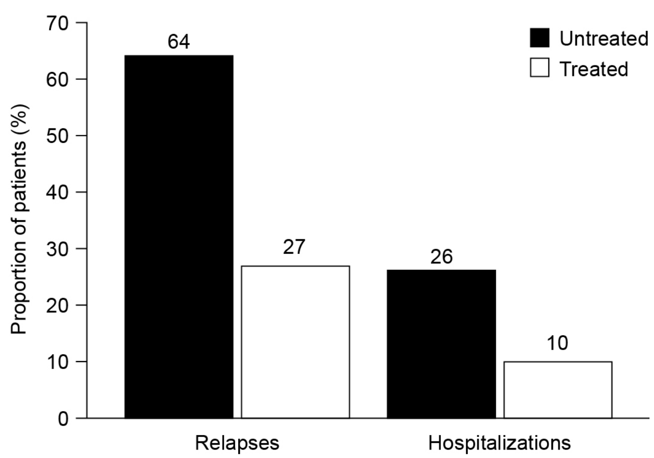

Fig. 4. Long-term (maintenance) antipsychotic medication significantly reduces the number of relapses (at 7–12 months) and the number of hospitalizations in patients with schizophrenia, compared with placebo (data from a combined analysis of 65 clinical trials).[8]

Reduced Suicidal Behavior Suicidal behavior is present in about 50% of those affected, and about 5%–10% of people with schizophrenia take their own lives.[82,83] Clinical trials with some antipsychotic medication have shown reductions in suicidal behavior[9,82]; in particular, clozapine is approved in the United States for the reduction in risk of suicidal behavior in patients with schizophrenia.[66]

Limitations of Current Antipsychotic Medication.

Limited Efficacy Against Negative Symptoms Negative symptoms of schizophrenia, such as apathy, lack of drive, and diminished emotional expression, may occur from the start of the disorder and may actually be the predominant symptoms; indeed, in about 70% of cases, these symptoms develop before positive symptoms.[66,84] Currently available antipsychotic medication has limited effects on negative symptoms.[10,66] This is a major concern because negative symptoms are associated with impaired occupational and social function and constitute a significant barrier to independent living.[10,85,86] Indeed, negative symptoms are more closely related to impaired functioning than positive symptoms.[87]

Inadequate Treatment of Cognitive Impairment Almost all people with schizophrenia show some degree of cognitive impairment, affecting functions such as verbal fluency, memory, attention, processing speed, prioritizing tasks, and making decisions.[65,66] These deficits occur early in the course of the disorder, usually years before the onset of full psychosis[65,88] and are strong predictors of poor functioning and outcome.[89] Unfortunately, the antipsychotic medication currently available has little impact on cognitive symptoms of schizophrenia: any improvements seen appear to be due to reductions in other symptoms, rather than to direct effects on cognition.[10,88,90] Some have argued that effective treatment of cognitive symptoms is the most urgent priority for the medical treatment of schizophrenia.[66]

Troubling Side Effects and Tolerability Issues Antipsychotic medication is associated with a number of side effects (table 2). These can be severely troubling and may limit adherence to treatment, thereby reducing the potential for recovery. Individual agents differ in their side-effect profiles, but among the most common effects are motor symptoms, metabolic disturbances, and hormonal disturbances.

- *Motor symptoms* affect movement and muscles, and result in parkinsonism (tremor and muscle rigidity resembling signs of Parkinson disease), muscle spasm (dystonia), or subjective and objective restlessness

Table 2. Potential Side Effects of Current Antipsychotic Medication

- Extrapyramidal side effects
  - Slow, stiff movement, and tremor (parkinsonism)
  - Abnormal muscle tone/muscle spasms (dystonia)
  - Involuntary movements (tardive dyskinesia)
  - Subjective experience of restlessness and restless movements (akathisia)
- Anticholinergic side effects
  - Dry mouth
  - Constipation
  - Blurred vision
  - Cognitive slowing
- Weight gain
- Metabolic side effects
  - Changes in blood glucose levels
  - Increases in cholesterol and triglycerides
- Sedation
- A feeling of being ill-at-ease (dysphoria)
- Hormonal changes
- Sexual dysfunction
- Changes in the electrical activity of the heart (rare)
- Orthostatic hypotension (a sudden fall in blood pressure when a person stands up)
- Neuroleptic malignant syndrome (a rare but life-threatening neurological disorder)
- Agranulocytosis (very low levels of white blood cells, also life-threatening but rare)

(akathisia). These symptoms are collectively known as acute extrapyramidal side effects (EPS). Another EPS, usually occurring later in treatment as the patient ages, is tardive dyskinesia, a syndrome of involuntary, repetitive movements of the limbs, trunk, and, most characteristically, the lips, tongue, and jaw.
- *Metabolic side effects* include weight gain or undesirable changes in the levels of glucose and cholesterol and other fats in the blood. Such disturbances, namely cardiovascular disease, diabetes mellitus, and obesity-related cancers, can add to the burden of physical ill-health often experienced by people with schizophrenia and lead to premature death.[91]
- *Hormonal side effects*, notably increases in prolactin (a hormone involved in the control of milk production in the breast), can give rise to secondary problems such as sexual disturbances and menstrual irregularities.[92]

First-person account

"At the end of my second year of taking [medication], I began to experience severe akathisia. ... My doctor switched my medication …, and the akathisia gradually diminished. I have now been taking [this other drug] for 3 years, and it seems to be working beautifully, except for the extra 20 lbs. of fat I'm carrying around. However, I wouldn't change it for anything. I have continued to notice steady improvement in my condition over the last 3 years, both for positive and negative symptoms."

From Snyder K. *Schizophr Bull* 2006;32:209–211.[93]

Poor Adherence to Therapy Adherence to antipsychotic medication (ie, the extent to which medication is actually taken as prescribed) is often low in people with schizophrenia:[69,71,94] the average nonadherence rate for oral antipsychotic medication is estimated at about 50%,[10] although higher rates have been seen in long-term studies. Principal reasons for low adherence include the following:

- insufficient information about the illness and its treatment,
- lack of improvement in psychotic symptoms,
- troublesome side effects (which may be relieved if the patient stops taking the medication),
- lack of awareness of the need for treatment,
- financial difficulty (especially in countries facing economic crisis),
- complexity of treatment schedules,[10]
- fear of discrimination,
- poor doctor-patient relationships, and
- lack of support from carers.

Negative symptoms and cognitive impairment may also contribute to poor adherence. A related problem is that many people with schizophrenia lack the insight to acknowledge that they are ill,[95] and this can contribute to poor adherence if the individual does not agree that he or she needs treatment.[10] Furthermore, the very fact that a person is receiving antipsychotic medication may make them feel stigmatized,[96] which can encourage nonadherence.[10] Social and cultural factors can either increase or decrease adherence.

Nonadherence to treatment is commonly associated with relapse,[97] often leading to hospitalization, although this association may partly reflect the fact that nonadherence may sometimes be a symptom of worsening of the disorder. The rate of hospitalizations (which are often used as an indicator of a severe relapse) are up to 400% higher in nonadherent patients than in adherent patients.[10,98] In addition, nonadherent individuals are more likely to have poor long-term function, to be violent,[81] to be arrested,[99] or to attempt suicide than adherent patients.[100]

Treatment-Resistant Schizophrenia. Antipsychotic medication is effective in reducing psychotic symptoms, but many patients show only a partial response to treatment. Even when remission is achieved, few people are completely symptom-free.[65,66] In addition, up to one-third of people with schizophrenia show a poor response to antipsychotic medication, and some may develop treatment-resistant schizophrenia.[10] Treatment resistance normally develops as the disorder progresses,[101] but in about 10% of cases, it is apparent after the first episode.[10]

Clozapine has been shown to reduce symptoms in some patients with treatment-resistant schizophrenia,[36,102,103] and it is the only medicine currently approved for use in this situation.[66] However, clozapine is underused in some areas and is often started only relatively late in the course of the disorder, in many cases only after years of ineffective treatment.[104–106] Reasons underlying the caution in prescribing clozapine include the risk of potentially serious side effects, including blood disorders (involving the need for regular blood tests), heart problems, and metabolic disorders. Therefore, clozapine must be administered with care: treatment should be started at a low dose and gradually increased. Regular safety monitoring is essential to detect early signs of blood disorders or other side effects.[10,66]

What More Can Be Done?

