People with lived experience and carers

1

SIMON SWINSON, MIKE HAZELTON AND TIM HEFFERNAN

LEARNING OUTCOMES

After completing this chapter, you will be able to:

1. Analyse why the term *deviant behaviour* lacks a definition that covers all situations.
2. Define and explain *mental illness*.
3. Compare and contrast the essential characteristics of mental health with mental illness.
4. Identify five types of mental illness that rank among the top 10 causes of disability worldwide.
5. Explain how societal attitudes, philosophical viewpoints and definitions of *mental illness* have changed over time.
6. Explore the lived experiences of people with mental illness and of their families and friends.
7. Explore the meaning and impact of stigma for people living with mental illness, their families and friends, mental health service providers and the wider community.

KEY TERMS

LIVED EXPERIENCE

Simon Swinson

One does not grow up intending to become a mental health consumer. It is something that life thrusts upon you, and society labels you with in the course of developing specific kinds of (mental) health problems. You start off with a blank sheet of possibilities, only to find that life is severely limited by the labels and experiences that surround mental illness. Fortunately, society is starting to find ways of being more responsive to, and supportive of, the real needs of people who live with mental illness. Slowly but surely, consumers are having a greater say in the services they receive as part of the constant project of personal recovery.

Increasingly, the consumer voice is being sought out in ways that it never was previously—by governments, health service managers, health professional practitioners and university academics. Nonetheless, many consumers still lack access to the resources that would enable them to be heard. Such problems are especially likely to occur: in rural and remote areas; in places of high socioeconomic disadvantage; among people of uncertain citizenship status, such as refugees and asylum seekers living in immigration detention centres.

Unfortunately, not all health professionals are as yet open to the consumer voice; for many consumers, exposure to mental health services, which invariably occurs under distressing circumstances, can be profoundly unsatisfactory. As the next generation of health professionals, you are encouraged to take on board the concepts of 'consumer voice' and 'recovery-oriented practice', and put these at the heart of your studies in mental health.

INTRODUCTION

The World Health Organization (WHO; 2014b) asserts that mental health is integral to all health, and that there is no health without mental health. The WHO (2007) also considers nurses to be an essential human resource for mental health care globally, and in low- to middle-income countries may be the only formal providers of care to people living with mental illness. Strategically, nurses are in a prime position to contribute to mental health and overall health outcomes; to provide comfort and support to people experiencing trauma and distress. While doing this work well requires rigorous formal education, another important source of learning is from people with a lived experience of mental illness and from those family members and friends who care for them.

Much of the work undertaken by nurses in the mental health field is different to that found in other areas of nursing. In particular, psychiatric–mental health nursing is about making interpersonal connections and using relationships as the basis to providing help. There are occasions when the work is unpredictable. Facing the unknown in a mental health setting can produce anxiety in students, new graduates and even more experienced nurses. It is not unusual for students and new graduates to ask:

- What kinds of people will I meet in a mental health setting?
- Will these people be hard to talk to?
- What do I have in common with them?
- What if I do something or say something wrong?
- How do I make a connection with them?
- Will I know what to do if a person becomes angry or upset?

This chapter discusses some of these questions. Other common concerns of nursing students and new graduate nurses are more fully addressed in Chapters 2 and 9 (see especially the Self-awareness feature in Chapter 2 on page 22).

What do you have in common with people who use mental health services? How can you ever hope to understand them? There are many approaches to understanding people—history, sociology, anthropology, philosophy, anatomy, physiology and psychology, among others. Each is like a searchlight, illuminating some facts while leaving others in shadow. One of the challenges you will face in your clinical experiences, in your classroom lectures, tutorials and discussions, and in reading this textbook, is how to judiciously and appropriately blend knowledge from these diverse sources. Learning from people with lived experience will almost certainly change the way you think about mental health issues. We have no doubt that had this chapter and other chapters in this textbook been written by nursing authors only, it would have been less relevant personally, professionally and educationally.

LIVED EXPERIENCE

Tim Heffernan

Mental health consumers are people just like you. In fact, if you look around your lecture theatre or workplace, at least 20 per cent of you and your colleagues are mental health consumers. Over your lifetime—say at your 50th high-school reunion—probably 50 per cent of your classmates will have experienced mental illness.

