CHAPTER 1

Introduction

This chapter introduces the concepts of mental health and mental illness. It provides an overview of the contexts within which mental illnesses are prevented, diagnosed, and treated and the many problems such conditions pose for patients and their families. The topics discussed in this chapter will be relevant throughout the entire book.

1.1 Mental health and mental illness

Mental health refers to the successful performance of mental function, resulting in productive activities, fulfilling relationships, and the ability to adapt to change and cope with adversity. Mental health provides people with the capacity for rational thinking, communication skills, learning, emotional growth, resilience, and self-esteem. People experiencing emotional well-being or mental health function comfortably in society and are satisfied with their achievements. Mental health is one of the leading health indicators that reflect the major public health concerns in the United States. Related indicators of interest to the mental health community include substance abuse, injury and violence, and access to healthcare.

The American Psychiatric Association (APA) defines mental illness as a clinically significant behavioral or psychological syndrome experienced by a person and marked by distress, disability, or the risk of suffering, disability, or loss of freedom. The symptoms of the disorder must be above and beyond expected reactions to an everyday event. The behavioral or psychological condition must result from brain functioning or malfunctioning, and it must cause the person distress, impairment, or both. It cannot be a cultural practice to which the majority culture in a society objects or that might cause distress to non-members of a cultural group. For example, some cultures believe that women should be subservient to men and expect the behavior of both sexes to reflect this idea. People of Western cultures might view such women as dependent or co-dependent, yet the behavior of these women is perfectly normal within the parameters of their own culture.

1.2 Incidence and prevalence of mental illness

Psychiatric illnesses are common in the United States and internationally. The prominence of mental disorders in the total pattern of worldwide morbidity and mortality has been reported by the World Health Organization (WHO). According to their 2002 estimates, mental illnesses account for 25% of all disability across major industrialized countries. Mental illness ranks first in terms of causing disability in the US, Canada, and Western Europe.

In the US an estimated 26.2% of people (57.7 million) suffer from a diagnosable mental disorder in a given year. Data from the National Comorbidity Survey suggests that an estimated 13 million US adults (approximately 1 in 17) have a seriously debilitating mental illness. The main burden of
illness is concentrated in this smaller population. Mental disorders are the leading cause of disability in the US and Canada for ages 15–44. Nearly half of people having any mental disorder meet the criteria for two or more disorders. In terms of morality, suicide alone is the eleventh leading cause of death in the US, with approximately 30,000 deaths per year, and this is an issue of concern worldwide as well. Determining the costs associated with mental illness is challenging, but estimates suggest annual treatment costs in the US of $100 billion, with significantly more for indirect costs; $193 billion per year is estimated for lost earnings alone.

At least 20% of children in the United States have a diagnosable mental disorder; only 5% of these children have severely impaired functioning. In adults aged 18–54 years, 14.9% have anxiety disorders, 7.1% have mood disorders, and 1.3% have schizophrenia. Depression, a serious mental health problem in any age group, is particularly problematic in older adults. Between 8% and 15% of older adults have depression, but the condition is often undiagnosed and untreated in this age group because depression is mistakenly thought of as part of “normal aging.” People aged 65 years or older have the highest suicide rates of any age group. According to the Alzheimer’s Association, Alzheimer’s disease occurs in 8–15% of those older than 65 years (4.5 million cases) and that number is expected to increase to 11–16 million in the US by 2050. Approximately 125,000 people age 22–64 with mental illness live in nursing homes, 283,800 are incarcerated. Of 2 million individuals who are homeless over the course of a year, 50% have a mental illness and/or substance abuse disorder.

Table 1.1 contains National Institute of Mental Health statistics on the prevalence of some of the more common mental illnesses.