The limitations of currently available drugs create considerable scope for improvements in antipsychotic medication.

New therapeutic approaches are under investigation, aimed at discovering novel drugs that are effective against negative symptoms and cognitive impairment.[66,88] There is also a general need for better tools to enable clinicians to assess negative symptoms and cognition in patients with schizophrenia.

Clozapine use should be encouraged in patients who do not respond to, or show only a partial response to, reasonable trial periods with other antipsychotic agents. Many psychiatrists are currently unwilling to prescribe this drug, partly owing to a lack of experience with it.[106] This unwillingness contributes to the delay in starting clozapine treatment, during which time patients may have received a number of ineffective medications, often at inappropriately high doses.

Adherence to antipsychotic medication can be improved by understanding an individual's reasons for nonadherence and by involving the patient in treatment decisions. ("Adherence" requires patient participation and an effective partnership with the health care provider, whereas "compliance" has more to do with following directions) One potential obstacle to adherence is the common practice of using multiple medications (polypharmacy) to control symptoms, which may make it difficult for patients with schizophrenia to remember when to take their medication. This practice should be avoided whenever possible. The use of long-acting injectable (depot) formulations of antipsychotic medication may help to improve adherence.[10,64,107] Shared decision making has also been found to help in enhancing adherence behavior. A recent survey by the Global Alliance of Mental Illness Advocacy Networks-Europe (GAMIAN-Europe) found that being a member of a patient organization/self-help group has a positive influence on adherence.[108]

Individualized therapy should be promoted, based on the recipient's choice and preferences. Care needs to be taken to match the side-effect profiles of different drugs to the needs of the patient (eg, avoiding drugs with a tendency to cause weight gain if this is an issue). This may be of particular importance in young patients. About 25% of patients with newly diagnosed schizophrenia are under 18 years of age, and they may be particularly sensitive to side effects such as weight gain or menstrual cycle disturbances resulting from drug-induced hormonal changes. Careful, systematic monitoring of side effects, and intervention if appropriate, is warranted for all patients on long-term medication.[109] Close collaboration with carers and provision of comprehensive education can prevent relapses and help to achieve adherence.

Addressing the challenges

Members of professional organizations

- Develop and implement programs to promote the use of individualized treatment, taking into account the patient's wishes and preferences whenever possible.

Clinicians

- Commit to the principles of good prescribing practice, avoid polypharmacy and the use of excessive doses whenever possible, and consider the use of clozapine at an early stage in patients who require it.
- Train junior doctors in thorough clinical assessment, accurate diagnosis, and good prescribing practice.
- Routinely monitor side effects of medication and initiate appropriate management if necessary.

National and international psychiatric organizations

- Work together to develop and implement consistent guidance for good prescribing practice.

Psychosocial Therapies and Schizophrenia

Psychosocial therapies play an important role in the treatment of schizophrenia. These therapies are aimed at improving the patient's functioning in the community, which in turn can result in clinical improvements, such as reductions in the number of relapses or hospitalizations. Substantial evidence already supports the use of many psychosocial therapies in schizophrenia, including cognitive behavioral therapy (CBT) for psychosis, cognitive remediation, and social skills training[11,17,75,110,111]; several other approaches also show promise (table 3).[17] The disability associated with schizophrenia is often wide-ranging, so psychosocial therapies may be combined to address multiple issues. For example, social skills training might be provided as part of an integrated program that also includes family psychoeducation, cognitive remediation, and CBT.[17]

Potentially Beneficial Psychosocial Therapies.

Assertive Community Treatment The assertive community treatment (ACT) model was developed to address the rise in relapse and hospitalization rates that followed the shift from institutionalized to community care in the United States from the 1980s.[17] This approach, aimed at a subgroup of patients who are high users of services, involves a multidisciplinary team working in the community to provide a range of services, including medication management, practical support (eg, with housing), and rehabilitation. It is characterized by a high frequency of patient contact and low patient-to-staff ratios, thus making substantial demands on health care resources[17,110]; however, for this and other psychological therapies, the increased time spent with patients may in itself contribute to positive outcomes.

Studies in several countries have shown that ACT results in lower rates of homelessness and hospitalization than standard care in patients who are high service users.[110,112–116] One analysis found that, on average, there was a 37% greater reduction in homelessness in participants undergoing ACT than in those receiving standard care.[112] Other studies of those who frequently use psychiatric services showed that ACT can reduce the number of hospital days by about 23% and hospitalizations by 60%–80%, making this a potentially cost-effective intervention from the perspective of health care providers.[117]

Some trials, however, showed less benefit, possibly because in those instances ACT was compared with a "usual practice" that consisted of generally high-quality services.[118,119] Furthermore, although ACT can help people with schizophrenia to live stably in the community, the available evidence suggests that it has only a limited impact on other outcomes, such as social functioning or employment.[17]

CBT for Psychosis Psychotic symptoms may persist despite antipsychotic medication, and this can create a significant barrier to recovery.[17] CBT (a talking therapy that helps people manage their illness by changing the way they think and feel) directed toward psychotic symptoms aims to reduce the severity and resulting distress. Many studies have shown that this approach improves social functioning, reduces positive and negative symptoms, and decreases mood disturbances, compared with control groups.[17,120] Other studies, however, have not shown such improvements, and the effects of CBT on outcomes such as hospitalizations, depression, suicidality, and insight have not been clearly established.[110] A recent systematic review concluded that CBT offers no clear advantage over other psychosocial therapies, including family therapy and psychoeducation.[121] The evidence supporting the use of CBT is largely driven by studies in which participants received at least 16 sessions[11]: cognitive behavioral therapists require specialist training and expertise, so cost is an important consideration. An analysis by the UK National Institute for Health and Care Excellence (NICE), however, concluded that CBT is likely to be cost-effective because the intervention costs are offset by decreased hospitalization costs.[11]

Cognitive Remediation Cognitive remediation programs usually involve exercises designed to improve aspects of cognition, often combined with teaching strategies to enhance performance of these exercises; they may also include strategies for coping with cognitive impairment.[17] Most studies have found that this approach is effective in improving cognition, but its effects on psychosocial functioning are more variable.[17,122,123] Cognitive remediation models vary considerably, however, and the number of

Table 3. Many Psychosocial Interventions Have Been Shown to Improve Outcomes in Schizophrenia (Evidence-Based Approaches), and Others Are Being Developed and Evaluated (Promising Approaches)[17,110]

Evidence-Based Approaches	Promising Approaches
• Assertive community treatment	• Cognitive adaptive therapy
• Cognitive behavioral therapy for psychosis	• Healthy lifestyle intervention
• Cognitive remediation	• Interventions targeting older individuals
• Family therapy/psychoeducation	• Prodromal stage intervention
• Peer support and self-help strategies	• Social cognition training
• Social skills training	• Social rehabilitation (Clubhouse Model)
• Supported employment	
• Integrated treatment for coexisting substance abuse disorder	

robust studies in this field is limited.[110] It has been suggested that cognitive remediation enhances the effects of other forms of psychotherapy by increasing the ability to learn new skills.[17] Furthermore, there is some (very limited) evidence that it may protect against schizophrenia-related loss of grey matter in the brain over a 2-year period[124] and improve the number and functionality of nerve cell connections in the brain.[125]

A cost-effectiveness analysis conducted as part of a clinical trial of cognitive remediation in the United Kingdom concluded that this approach is likely to be cost-effective in the short term but might ultimately have only a limited potential for long-term cost savings because it could increase the use of other services.[126]

Family Therapy/Psychoeducation Many people with schizophrenia live with their families, so family therapy (also known as family psychoeducation in the United States) can play an important role in promoting recovery.[14,17] This process of educating individuals and families about the nature and symptoms of the illness enables them to develop adaptive coping strategies, capitalize on their strength, and learn self-care. An educated individual (and their family) is then better able to participate in shared decision making.