The thing is, they are still your workmates and classmates, and you are probably unaware of their struggles, their 'illness'. We, the people you will work with if you choose to become a mental health nurse, are mostly not much different than your friends and colleagues. Despite our illness, we all hope to be able to attend our 50th-year reunion, and we hope to reclaim or gain our place in the workforce and in the community.

When I talk to student nurses, I often say that yours is the most wonderful job in the world. How good is it to be able to help people heal and begin their journey of recovery? How good is it to find out later that that hopeless person now has a job and family? How good is it to make a difference most days at work?

We are all recovering, and most consumers understand that their illness is a normal human reaction to extraordinary life experiences. For many, this means adverse childhood experiences or trauma; for others, it can be bullying or a lack of love during those crucial teenage years. We mostly reject the medical or biological model of mental illness—we mostly don't believe that we have a brain disease.

The idea of disease was a good one initially. If it is a disease, we can cure it. But we now know that it is much more complex than this. We think that the best way nurses can assist us on our recovery journey is to be with us, share bits of yourself with us, be our confidant, listen to us, laugh with us, cry with us. Mental health nursing is so special because you are sometimes nursing our soul, our most vulnerable being.

Mostly, we see nurses who are task-driven—checking off the clipboard or on the computer writing things we

never own. Some seem scared of us, and like to spend most of the shift behind the 'fishbowl' looking out over us. Some, the ones I remember, stayed with us on the floor, asked about our lives, took an interest and then the best shared something of themselves. They said: 'You are a person, I am a person—let's share.'

As for mental illness being a global problem, we have to recognise that our global, national and local problems cause mental illness. We are not a problem: if you get to know us, you will discover that we hold many solutions. We need to be strong together.

Most people with mental illness do not seek treatment. We get the blame. The reality is that historically the treatment has alienated us, traumatised us and made us wary of the mental health system.

You can make this history.

The strategies in this book are designed to help you become a therapeutic, confident and safe psychiatric–mental health nurse. This chapter discusses what it means to live with mental illness, sometimes also referred to as 'mental disorder'. We review the attitudes and philosophical viewpoints that have influenced the understandings and approaches to mental health care throughout history, and the stigma connected with mental illness. We also identify the burden of mental illness, both nationally and globally. Our goals in this text are to encourage you to think seriously about what constitutes mental health and mental illness, to appreciate the humanity of people who live with mental illness, and to approach your mental health professional practice in a confident, open-minded and respectful manner.

It is possible that your studies in mental health and associated clinical placements may lead to anxiety, or self-doubt. We encourage you to approach psychiatric–mental health nursing with energetic enthusiasm, and an eagerness to understand and develop your skills in this critically important field. In doing so, you will find the humanity, creativity, caring and joy inherent in the people with whom you are working.

THE CONCEPTS OF DEVIANCE, MENTAL HEALTH AND MENTAL ILLNESS

Defining what is 'normal' *and* what is 'abnormal' is not as simple as it might seem. Whatever else they imply, concepts such as *deviance, mental health* and *mental disorder* are social constructions which derive their meaning from how society defines certain behaviours by certain people. Accordingly, we advocate taking a critical look at the social conditions (Hewitt & Shulman, 2011) under which someone is called 'mentally ill'.

Deviance

You will undoubtedly hear about, and see, 'deviant' behaviour. We use a sociological definition in approaching **deviance**—behaviour outside or away from the social norm of a specific group—in this text. Within its social context, *deviant* does not mean 'bad' or abnormal (Cockerham, 2011). Behaviour that is considered bizarre or unreasonable in one cultural context or in one particular time span may be considered acceptable in another. For example, 20 or 30 years ago, tattoos and body piercings (see Figure 1.1 ■) would have been thought to be extremely deviant. Today, such forms of body adornment are not unique. Not only are they commonplace, they are also considered fashion statements in some social contexts.