<table>
<thead>
<tr>
<th>Disorder</th>
<th>Prevalence</th>
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<tbody>
<tr>
<td>Mood disorders (major depressive disorder, dysthymic disorder and bipolar disorder)</td>
<td>Approximately 20.9 million US adults, or about 9.5% of the population aged 18 and older, have a mood disorder in a given year</td>
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<tr>
<td>Major depressive disorder</td>
<td>Major depressive disorder affects approximately 14.8 million US adults, or about 6.7% of the population aged 18 and older in a given year</td>
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<tr>
<td>Dysthymic disorder</td>
<td>Dysthymic disorder affects approximately 1.5% of the US population aged 18 and older in a given year (this translates to about 3.3 million US adults)</td>
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<tr>
<td>Bipolar disorder</td>
<td>Bipolar disorder affects approximately 5.7 million US adults, or about 2.6% of the population aged 18 and older in a given year</td>
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<tr>
<td>Suicide</td>
<td>In 2006, 33,300 (approximately 11 per 100,000) people died by suicide in the US</td>
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<tr>
<td>Schizophrenia</td>
<td>Approximately 2.4 million US adults, or about 1.1% of the population aged 18 and older, have schizophrenia in a given year</td>
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<tr>
<td>Anxiety disorders</td>
<td>Approximately 40 million US adults aged 18 and older, or about 18.1% of people in this age group, have an anxiety disorder in a given year</td>
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<tr>
<td>Obsessive–compulsive disorder (OCD)</td>
<td>Approximately 2.2 million US adults aged 18 and older, or about 2.7% of people in this age group, have panic disorder in a given year</td>
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<tr>
<td>Post-traumatic stress disorder (PTSD)</td>
<td>Approximately 7.7 million US adults aged 18 and older, or about 3.5% of people in this age group, have PTSD in a given year</td>
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<tr>
<td>Generalized anxiety disorder (GAD)</td>
<td>Approximately 6.8 million US adults, or about 3.1% of people aged 18 and over, have GAD in a given year</td>
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<tr>
<td>Social phobia</td>
<td>Approximately 15 million US adults aged 18 and over, or about 6.8% of people in this age group, have social phobia in a given year</td>
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Source: National Institute on Mental Health
1.3 Etiology of mental illness

The specific causes of mental illnesses are largely unknown. The pathways leading to mental disorders involve an enormously complex set of interactions. Multiple factors involving genetic predispositions and environmental influences contribute to the development of mental disorders. Mental Health: A Report of the Surgeon General identifies the roots of mental illness as some combination of biologic and environmental factors; however, the document cautions against thinking that any one gene is responsible for any mental disorder. In all likelihood small variations in many genes disrupt healthy brain functioning, and under certain environmental conditions this disruption can result in mental illness.

1.4 The burden of mental illness

Given the significant numbers of people with a mental illness, nearly two-thirds of affected individuals fail to seek treatment. Several factors contribute to this reality; they are part of the world within which people with mental illnesses and their families contend.

1.4.1 Stigma

Mental illnesses are exceedingly stigmatized, evoking fear and prejudice based on misunderstanding and misconceptions of these conditions. This stigma is not limited to the public itself but to professionals as well. Misconceptions have ranged from attributing mental illnesses to demonic possession to blaming victims for their problems. This stigmatization has led to discrimination and intolerance based on ignorance of mental illness itself. Stereotyping has had profound consequences for individuals with mental illnesses and their families. It has discouraged public sympathy for the traumatic life dislocation of people with brain disorders, and has prevented public policy from allocating resources (such as medication parity) that would meet their needs. For example, many health plans cover the costs of psychotropic medications at far lower rates than they do for other medications.

Of great concern is the role that stigma plays with children in that it can lead parents to avoid seeking treatment that could dramatically improve their children’s condition. Children with psychiatric disorders are stigmatized as much as their adult counterparts by both other children and adults. In a large study of US parents, 30% said they would not want their child to become friends with a child who had depression, and 25% said the same about a child with attention-deficit hyperactivity disorder. Almost 20% of the sample said they would not want a child with either disorder to live next door. Responses to the same questions substituting a “physical” illness were much more generous and understanding. Similar levels of stigmatization have been found repeatedly across other studies with others, such as adolescents, adults, and geriatric populations.

In the policy arena, research funding for the treatment of mental illnesses is often far lower than funds allocated for funding of other disease states. At an individual level, people with mental illness must deal with a painful level of rejection, isolation, and discrimination that erodes their self-assurance and can systematically undermine their self-confidence. People with mental illness are often discounted and invalidated. In the late 1990s when patients and families reported to state officials that they were being mistreated in private mental hospitals, they were dismissed by their third-party payers and regulators until investigative journalists exposed very real instances of systematic abuse. The very label of a mental illness can lead patient behavior to be needlessly pathologized. Stigma builds or reinforces interpersonal, financial, employment, and social barriers to accessing care.
1.4.2 The context of treatment

The President’s New Freedom Commission on Mental Health was charged with studying the mental health care delivery system, identifying the problems and gaps, and recommending changes that would facilitate better outcomes for adults and children with serious mental and emotional conditions. Spanning 12 months of document review, interview with patients, families, providers, and experts, the Commission declared that the mental health delivery system in the US is fragmented and in disarray and that fragmentation too often lead to unnecessary and costly disability, homelessness, school failure and incarceration. Particularly devastating was its conclusion that the US mental health system was not oriented to the most important goal of the people it serves: the hope of recovery.