Family psychoeducation offers a valuable opportunity for people with schizophrenia, their families, and health care professionals to exchange insights about their personal experiences of schizophrenia and the care available. Importantly, family members can provide continuity for a person with schizophrenia even if health care professionals involved in their care change.

First-person account

"[My psychiatrist] listened to me patiently, got me on the right dose of medication, and after 6 months diagnosed me with schizophrenia. He described to me what the illness was and gave me literature references to read to help me understand the illness. I remember sitting in the family room with my mum and spending hours reading everything I could get my hands on."

From Scotti P. *Schizophr Bull* 2009;35:844–846.[55]

The family therapy/psychoeducational approach aims to foster collaboration among family members and health care professionals. Studies have consistently shown that family psychoeducational approaches are effective in reducing relapses and hospitalizations and, to some extent, in improving social functioning,[17,110,127,128] and there is evidence that these benefits persist during long-term therapy (5 years).[129] One early analysis showed that relapses and hospitalizations could be reduced by about 20% when families were included in the treatment, compared with usual care.[12] In another study, the relapse rate at 2 years was 40% in patients whose families received psychotherapeutic support, compared with 75% in those whose families received no help.[130] The greatest benefits of family psychoeducation appear to be seen in people with a first episode of psychosis or a recent onset of schizophrenia.[131] Furthermore, the benefits of psychoeducation also extend to family members, who report reduced levels of distress, improved family relationships, and enhanced coping and empowerment.[110,132,133]

The economic data available suggest that family therapy is superior to standard care, in that it can offer cost savings as well as better clinical outcomes.[20] An economic analysis by NICE in the United Kingdom suggests that family therapy is likely to be cost-effective because the costs of therapy are offset by a decrease in the cost of treating relapses.[11]

Multifamily group psychoeducation is another useful family-based intervention. In this model, trained staff lead a group of individuals with schizophrenia and their families, who are provided with information about the course and treatment of psychotic disorders. They are also trained in the use of structured problem-solving exercises designed to help them meet the challenges of living with or caring for a person with a psychotic disorder.[134,135] Such a multifamily approach can reduce relapse rates to a greater extent than single-family psychoeducation, which itself improves relapse rates to a greater extent than treatment without family psychoeducation (figure 5).[136,137] Moreover, the addition of multifamily group psychoeducation to antipsychotic medication approximately doubles the effect size of medication alone.[136,137]

Paradoxically, however, the provision of information can increase "self-stigmatization" among people with schizophrenia, causing them to anticipate prejudice and discrimination.[138–140] The potential impact of self-stigmatization is illustrated by the 27-nation International Study of Discrimination and Stigma Outcomes, in which 64%

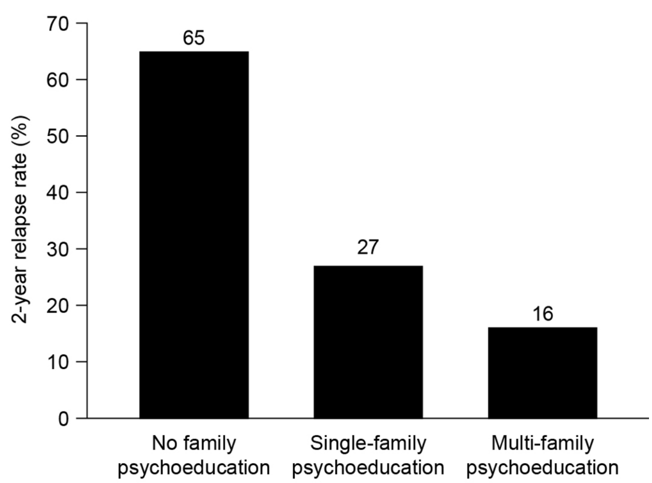

Fig. 5. Family psychoeducation reduces schizophrenia relapse rates, compared with treatment without family psychoeducation, and multifamily group psychoeducation is particularly effective.[137]

of participants reported that they had refrained from applying for work, training, or education, and almost three-quarters felt a need to conceal their diagnosis because of anticipated discrimination.[138] Nevertheless, in the long term, psychoeducation—supported by appropriate antipsychotic and psychosocial therapies—appears to be effective in reducing the burden felt by many people with schizophrenia and their families.[129]

Peer Support and Self-Help Strategies People who are affected by schizophrenia, both the patients themselves and those who care for them, can offer powerful and eloquent insights into the condition. As a result, peer-led interventions have an important place in schizophrenia care, and this approach has been actively promoted in both the United States and the United Kingdom.[6,141,142] Peers play an active role in mutual support or advocacy groups.[14,142] Peer-led groups such as the National Alliance on Mental Illness (NAMI), the European Federation of Associations of Families of People with Mental Illness (EUFAMI), and GAMIAN-Europe work together to help both themselves and the people they care for. Such groups can provide support in a number of areas (table 4).

Evidence from the United States suggests that many users of peer-led strategies also use conventional therapies such as medication and psychotherapy.[142,143] While peer-to-peer counseling appears to be beneficial when included as part of routine care,[144] the self-help approach has generally been more effective in other settings (eg, alcohol abuse or weight control) than in schizophrenia. Nevertheless, in the recent report from the UK Schizophrenia Commission, 48% of people with schizophrenia identified self-management strategies as an important factor in their recovery.[13] The importance of peer-led interventions is highlighted by experience with the Wellness Recovery Action Plan program, which represents an important landmark in the application of self-help strategies in schizophrenia. This program has been shown to improve symptoms, hopefulness, and quality of life compared with standard care, in patients with severe, persistent mental disorders.[145] Such support can substantially improve patients' wellbeing and quality of life, and should be available to all people with schizophrenia.