Further, your ideas about deviant behaviour are likely to be influenced by your upbringing, what you have seen and heard in your own communities and neighbourhoods (as illustrated in the Practice Example on the next page), what you have read about in newspapers or magazines, or what you have seen and read about on the internet and in social media. All of these experiences influence your attitudes towards, and beliefs about, deviance, mental health and mental illness.

FIGURE 1.1 ■ Nonconforming behaviour or appearance that flouts social norms is an example of social deviance—not evidence of psychopathology or abnormal behaviour.
Photo courtesy of Michael Newman/PhotoEdit.

You will also find that people living with mental illness are everyday, ordinary people. They are your neighbours, your friends, your family members; your teacher, your doctor; or even yourself. It is highly likely that you know someone who has been diagnosed with a mental illness or has sought mental health counselling to deal with problems in living.

Practice example

A mental health nurse, recalling her childhood experiences with what were then considered community deviants, described how she and her friends taunted 'Crazy Helen', causing her to shout incoherently at them.

Peter, a student in the Bachelor of Nursing, recalled that one of his close schoolfriends had an older brother who was said to be very smart but 'odd'; in his early teenage years he used to feel both apprehensive and intrigued when visiting his friend—wondering whether the older brother would answer the door. Peter admitted to similar feelings of anxiety and fascination as he prepared to undertake his first mental health clinical placement.

People, not patients

As you work through the chapters in this text, you will notice the terms *person, individual* or **consumer**, not client or patient, being used to refer to persons who seek or receive mental health services. We prefer the terms *person, individual* and *consumer* over patient because of their association with empowerment and self-responsibility, respect and an optimistic belief that people are capable of recovery. The term *patient* is associated with the traditional sick role, in which people relinquish responsibility to health care experts who have decision-making authority. We believe that in the traditional sick role, people are vulnerable and disempowered.

More people than ever before engage in partnerships with their health care providers and act on their own behalf (or, an advocate does, if the person is unable). Not all people are capable of participating in their own health care all of the time—for example, in some emergency situations, when comatose, or when a mental or physical condition prevents it. However, they are more likely to do so when they are informed consumers of mental health care and know that options exist, and when they are encouraged, and even expected, to do so. The term 'partnership' is a reminder—to all of us—that, among other things, recovery involves collaboration with others.

In health care today, the power balance has shifted. The same principles apply to the use of the terms *adherence* and *compliance*. These days, people are supported to adhere to a treatment protocol rather than to 'comply' with it; that is, people should be active participants in the treatment regimen.

Mental health

There is no one overall accepted definition of **mental health**. In general, a person is considered to be mentally healthy when what that person does (the person's behaviour), how that person relates to others (the person's **interpersonal** relationships between oneself and others), and how that person relates to him- or herself (the person's **intrapersonal** relationships within the mind or the self) give evidence of psychological, emotional and social health. It is a lifelong process of growing towards one's potential. Just as physical health is more than the absence of disease, mental health is more than the absence of mental illness.

Mentally healthy people are independent and autonomous. They think well of themselves and others, but are also realistic about their own and others' abilities and shortcomings. They can accept the ups and downs of life, and often come out even stronger than before. They have a wide range of behaviours, emotions and values that are usually consistent with one another. These and other characteristics of mentally healthy people are discussed in Box 1.1.

Mental illness

Mental illness and mental health, we believe, are outgrowths of both intrapersonal and interpersonal processes. Determining that someone has a mental illness is often a matter of judgment. The appropriateness of behaviour depends on whether it is judged plausible or not (e.g. deviant) according to a set of social, ethical and legal rules that define the limits of appropriate behaviour and reality within particular social, cultural and historical contexts. For example, if a man on a street corner says he is the King of England, people will not believe him and will consider him deviant and his statement symptomatic or disturbed. If a man at a fancy-dress party says he is the King of England, people reach a different conclusion, because in that social setting his behaviour and dress fit the norm. We would not label deviant political, religious or sexual behaviour, or conflicts primarily between an individual and society, as a **mental disorder** unless the deviance or conflict is a symptom of dysfunction in the individual.