The fragmented mental health care delivery system in the US often provides inadequate, inappropriate, or no care. It is very difficult for clients and their families to determine what services are needed and where to find them. The majority of inpatient mental health settings provide services based on a traditional model of care that is often uninformed by recovery-oriented principles or research. This traditional approach is often characterized by paternalistic attitudes, staff-to-patient power differentials, homogenized treatment practices, a lack of voice from the individuals being served, outdated programming, and blatant discrimination as to language practices and policies in inpatient settings.

Common practices include talking about people as if they are their disease (“schizophrenics”), documentation in the medical record that is pejorative (“needy,” “attention-seeking” or “manipulative”), arbitrary wake-up and bedtime rules, and expectations that patients and their families will passively accept treatment team recommendations that they may not have been involved with developing. These conventions can be experienced as patronizing, shaming, and disrespectful, and they can contribute to lack of trust, lack of treatment adherence, and poor outcomes.

Poor outcomes also result from the lack of resources for effective care. While the effectiveness of psychotropic medications has reduced the need for hospitalization when hospitalization is necessary, lengths of stay in hospitals have decreased. Managed care companies often mandate certain types of treatment, favoring short-term time-limited approaches, even when a person’s needs are for longer, more intensive treatment. For these and other reasons, many patients are being discharged from hospitals and long-term facilities when they lack the skills to survive or live adaptively outside institutionalized settings.

To recover and become completely well, patients must be reintegrated into their communities. The money for treatment must follow them back into their community to be used for appropriate and accessible care. Coordination and collaboration among agencies providing services are needed but, as the New Freedom Commission concluded, they are lacking.

1.5 The recovery movement

Historically, people with serious and persistent mental illness have generally been viewed as a marginalized population of human beings who suffered from a chronic, unremitting illness for which there was no “cure.” This widely accepted belief destined people with severe and persistent mental illness (SMI) to live without hope of ever attaining the usually expected adult roles in society, such as student, spouse, employee, parent, or homeowner. This pervasive belief also assumed that a person with SMI could expect a life characterized and defined as a “patient” and by “hospitalizations” and that the diagnosis of SMI was akin to a death sentence. People with these illnesses, their families, and the professional licensed and non-licensed staff who were providing healthcare services for
them were both directly and subtlety trained to accept this view and to believe that the best outcome that could be hoped for was longer remissions of florid symptoms and a lifelong need for professional care.

In the last three decades, this pessimistic view has been radically challenged and a new theoretical model postulated. Beginning with the emergence of the consumer movement, people labeled with a SMI diagnosis have tried to communicate to us what works for them and what does not. These early pioneers and advocates identified, documented and lived their truths; that recovery from SMI was possible and was occurring, often with very little help from the public mental healthcare establishment. These courageous people were recovering from schizophrenia, bipolar illness, major depressions, and from labels of personality disorder. They spoke and wrote about a phenomenon of recovery that did not seem to be predicated on symptoms, but rather on social supports, adequate medical care when needed, the provision of hope and opportunities that involved real choices and real life. From the 1930s to the early 1980s this grassroots movement received little attention and its proponents often were seen as anomalies.

The Mental Health: A Report of the Surgeon General published in 1999 included a comprehensive description of the phenomenon of recovery and described it as having a tremendous impact on “consumers,” their families, mental health research, and service delivery. The report credited this turnaround in attitudes as a result of the consumer movement. Recovery had become a rallying cry and a demanded outcome by consumers, their families and advocacy organizations, even while current philosophies, treatments and attitudes continue unchanged in many settings.

1.6 Vision of a transformed mental health system

The New Freedom Commission’s report clearly identified the vision of a transformed mental health system when it stated that a successful transformation rested on two principles: (a) services and treatments must be consumer and family centered, geared to give individuals real and meaningful choices about treatment options and providers – and not oriented to the requirements of bureaucracies, and (b) care must focus on increasing the individual’s ability to successfully cope with life’s challenges, on facilitating recovery, and on building resilience, not just managing symptoms.

In addition to the vision of recovery as a guiding theme, priority goals include: the need to make mental-health care services consumer and family driven, to reduce discrimination and coercion, to eliminate disparities in service provision, to adopt and use promising and evidence-based practices, and to use technology to improve access to care and to information. These goals reflect strong philosophical and value-laden statements that clearly separate the current system of care from the transformed system envisioned by the Commission.

Further Reading