There is also some evidence that self-help strategies may be useful in postponing readmission to hospital although 1 study found no differences in clinical or social outcomes between individuals who participated in self-help groups and those who did not.[146] It has been suggested that peer-led strategies in mental health reduce psychiatric inpatient bed use in the United States and Australia, resulting in cost savings that outweigh the costs of the intervention.[147]

To date, few rigorous controlled trials have evaluated the effectiveness of self-help strategies in schizophrenia.[142] Although controlled trials are regarded as the "gold standard" to inform evidence-based treatment decisions, their absence should not constitute a barrier to implementation of potentially effective strategies: qualitative research, observational studies, and clinical experience can also provide valuable insights.[75]

Social Skills Training In people with schizophrenia, problems with psychosocial functioning are related to impairments in social skills that may be present before the onset of illness and that persist if not addressed.[17] Social skills training can improve social and daily living skills, community functioning, and other aspects of social functioning. This approach also has a small but significant effect on relapse rates.[111,148] The value of social skills training may be limited somewhat by decreased attention in people with schizophrenia[111]; however, attention-shaping therapy or cognitive remediation (ie, strategies to improve attention and cognitive performance) appears to be useful in improving the acquisition of social skills in schizophrenia.[149]

Supported Employment Schizophrenia can significantly reduce a person's ability to work: on average, only 10%–20% of people with schizophrenia are in competitive employment.[17] People with severe mental disorders such as schizophrenia are about 6–7 times more likely to be unemployed than those without such illnesses.[18] UK data suggest that only about 8% of people with schizophrenia are employed despite evidence that many of them want to work.[150] A supported employment approach can help people with schizophrenia to achieve competitive employment and to work for longer and earn higher wages than people without such support.[110] At least 50% of people receiving supported employment obtain competitive employment at some stage during follow-up, according to most studies.[110] The key features of such interventions are the following:

- a focus on competitive employment;
- a rapid search for a job, rather than prolonged preparation for work;

Table 4. Areas in Which Peer-Led and Advocacy Groups Can Provide Support to People With Schizophrenia[142]

- Social environment
  - Provision of feedback about current status and experiences
- Psychoeducational information
- Cognitive and environmental antidotes
  - Beliefs and attitudes that define the activities of group members
  - The recovery model is an example of a cognitive antidote that can change an individual's attitude to his/her illness
- Patient and family education

- integration of employment and psychiatric services;
- an emphasis on the individual's job preferences; and
- continuing job support.[110]

One of the most widely used supported employment models is the Individual Placement and Support (IPS) model, for which the only eligibility criterion is that the person wants competitive work.[17,151] The IPS model can demonstrate substantial savings in health care and societal costs (figure 6), as well as potential benefits to the individual in terms of fewer hospitalizations and increased rates of competitive employment.[20,152–154] Supported employment measures, however, have not been clearly shown to improve long-term employment and economic independence in people with schizophrenia. For this reason, it has been suggested that these strategies should be adequately integrated with interventions such as CBT, cognitive remediation, and social skills training.[110]

Although access to employment can have a positive impact on mental health, this must be the right sort of employment; poor-quality jobs can result in job strain, which itself can lead to poor mental health.[18] This is an important issue because employers often have low expectations of people with schizophrenia, and hence these individuals may end up in low-skilled jobs with little responsibility or in noncompetitive (voluntary or sheltered) work.[150] Paid employment may be beneficial to people with schizophrenia even if this entails the risk of disrupting established routines and habits—the so-called "dignity of risk."[45]

First-person account

> "I would love to be able to work like a regular person. I love to be busy. I love to feel useful. I don't get celebrated or applauded because I have nothing to show for all my daily hard work. It is horrible to feel this unappreciated, this uncelebrated."
>
> Johnson A. *Schizophr Bull* 2012;38:207–208.[155]

Limitations of Psychosocial Therapies.
Psychosocial therapies do have limitations, however, and they may not be appropriate unless symptoms are significantly well controlled and patients have insight into their condition and the need for treatment. Patient selection, eg, may be important for a successful outcome: highly motivated individuals generally respond to cognitive remediation better than those who are less motivated.[156] Moreover, some people with schizophrenia may, if not treated with antipsychotic medication, worsen when stressed by psychosocial interventions.[157]

The cost of some therapies, such as CBT, may be prohibitive in countries where they are not available through public health services. Where public funding for CBT is available, priority may be given to patients with other mental health problems deemed to have a high likelihood of remaining in paid employment.[158] In the United States, many psychiatrists will not accept Medicaid patients, who are therefore excluded from potentially beneficial psychosocial therapies. Similarly, family psychoeducation for relatives is not currently funded in many countries.

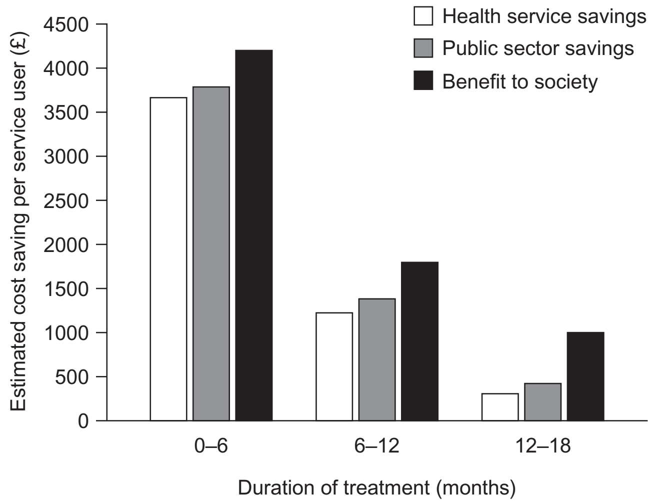

Fig. 6. The Individual Placement and Support model of supported employment can demonstrate substantial savings in health care and societal costs. The figure shows estimated savings (in British pound sterling) per patient, using UK data from the Enhancing the Quality of Life and Independence of Persons Disabled by Severe Mental Illness Through Supported Employment (EQOLISE) study.[20,153] Figure adapted from Andrew et al.[20]

The design of studies to investigate the effectiveness of psychosocial therapies is not always as robust as the methodology applied to clinical trials for licensing a new drug. Therefore, carefully designed randomized controlled trials are needed in appropriately sized groups of patients before firm recommendations can be made for further investment in some of these treatments.

What More Can Be Done?

There is evidence supporting the use of some forms of psychosocial therapies (table 5), but these interventions are often underutilized.[110,159] Unlike medication, which is available to most patients who need it, psychosocial interventions are generally available only to smaller populations, usually in specialized centers.

In a recent US analysis of Medicaid claims data over 1 year, 59% of claimants with schizophrenia or bipolar disorder had a claim for an evidence-based psychosocial therapy, primarily some form of individual psychotherapy; however, fewer than 5% had claims for ACT, family psychotherapy, or social skills training, and almost none had a claim for CBT or supported employment.[160] Therefore, there are ample opportunities to increase the uptake, and hence the effectiveness, of psychosocial therapies. Effective therapies could be used earlier in the course of

Table 5. Potential Benefits of Psychosocial Therapies[17,110,133,159]

Intervention	Potential Benefits
Assertive community treatment	Reduction in rates of homelessness and length of hospital stays
Cognitive behavioral therapy for psychosis	Decreases in both positive and negative symptoms and mood disturbances, and improved social functioning
First-episode intervention for psychosis	Improvements in quality of life, social functioning, and adherence
Cognitive remediation	Improvements in cognition and psychosocial functioning
Family psychoeducation	Some improvement in social functioning, and family coping and empowerment
Peer support and illness self-management training	Enhancement of empowerment and ability to cope with the illness
Social skills training	Improvements in social functioning
Supported employment	Increases in employment rates, hours worked, and wages earned. Gains in self-esteem and quality of life
Integrated treatment for coexisting substance abuse disorder	Reductions in substance use and arrests; improved functioning

the disorder: the evidence base for many forms of psychosocial therapies is so strong that there is a good case for trying them before other potential treatments, for which less supporting evidence is available. Clinicians and purchasers need to understand the potential benefits of psychosocial therapies better if these treatments are to be made more widely available. It is also important to ensure continuity of care for people with schizophrenia when they transfer from adolescent services to the adult care system.

The use of CBT could be extended by using specialized therapies to treat individual symptom domains; however, this raises the important question of how to identify people who might benefit from this approach and how it should be funded.

A strong therapeutic relationship between the clinician and patient has the potential to yield improvements in adherence to medication,[161] work performance,[162] and symptoms and reductions in hospitalizations.[163] They should work together to agree treatment goals and to review progress in meeting these goals.