With the preceding as philosophical background, we understand the concept of **mental illness** as a group of

Box 1.1 Characteristics of people considered to be mentally healthy

People who are considered mentally healthy:

- ***function independently and autonomously***—mentally healthy individuals respect and seek out the opinions of others, but assume responsibility for solving their own problems; they can plan ahead and formulate realistic goals
- ***hold a positive attitude toward themselves***—their self-esteem is combined with a realistic estimate of their abilities and their limitations
- ***take life's disappointments in stride***—mentally healthy people have a variety of coping mechanisms that help them to deal with the ups and downs of everyday life
- ***remain healthy even under high levels of stress or in the face of loss or trauma***—this characteristic is called **hardiness**
- ***adapt successfully to even very difficult experiences***—this characteristic of being able to bounce back to normal functioning or an even higher level of functioning is called **resilience**
- ***integrate their emotions, behaviours and values into a coherent whole***—their emotions, behaviours and values are consistent and fit together
- ***experience a wide range of emotions***—the emotions that mentally healthy people experience run the gamut—sadness, hopefulness, anger, joy, anxiety, disgust, fear, surprise, elation and happiness, among others
- ***master their environment***—mastering the environment includes being able to capably deal with what goes on around them, thus achieving a sense of connectedness, harmony and balance among themselves, their families, their friends and the community
- ***perceive reality clearly***—the mentally healthy person can distinguish between fact and fantasy and lives in the real world.

symptoms, such as a pattern or a syndrome, in which the individual experiences significant **distress** (the person suffers psychologically) and **disability** (impairment in one or more important areas of functioning in daily life), or causes them to harm themselves or others.

The signs and symptoms of mental illness are known as **psychopathology** (literally, 'pathology of the mind'). Mental health professionals refer to mental illnesses as psychopathological conditions. Mental illnesses are identified, standardised and categorised in two diagnostic classification systems: the *Diagnostic and statistical manual of mental disorders* (DSM-5) of the American Psychiatric Association, the 5th edition of which became available in late 2013; and the International Classification of Diseases (ICD-10) of the World Health Organization, a new 11th edition of which is expected to be released in 2018. Later in this textbook, you will learn about major types of mental illness, some of which are as follows:

- *disorders of mood*, such as depression and bipolar disorder, which can significantly interfere with a person's thoughts, behaviour, mood, activity and physical health
- *schizophrenia*, a disorder of thinking characterised by social withdrawal, distortions of thinking and perception, and bizarre behaviour, that first develops in the later teenage and early adult years
- *anxiety disorders*, with the common theme of excessive, irrational fear and dread
- *personality disorders*—persistent and rigid behaviour patterns that can significantly affect the person's ability to reasonably function in society
- *cognitive disorders* or disorders of thinking, which usually develop in the later adult years
- *substance-related disorders* that include addictions to alcohol, drugs, tobacco and other substances
- *dissociative disorders*, complex disorders in which a cluster of events is beyond the person's ability to recall
- *somatic symptom disorders* in which symptoms suggest physical disorders for which there is no evidence, and factitious disorders in which a person intentionally produces or feigns physical or psychological symptoms
- *eating disorders* in which disturbed eating patterns develop as a way of coping with stress
- *disorders specific to children*.

Given the right circumstances, anyone can develop a mental health problem, ranging from a mild, temporary increase in anxiety to the most severe types of mental illness. Fame, status and money do not ensure mental health or happiness, at least not according to the celebrities we hear about—actors, sports stars, authors, musicians, singers, movie directors and scientists. Many celebrities are speaking out about their experiences with mental illness, such as those in the following list:

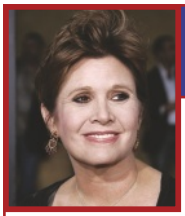
- Paula Abdul has spoken about her experience with the eating disorder, bulimia.
- Jessica Rowe and Brooke Shields have spoken about their post-natal depression.
- Drew Carey has spoken about bouts of depression and suicide attempts.
- Catherine Zeta-Jones, Mel Gibson and Carrie Fisher have spoken about living with bipolar disorder.
- Matthew Mitcham and Ruby Rose have spoken about having depression, and Garry McDonald has spoken about having both anxiety and depression.

People, especially those who are public figures who openly discuss their mental health problems or write books about their experiences, help increase public awareness. They contribute to making it easier for others to reveal their own struggles and seek help. The Mental Health in the Media feature, below, highlights Carrie Fisher's success in coping with problems with drugs and alcohol, addiction to prescription medications, and bipolar disorder.

Like many concepts in the human sciences, the concept of mental illness lacks a definition that covers all situations. In addition, definitions of mental illness have shifted throughout history. The historical shifts in attitude and philosophical viewpoints from preliterate cultures to the present day are reviewed later in this chapter. The history of mental health nursing is reviewed in Chapter 3, and the history of psychiatric treatment in Chapter 5.

MENTAL ILLNESS AS A GLOBAL PROBLEM

How many people worldwide have a diagnosable mental illness? Answers to this important question, most of which are derived from epidemiological studies, contribute to the planning and implementation of mental health services.



MENTAL HEALTH IN THE MEDIA
Carrie Fisher

As the daughter of Debbie Reynolds and Eddie Fisher, Carrie Fisher was a real-life Hollywood princess before she became Princess Leia of the Star Wars movie trilogy in the 1970s. As an author, Fisher wrote *Postcards from the Edge (1987)*, a semi-autobiographical novel that discussed her addiction to cocaine and other drugs. *Postcards from the Edge* became a movie, for which she also wrote the screenplay. She became a Hollywood script 'doctor', working on and refining the screenplays of other authors, writing other novels and screenplays, and acting in movies, television and stage plays. Her memoir *Wishful Drinking* was published in 2008. She recently returned to the role of Princess Leia in *Star Wars: The Force Awakens*.

Carrie Fisher publicly discussed her problems with drugs and alcohol, addiction to prescription medications, and bipolar disorder. A highly productive person, Carrie Fisher's successes provided hope to others in coping with and recovering from mental illness. Carrie Fisher passed away in December 2016.

Photo courtesy © Allstar Picture Library/Alamy.

Psychiatric **epidemiology** is the study of the distribution and determinants of mental illness in human populations, and is used to do the following:

- determine causative factors for specific types of illness
- identify groups of people at high risk of developing specific types of illness
- recognise changes in health problems, especially the emergence of new problems
- plan for current health needs and predict future needs
- evaluate preventive and therapeutic measures.

Psychiatric epidemiology can assist psychiatric mental health nurses to better understand the prevalence of mental illness and the organisation of mental health services. Information about mental health in Australia can be obtained from the Australian Institute of Health and Welfare (AIHW).

Australian epidemiological data is collected in a number of data sets: Admitted Patient Mental Health Care Data Set; Mental Health Establishment Data Set; Community Mental Health Care Data Set; and the Residential Mental Health Care Data Set. In addition, the National Minimum Data Sets Mental Health Care are gathered by state and territory governments annually. All data element definitions have been agreed by the National Health Information Standards and Statistics Committee to ensure alignment with national standards. These are available at www.aihw.gov/mental-health-information-sources/.

In addition to these Australian data sets, international mental health data can be obtained from the World Health Organization (see www.who.int/mental_health/en/).

Mental illness in Australia

Mental illness affects a large number of Australians every year; for adults, this is estimated to be up to 20 per cent of the population, and for children and adolescents up to 25 per cent. Up to 45 per cent of Australians aged 16–85 will experience a mental illness at some point in their lifetime. Anxiety disorders affect about 14 per cent and depression about 6 per cent of adults annually. The remainder are affected by substance use disorders, psychotic illness such as schizophrenia, personality disorders and other conditions. While mental illness is common, a large number of those affected do not seek any form of help for their problems—far fewer than for physical health problems. For depression this is about 25 per cent; for other common forms of mental illness it is higher, about 60 per cent for people living with anxiety disorders and over 75 per cent for those living with substance use disorders (Australian Bureau of Statistics [ABS], 2007).