In addition, it is important to consider cross-cultural differences in belief systems, including religion and spirituality, which may have an impact on mental health.[164] Such factors are relevant during diagnosis, when spiritual ideas need to be differentiated from delusions. They are also important from a treatment perspective, when religious beliefs can potentially help in the recovery process by encouraging help-seeking behavior and engagement with treatment.[165]

Psychoeducation

Psychoeducation should be made more widely available to people with schizophrenia and their families because improved provision of information could result in better empowerment of people with schizophrenia. Psychoeducation alone, however, is of little value: such educational initiatives need to be accompanied by appropriate antipsychotic and psychosocial therapies.

As described above, recovering patients have a valuable part to play in sharing their experiences and serving as role models, and peer-led interventions are increasingly recognized as an essential feature of recovery-oriented care.[110] Schizophrenia services, however, are often fragmented, involving numerous health care providers and agencies, and people with schizophrenia may therefore find it difficult to navigate through the system. More effort should be devoted

Addressing the challenges

Policy makers and payers

- Ensure that potentially useful and cost-effective psychosocial therapies are made available to as many people with schizophrenia as possible—not just to those fortunate enough to have access to specialized centers and to be able to pay for their therapy. Moreover, these interventions should be tried early in the course of schizophrenia.
- Fund research into psychosocial therapies.
- Establish programs to communicate the potential benefits of psychosocial interventions to health care commissioners and other health care policy makers, and ensure that the benefits of effective therapies are recognized and acknowledged.
- Support local, regional, national, and international patient and family associations financially.

Clinicians

- Establish a strong therapeutic alliance with patients and their families, and ensure that recommendations on treatment goals and strategies are reached through such alliances.

- Encourage recovered patients to share their experiences with others and to act as role models for those undergoing treatment, and to provide such patients with appropriate support during this process.
- Engage with other stakeholders to ensure that effective psychoeducation and public education programs are appropriately targeted and implemented and that peer-led services are adequately supported and made available to all who could benefit from them.
- Include courses focusing on evidence-based psychosocial therapies in training programs for psychologists, rehabilitation technicians, and psychiatrists.
- Provide information and refer patients and families to patient associations and self-help groups.

to ensuring that peer-led support and advice is readily accessible, particularly for young people with schizophrenia.

Management of Coexisting Physical Illness

Schizophrenia is associated with a substantial burden of physical illness: on average, people with schizophrenia die 15–20 years earlier than the general population (data from the United Kingdom are shown in figure 7)[15,16,166,167]—a situation that has been described as "a scandal."[16] This burden is the result of a number of factors, including the following[168]:

- a high frequency of poor health behaviors (eg, poor diet, lack of exercise, high rates of smoking, and alcohol or substance abuse),
- underdiagnosis of physical illness,[30]
- decreased access to health care compared with the general population (furthermore, when care is provided it is often too late and of poor quality),[13,16]
- inadequate self-care,
- medication side effects,
- increased risk of cardiovascular disease,
- suicide,
- self-stigmatization (people with schizophrenia may be reluctant to seek health care because they fear prejudice and discrimination), and
- self-neglect or inadequate self-care, as a consequence of schizophrenia.

The scale of the problem is illustrated by a recent survey of people with mental health problems in 27 European countries, 20% of whom had schizophrenia. This survey found that 86% of participants had at least 1 physical health problem, of which the most common were weight gain (45.7%), smoking (38.3%), and heart problems (25.2%).[169]

Weight gain and metabolic problems are common in people with schizophrenia. It is not uncommon, for example, for an individual to gain up to 5 kg or 6 kg in weight within 2 months of starting antipsychotic medication,[170] and in many cases this can result in an increased risk of conditions such as obesity, type 2 diabetes mellitus, or heart disease.[168]

First-person account

"Mother's health plummeted. Lifestyle habits probably contributed to the deterioration … the diagnoses indicated congestive heart failure along with adult-onset type 2 diabetes. ... Over time she refused the substantive dietary and exercise alterations along with medication refills. Ten months from the first hospitalization, mum went into heart failure; extensive cardiac damage led to her passing at the age of 56."

Puffer K. *Schizophr Bull* 2010;36:651–654.[171]

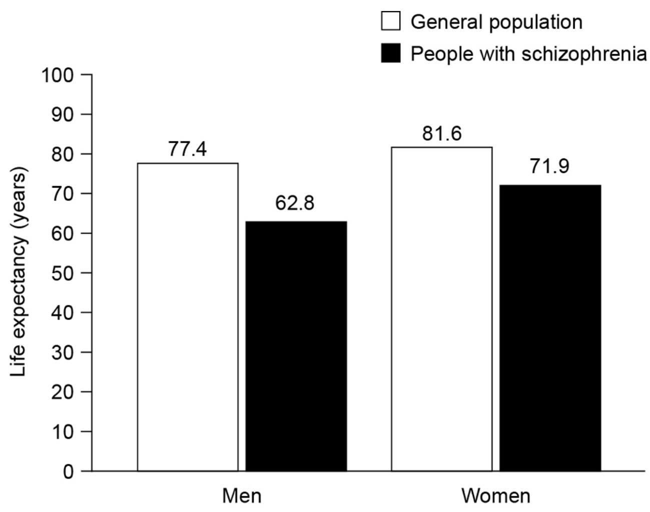

Fig. 7. On average, people with schizophrenia die earlier than the general population. The figure shows the mean decrease in life expectancy at birth in people with schizophrenia, compared with the general population, in London, UK.[15]

Increased rates of heart disease, compared with the general population, are major drivers of early death and ill-health among people with schizophrenia. A study from Sweden has shown that deaths from heart disease, while decreasing in the general population, are actually increasing among people with schizophrenia.[172] Underdiagnosis and undertreatment may contribute to this high mortality. Deaths from heart disease are up to 5 times higher in people with schizophrenia than in the general population; however, diagnosis rates may actually be lower according to recent data from Sweden.[30]

Inadequate attention to physical illness: health care professionals sometimes pay too little attention to treating physical illness in people with mental illness.[16,173] Importantly, people with schizophrenia or other mental illnesses are less likely to undergo procedures such as angioplasty after a heart attack than individuals without such disorders.[174–176] Similarly, data from the United States show that individuals with diabetes mellitus and schizophrenia are less likely to receive statins to lower their cholesterol levels than those without schizophrenia.[177] In one study, people with both diabetes and mental illness were less likely to be hospitalized for treatment of diabetic complications than those without mental disorders.[178]

Recent years have seen increased attention to physical illness in people with schizophrenia, resulting in better coordination of health care services, with primary care physicians playing an increasing role. Carers too are becoming increasingly involved in monitoring the physical wellbeing of people with schizophrenia, forming a "therapeutic alliance" with health care professionals. Indeed, family members and physicians often recognize physical health problems more readily than people with schizophrenia themselves.[13]

Smoking is another major cause of ill-health in people with schizophrenia. In the United Kingdom, an estimated 65% of people with schizophrenia smoke, compared with 33% of the general population,[13] and in the United States, 4 times as many people with schizophrenia smoke (~88%)[179] compared with the general population (19%).[180] Smoking is often combined with a poor diet and obesity.[181] Indeed, tobacco-related illness may be the leading cause of death among people with mental health problems such as schizophrenia.[182] Interventions to stop smoking should therefore form part of schizophrenia care.[10,182] Importantly, evidence suggests that smoking cessation strategies that work in the general population are also effective in people with schizophrenia (unpublished data).[183] Research is also needed to identify why smoking is so common among people with schizophrenia.

Alcohol and substance abuse are also common in people with schizophrenia: about 50% have a substance use disorder at some time in their lives, compared with about 15% of the general population.[17] Such individuals are often specifically excluded from clinical trials, meaning that the evidence base for interventions in this population is limited. Alcohol and substance abuse are associated with a poor outcome in terms of relapses, hospitalizations, impaired functioning, and physical illness.[10,184] Cannabis abuse is of particular concern, given that it is a recognized risk factor for the development of schizophrenia, particularly in young individuals.[185] For these reasons, reducing substance abuse in people with schizophrenia is a priority.[17] Ideally, substance abuse should be treated using a combination of medication with psychological and behavioral therapies.[186] Such treatment should be integrated into psychiatric care, rather than being provided by discrete agencies.[17]

What More Can Be Done?

Addressing the Limitations of Current Care.

Despite these advances, the management of physical ill-health in schizophrenia remains far from ideal.[169] Schizophrenia itself, the medications used, and the patient's lifestyle can all lead to physical illness, particularly weight gain and metabolic disturbances that may contribute to the development of heart disease or diabetes mellitus. Monitoring for risk factors, such as raised cholesterol, and providing treatment if appropriate are important aspects of care, but monitoring often falls short of optimal care.

Different health care systems can result in marked variations in care pathways, and thus it may not always be clear who is primarily responsible for a person's physical health. In some countries, the primary care physician is largely responsible for the management of physical illness in patients with schizophrenia, whereas in others, the psychiatrist takes the lead. It should be emphasized, however, that *all* health care professionals should be involved in looking for and treating physical illness in patients with schizophrenia. Schizophrenia care requires an integrated approach led by mental health services. As medically trained professionals, psychiatrists should therefore be actively involved in monitoring the physical health of their patients, and equipped with the necessary tools (and training) to measure cardiovascular risk factors. Among these risk factors are obesity (measured by body mass index or waist circumference), high blood pressure, raised blood glucose, and disrupted levels of fats in the blood (including raised cholesterol and triglyceride levels). Programs aimed at promoting a healthy lifestyle have been shown to be beneficial in schizophrenia,[110,187] and such programs should be implemented more widely. A welcome trend in this respect is the increasing provision of exercise equipment and other lifestyle measures in schizophrenia clinics.

Decreasing the Burden of Ill-Health.

The provision of adequate measures to decrease the burden of illness, both mental and physical, among people with schizophrenia will depend on local legislation in each country. In addition, such provision will require effective coordination of services and funding, continuity of health and social care, and synchronization with the criminal justice, benefits, and employment systems. Extensive evidence exists that initiatives designed to improve continuity of care can produce a favorable outcome.[188,189] There is, however, a risk that reorganizations of health care systems currently underway in some countries could compromise this continuity.

Addressing the challenges

Health care providers and professional organizations

- Ensure that mental health services are able to accept responsibility for their patients' physical health as well as their mental health. This will involve providing mental health facilities with the tools needed to monitor for major risk factors, as well as co-coordinating mental health, primary care, and other health services to ensure a seamless delivery of care.

- Provide clinical training for psychiatrists to equip them with the knowledge and skills to address patients' physical illnesses where possible and to refer patients to appropriate specialists if necessary.
- Enhance the teaching of mental health in medical schools to match the public health burden of mental illness.

Clinicians

- Offer targeted smoking cessation interventions, and interventions to address alcohol or substance abuse, to all people with schizophrenia who need them. Interventions aimed at alcohol or substance abuse should form an integral part of mental health care for people with schizophrenia.
- Be attentive to the physical health needs of patients with schizophrenia.

All relevant stakeholders

- Ensure that people with schizophrenia are not prevented from seeking or receiving appropriate care for their physical health, or from having the choice to participate in research, because of prejudice or discrimination.

The world of research

- Ensure that patients with alcohol or substance use disorders should not be excluded from clinical trials of new schizophrenia therapies.
- Ensure that investment in research for mental health matches its global public health burden.

Creating a Supportive Environment That Promotes Recovery

Key points

- Creating a free, healthy, and supportive environment to promote recovery is central to schizophrenia care.
- Information for people with schizophrenia about the support available for employment, housing, and other issues is often lacking.
- People with schizophrenia should receive the benefits to which they are entitled.
- A better understanding of incentives for work and the availability of work opportunities could help in the provision of employment.
- Appropriate resources are needed to ensure that supportive environments can be in place for people with schizophrenia to achieve recovery.
- Employers should take appropriate measures to ensure that the workplace needs of people with schizophrenia are adequately met. Similarly, because schizophrenia often develops during adolescence, educational institutions should also take appropriate measures to accommodate the needs of students with schizophrenia.

The creation of a supportive environment in which people with schizophrenia can work toward recovery is central to schizophrenia care. Indeed, it may be a prerequisite for all other approaches discussed in this report to be effective. A supportive environment is a wide-ranging concept comprising various social and legal factors (table 6). At present, however, many people with schizophrenia are not in a supportive environment. Although the importance of the environment in people with mental health has long been recognized, the systematic manipulation or changing of the environment has only been formalized in recent years.[190]

Improving the Environment Results in Better Symptom Control and Function

Attention to environmental needs can pay dividends in helping people with schizophrenia achieve their desired outcomes. Key environmental needs include the ability to perform work tasks adequately, good financial management, and secure interpersonal relationships; social function often improves when these needs are addressed.[190] People with schizophrenia, however, often face prejudice and discrimination when seeking employment or training, or when trying to form close relationships.[140]

First-person account

"I enrolled in a program called Work on Track that helps people with mental illness prepare to re-enter the work force. ... Although Work on Track had helped me to prepare a good résumé, I had a 5-year gap. ... I was told to say that it was due to a medical condition but that it was now under control and that it would not be a factor in my job. … I never got a second interview."

Scotti P. *Schizophr Bull* 2009;35:844–846.[55]

Unemployment rates are substantially higher among people with schizophrenia than in the general population; as we have seen, supported employment interventions can produce substantial savings in health care and societal costs and can reduce the risk of hospitalization.

Table 6. Factors Contributing to a Supportive Environment

- Supportive legislation
- Social inclusion
- Employment
- Housing
- Befriending
- Protection against discrimination
- Promotion of competence/capacity
- Use of the least restrictive treatment possible
- Family support and provision of childcare during acute episodes
- Provision of social services

Employers should ensure that adequate measures are taken to accommodate the needs of people with schizophrenia in the workplace. Such measures might include the following:

- allowing flexible scheduling if needed (eg, if the employee is experiencing drowsiness as a side effect of their schizophrenia medication),
- providing a quiet working environment free from distractions,
- allowing the employee to make up for time lost due to doctor's appointments,
- permitting home working when appropriate,
- dividing large assignments into smaller tasks with clearly achievable goals, and
- providing support and encouragement.[191]

Schizophrenia can adversely affect a person's earning potential in adulthood because it often develops during adolescence and can severely disrupt education. Studies have shown that application of IPS principles to education (supported education) can help young people with schizophrenia to complete their education and find paid employment.[192,193] Given these positive findings, educational establishments should take appropriate measures, such as those described above, to ensure that the needs of adolescents with schizophrenia are adequately met in the education system.