For some people, the extent of disability caused by mental illness is so great that participation in society is severely compromised. Schizophrenia can be a particularly disabling condition that affects about 1 per cent of Australians at some stage in their lives. In severe forms of mental illness such as schizophrenia, mental health professionals typically give priority to managing the symptoms. However, for people living with mental illness the priorities can be different. When asked about the challenges they expected to face in the coming year, participants in the Survey of High Impact Psychosis (SHIP) ranked financial concerns, loneliness/social isolation, lack of employment and poor physical health above uncontrolled symptoms of mental illness (Carr, Whiteford, Groves, McGorry & Shepherd, 2012). It has been estimated that up to 75 per cent of homeless people have a mental illness (Mental Health Council of Australia, 2009).

Most people living with mental illness receive their care from a primary care practitioner, a general (medical) practitioner or a mental health nurse working in a community mental health team, or in schemes such as the Mental Health Nurse Incentive Program (MHNIP). However, Australia is a large continent, and the majority of mental health services are located in highly urbanised locations, such as capital cities or regional centres. Access to mental health care is much more difficult in rural and remote areas.

It is estimated that mental illness is responsible for almost 13 per cent of the total burden of disease in Australia, placing it third as a disease group after cancer and cardiovascular disease (Australian Institute of Health and Welfare [AIHW], 2016). Thus, the principles of psychiatric mental health nursing that you will learn in this textbook have major implications for your work in nursing, regardless of your future area of specialisation.

Comorbidity of mental disorders

Many people living with mental illness have two or more psychiatric disorders—particularly depression, anxiety, and alcohol and other substance abuse—at any one given time or during their lifetime. People living with mental illness are also much more likely to experience poor physical health when compared to the general population, with life expectancy

LIVED EXPERIENCE

Simon Swinson

With the commencement of my National Disability Insurance Scheme (NDIS) Plan, I have been able to participate in regular gym sessions as part of an exercise plan developed in collaboration with my service provider. This involvement has been made possible by a recent Commonwealth Government initiative and community donations (of equipment), and has enabled me to address long-term concerns regarding my cardiovascular health. Weight has been a constant issue associated with the use of prescribed antipsychotic medication and an illness-related sedentary lifestyle. Such opportunities have been rare up until now, and I believe represent changes in the way society thinks of and responds to people living with mental illness. I now feel that my life is valuable.

being reduced by as much as 30 years (Ehrlich, Kenall, Frey & Compton, 2014). In the past few decades, metabolic syndrome has emerged as a problem, especially for people living with psychotic disorders such as schizophrenia (Morgan et al., 2012). Living with more than one form of illness is referred to as **comorbidity**. Issues related to comorbidity are receiving significant attention in mental health research.

Over a decade ago, Kessler and colleagues (2005) replicated an earlier North American comorbidity study to examine what changes, if any, had occurred in the prevalence of mental disorders in the years since the original study. The comorbidity replication study is one of the most extensive studies of psychiatric disorders to date. It was found that the prevalence of mental disorders had not changed during the decade in question. The main findings of this study are summarised below, and were consistent with previous research:

- Women had higher rates of affective and anxiety disorders.
- Men had higher rates of substance abuse disorders and antisocial personality disorder.
- Most disorders declined with age and with higher socioeconomic status.
- Fewer than 40 per cent of those with a lifetime disorder had ever received professional treatment.

A most striking finding is that mental illnesses are more highly concentrated than previously recognised in approximately 14 per cent of the population who have had a history of three or more comorbid disorders. When severity is considered, this group also includes the great majority of those with severe disorders. Less than 50 per cent of this highly comorbid group ever obtained specialty mental health treatment, despite the number and severity of their disorders. These North American findings are consistent with the Australian data (ABS, 2007), and point to the need for community-based preventive programs aimed at more outreach. There is also a need for more research on barriers, including cultural barriers, to accessing mental health services.

Help-seeking patterns in mental health care

The research on help-seeking patterns may be summarised as follows:

- Most people with mental disorders do not seek professional treatment.
- Comorbidity increases the likelihood that a person will seek treatment. Still less than half of the highly comorbid group identified by Kessler and colleagues (2005) ever obtained specialty mental health treatment, despite the number and severity of their disorders.
- When seeking treatment, most people living with mental illness seek treatment from primary care practitioners such as general practitioners, who prescribe the majority of medications. Yet there is a lack of general practitioners with mental health expertise, especially in rural and remote areas.
- Individuals with chronic mental illness comprise the majority of those who seek treatment.