Homelessness is common among people with schizophrenia[194]; recent data from the United States indicate that 35% of people with serious mental disorders, including schizophrenia, have experienced homelessness or have been in jail,[194] while in a European study, 15% of individuals with schizophrenia have been homeless at some time during their illness.[19] Furthermore, approximately 22% of homeless single adults and 8% of homeless adults with children have a serious mental illness in the United States.[195]

This represents a major barrier to recovery because homelessness is associated with an increased duration of hospitalization,[196] diminished function,[197] and other adverse outcomes, such as suicide or self-harm, substance abuse, discrimination, and violence.[198]

Supported housing for people with schizophrenia has been defined in a number of ways. In the United States, the term usually describes specific interventions designed to provide private housing with external support for people with schizophrenia, whereas in Europe it refers to the provision of staffed facilities with on-site support. The latter approach may provide a "safe haven" for people in need of stability and support, but this may be at the cost of increasing dependence and continuing social exclusion; the effectiveness of such interventions needs to be demonstrated in randomized studies.[199]

A critical time intervention (CTI) approach, in which social workers organize support plans and work intensively with the homeless person for 6 months to help them obtain housing, can be effective in helping people with schizophrenia.[200,201] The CTI approach reduces the time and intensity of stays in very staff-intensive services, such as ACT, and permits transfer of patients to more routine services in the community if available. Thus, those who receive services from an ACT team are no longer expected to receive ACT services indefinitely.

Contact with the criminal justice system is disproportionately high among people with serious mental disorders such as schizophrenia. Data from the United Kingdom suggest that about 8% of the prison population have psychosis and 2% qualify for a formal diagnosis of schizophrenia, compared with 0.5% or less of the general population[20]; in a more recent study from the United States, 46% of people receiving antipsychotic medication had at least 1 encounter with the criminal justice system.[202] Involvement with the criminal justice system dramatically increases the economic costs associated with schizophrenia—potentially doubling the cost according to a recent US study.[203] In some countries, people with schizophrenia who have committed serious crimes are confined in secure hospital facilities, rather than in prison. This approach can account for a significant proportion of mental health care expenditure.[20] Conversely, a study in the United States found that a decrease in the availability of inpatient psychiatric beds was associated with an increased risk of imprisonment for minor charges among people with a severe mental illness, and that this was particularly driven by substance abuse.[204]

In the United States and some other countries, criminal justice diversion programs have been introduced, aimed at identifying offenders with mental disorders and linking them to health and social services, rather than the criminal justice system.[205,206] Several approaches have been used in such programs, including mental health courts (MHCs), ACT, intensive case management, intensive psychiatric probation and parole, and residential support[205]; the most widely used approach in the United States is MHCs, which may either divert the defendant before trial or provide treatment-oriented options as an alternative to incarceration after conviction.[207] Diversion programs have been shown to be beneficial in decreasing incarceration and the risk of reoffending and, in the longer term, hospitalizations; in addition, some studies have reported reductions in symptoms and alcohol or substance abuse, and improvements in quality of life.[205,206] Clearly, however, it is desirable that people with mental disorders such as schizophrenia do not become involved with the criminal justice system at all: MHCs and other diversion programs are not a substitute for an adequate mental health system.[207] Moreover, there is only limited information about the cost-effectiveness of diversion programs; although they may reduce costs to the criminal justice system, treatment costs may increase, at least in the short term.[205]

Communication and Education About Schizophrenia

Awareness campaigns aimed at the general public can be beneficial in increasing awareness of the nature of schizophrenia and its treatment. The experience in a number of countries worldwide has shown that public campaigns to increase awareness and tackle the discrimination toward schizophrenia can be effective in diminishing negative attitudes toward mental illness.[14] Such programs include the World Psychiatric Association's *Open the Doors* program[208,209] and the *Like Minds* campaign in New Zealand.[208] The UK *Time to Change* campaign has recently been shown to have resulted in a positive shift in public attitudes toward mental illness, with patients experiencing less discrimination overall and when looking for a job.[210]

Mental Health First Aid is an example of an internationally recognized evidence-based training practice that educates the public about mental illnesses, including schizophrenia and substance abuse disorders.[211] People around the world have learned strategies to recognize, react, and respond appropriately to provide help to individuals who are developing a mental health problem or who are facing a mental health crisis.

Importantly, educational campaigns should be a continuing process: single campaigns usually do not have much effect, and sometimes result in disappointment for people with schizophrenia and their families once the campaign is completed.[208] A study in Norway found that patients were less likely to seek help in the absence of such campaigns or when campaigns were stopped, resulting in a longer duration of untreated psychosis (figure 8) and more severe symptoms.[212]

The role of advocacy and peer-led groups: People who are affected by schizophrenia, both the patients themselves and those who care for them, can offer powerful and eloquent insights into the condition. As a result, advocacy groups, peer-led "self-help" groups, and volunteer groups that work with their peers who are mentally ill are having an increasingly important influence on the care of people with schizophrenia (it is important to recognize, however, that the aims of self-help groups may not necessarily coincide with those of advocacy groups).

Advocacy groups represent the interests of people affected by mental illness and promote their rights. They speak out in support of those affected by mental disorders, provide information and education, campaign against stigma and discrimination, and much more. National or international schizophrenia advocacy groups include EUFAMI in Europe, GAMIAN in the United States and Europe, and NAMI in the United States. In addition, local networks or groups have an important role to play and are greatly appreciated by people with schizophrenia. At an individual level, clinicians treating people with schizophrenia can also be powerful and influential advocates for improved care.

Barriers to the Creation of a Supportive Environment

Inconsistent Mental Health Policy.

Even in Europe, where many countries have specific mental health legislation to cover areas such as housing or employment, many people with mental disorders may not be adequately protected. For example, 81% of the total population of Europe live in countries that currently have such legislation, but only 38 of 52 countries have mental health policies that set out the priority given to mental health (table 7).[213]

A Problem With Benefits.

While social security benefits are clearly essential for people with schizophrenia who are temporarily unable to work, the benefit system can actually make it difficult for

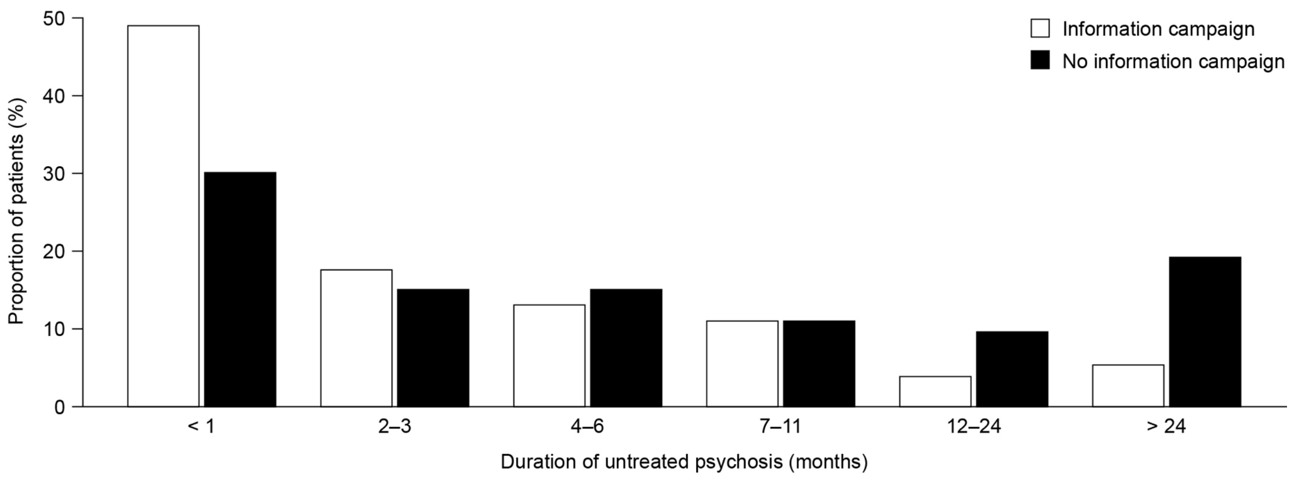

Fig. 8. Intensive information campaigns have been shown to have a beneficial effect on the duration of untreated psychosis.[213] The figure shows the proportion of patients with a given duration of untreated psychosis in the presence or absence of information campaigns. People are more likely to seek help when information campaigns are in progress, so the duration of untreated psychosis is shorter. Figure adapted from Joa *et al*.[213]

Table 7. Regions of the World With Dedicated Mental Health Policy[213]

Region	Countries with mental health policy	Population coverage, %
Africa	19/45	60.1
Americas	18/32	88.1
Eastern Mediterranean	13/19	84.8
Europe	38/52	90.8
South-East Asia	7/10	31.8
Western Pacific	15/26	94.9
World	110/184	71.5

them to find employment; even with supported employment measures, many find it difficult to come off benefits.[214,215] Work can be stressful and, if a person is only able to work for a few hours each week, it may actually be less lucrative than remaining on benefits. Similarly, older people with schizophrenia receiving a pension have little incentive to seek employment.

The "Social Paradox."
A "social paradox" exists in some countries, whereby individuals are concerned about losing disability and other benefits if they present themselves for employment. For example, qualifying for disability benefits from the Social Security Administration in the United States provides eligibility for health insurance benefits; hence, beneficiaries who return to work and give up their disability income support risk losing their health insurance. The passage of the recent Affordable Care Act in the United States has provided alternatives to disability status for gaining health insurance benefits. It is hoped that this reform will help to reverse the incentives that led to the finding that about 96% of people with schizophrenia who start to receive social security disability benefits remain on them permanently.[216,217] Similar situations have been reported in other countries.

Complications of the Benefit System.
Information for patients about the support available for employment, housing, or other issues is often lacking. Even when information is available, it may be difficult to access or use, especially if literacy is an issue. This is of particular concern among immigrant communities, where cultural differences and language barriers often hinder access to services.[13] The lack of information can also cause delays in benefits being received. One study in France, in which more than half of the participants became unemployed following the onset of schizophrenia, demonstrated a median delay of 4 years between the onset of the disorder and the first application for disability benefits; in many cases, the financial hardship caused by this delay exacerbated the social consequences of their schizophrenia.[218] Marked differences exist among countries in their attitude to job provision; in some countries, this is regarded as a governmental responsibility, whereas in others a free-market approach prevails.

What More Can Be Done?

Creative approaches are needed to change public attitudes to schizophrenia and to end the discrimination faced by many people with schizophrenia when seeking employment or training.

Improving the Benefit System.
The rights of people with schizophrenia are enshrined in the 2006 UN Convention on the Rights of Persons with Disabilities[219] and the forthcoming WHO Mental Health Action Plan.[25] In the United Kingdom, however, where mental health problems are associated with long periods of unemployment, benefit claimants with a mental health problem are less likely to be successful than those without.[18] This situation contrasts with that in Australia, where there is an effective "one-stop" system for identifying claimants with mental health problems.[18] More should be done to ensure that people with schizophrenia receive the benefits to which they are entitled. Importantly, a recent review conducted for the US Social Security Administration has shown that more than 80% of people with schizophrenia meet the criteria for disability benefits; furthermore, of those whose applications were initially unsuccessful, many actually met the criteria for benefits but were simply unable to cope with the appeal system.[220]

A better understanding—across cultures and across social insurance systems—of incentives for work and the availability of work opportunities could help in the provision of employment for people with schizophrenia. In Belgium, people with mental disorders who lose their job generally receive unemployment benefits rather than disability benefits; they thus remain in close contact with the labor market, which facilitates their re-employment.[221] Importantly, voluntary employment that offers a "worthwhile day" may benefit the patient even if paid employment is not an option.

Supporting Education Campaigns.
Education campaigns should be directed toward the general public, in order to change negative perceptions about mental illness; however, successful psychoeducation campaigns will require substantial resources. Multimedia campaigns are needed that include a social marketing approach, similar to those employed to promote smoking cessation and to prevent acquired immunodeficiency syndrome and other health-related issues.[14] The effectiveness of such campaigns can be enhanced by using "audience segmentation," whereby specific and culturally appropriate messages are delivered to defined segments of the target audience.[14]

Encouraging Early Diagnosis and Intervention.
Initiatives aimed at creating a supportive environment to promote recovery are tertiary prevention measures

in people with established schizophrenia. Much can still be done in secondary prevention, however, to reduce the potential impact of the disorder by early diagnosis and intervention. Early intervention can reduce the number and duration of hospitalizations over 1–2 years after a first episode of psychosis[42,43] although the impact is less clear during the longer term.[13,41] Importantly, early intervention services have been shown to produce significant savings in health care and societal costs,[40] through preventing hospitalizations, increasing employment rates, and decreasing involvement with the criminal justice system.[20]

Addressing the challenges

Clinicians

- Engage with policy makers and other relevant stakeholders to recognize that a supportive environment is essential for recovery in schizophrenia, and encourage the use of cost-effective measures to achieve this.

Health care providers and other relevant agencies

- Ensure that the needs of people from ethnic minorities who have schizophrenia are identified and addressed in a culturally appropriate manner.

Conclusions

Better lives for people living with schizophrenia: this is a reachable goal! We have come a long way toward achieving this in recent years, but much can (and should) still be done. Successful care requires an integrated team approach, involving psychiatrists, a range of health care professionals, social care providers, and other external agencies. It also involves collaboration with people with schizophrenia, their families, and other sources of support. For private health care systems, such a team approach will require careful alignment of reimbursement mechanisms to support high-quality care.

A second prerequisite for successful care is adequate funding—at least equivalent to that for other medical conditions such as cancer and heart disease—for research, treatment, services, and teaching of future mental health care professionals. At present, the extent to which potentially effective psychosocial therapies are funded by public health care systems varies across countries; hence, many patients are denied treatment. More support is also needed for independent studies of potential beneficial interventions.

Implementation of the recommendations summarized in table 8, and in each chapter, will require engagement by every stakeholder: from policy makers at every level, from clinicians, and from public agencies. The challenge for the future will be how to implement the recommendations from this report in order to bridge the current unmet needs. With commitment from all, change can be achieved.

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Table 8. Recommendations for Policy Change. Schizophrenia Has a Profound Personal, Social, and Economic Impact. Furthermore, Public Attitudes Toward Schizophrenia Lead to Prejudice and Discrimination. The Authors of This Report Recommend the Following Policy Actions to Local, National, and Regional Policy Makers.

1. Provide an evidence-based, integrated care package for people with schizophrenia that addresses their mental and physical health needs. This should be underpinned with an integrated approach by their health care professionals and supported by the national health care system and by educational and research facilities.
2. Provide support for people with schizophrenia to enter and to remain in their community, and develop mechanisms to help guide them through the often complex benefit and employment systems to enhance recovery. Guidelines and educational programs should be developed and implemented to support the inclusion of people with schizophrenia in their community, workplace or school.
3. Provide concrete support, information and educational programs to families and carers on how to enhance care for an individual living with schizophrenia in a manner that entails minimal disruption to their own personal lives.
4. Consult with health care professionals and other stakeholders directly involved in the management of schizophrenia, including organizations that support people living with schizophrenia, their families and their carers, in order to regularly revise, update and improve policy on the management of schizophrenia.
5. Provide support, which is proportionate to the impact of the disease, for research and development of new treatments that improve the overall outlook for people with schizophrenia, including those that target negative symptoms and cognitive impairment.
6. Establish adequately funded, ongoing and regular awareness-raising campaigns to: increase the understanding of schizophrenia among the general public; emphasize the importance of positive societal attitudes toward mental illnesses; highlight available support for the management of schizophrenia; and deter discriminatory attitudes and actions. Such campaigns should form an integral part of routine plans of action.

Our recommendations are based on research evidence, stakeholder consultation, and examples of best practice worldwide.

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