Awareness of these help-seeking patterns is essential in order to address the problems of nonuse or misuse of mental health services. Pivotal issues are the availability, accessibility, cost and quality of mental health services, especially because prognosis is affected by the duration of any mental disorder.

Severely under-served groups in relation to mental health services include the following:

- people with substance use disorders
- people from culturally and linguistically diverse backgrounds
- people living with severe socioeconomic disadvantage
- people who are homeless.

Unfortunately, mental health funding in Australia has tended to go to services that are reactive rather than proactive, situational rather than long-term and strategic, and rehabilitative rather than preventive. In addressing these problems, the Commonwealth Government recently announced a major reallocation of funding from mental health services in hospitals to community mental health and primary care services.

Adequacy of mental health services

Australia has a number of government and non-government organisations that provide advice and support to people living with mental illness, their families and health professionals. The contact details of some of these are provided in Table 1.1 ■.

Mental illness around the globe

A classic and still relevant major study by the WHO has shown an underestimation of the incidence of mental illness worldwide. The Global Burden of Disease study, which collects and compares health data from across the globe, indicates that mental illnesses such as depression are among the leading causes of disability worldwide (WHO, 2014a). Globally, about 400 million people of all ages live with depression, with more women affected than men, 60 million people live with bipolar disorder, and schizophrenia affects about 21 million people worldwide (WHO, 2014a).

The WHO's Mental Health Action Plan 2013–2020 recognises the essential role of mental health in achieving health for all people. The Action Plan includes the following objectives:

- more effective leadership and governance for mental health
- provision of comprehensive, integrated mental health and social care services in community-based settings
- implementation of strategies for promotion and prevention
- strengthened information systems, evidence and research.

More information on the Action Plan can be obtained at www.who.int/mental_health/publications/action_plan/en/.

Researchers suggest that the personal, social and economic costs associated with mental illness are very high, and are likely to be underestimated. Under-reporting due to stigma and a lack

Table 1.1 ■ Mental health support organisations

Organisation	Purpose	Contact details
SANE	To help Australians affected by mental illness lead a better life. SANE pursues its mission through three key areas of activity to promote a better life for all Australians affected by mental illness: support, training and education.	https://www.sane.org/
Beyond Blue	Beyond Blue was established in 2000 as a national initiative to create a community response to depression. The aim was to move the focus on depression away from a mental health service issue and towards one which is understood, acknowledged and addressed by the wider community.	http://www.beyondblue.org.au Tel: 1300 22 4636
Headspace	Headspace was established in 2006 and is the National Youth Mental Health Foundation. Headspace helps young people who are going through a tough time. People aged 12–25 years can get health advice, support and information about general health, mental health and counselling, education, employment and other services, and alcohol and other drug services	http://www.headspace.org.au
The Black Dog Institute	The Black Dog Institute is dedicated to improving the lives of people affected by mood disorders through high-quality translational research, clinical expertise and national education programs.	http://www.blackdoginstitute.org.au Bipolar Disorders Clinic Tel: (02) 9382 2991 Depression Clinic Tel: (02) 9382 2991 Psychology Clinic Tel: (02) 9382 2991
Kids Helpline	Kids Helpline is Australia's only national 24/7 telephone and online counselling and support service for young people aged between 5 and 25 years.	http://www.kidshelp.com.au Tel: 1800 55 1800
Lifeline	Lifeline is a national charity providing all Australians experiencing a personal crisis with access to 24-hour crisis support and suicide prevention services.	https://www.lifeline.org.au Tel: 13 11 14
Mental Health Carers ARAFMI Australia	Mental Health Carers ARAFMI is a collective of organisations whose members are mental health carers. ARAFMI represents the views and perspectives of carers, and has advocated for changes and services to improve the lives and wellbeing of people affected by mental illness, including carers and family members. Members include: Mental Health Carers ARAFMI Qld; Mind Australia, ARAFMI Tasmania; Mental Health Carers ARAFMI NSW; Mental Health Carers ARAFMI WA; and Mental Illness Fellowship of Australia (NT).	http://www.arafmiaustralia.asn.au Tel: (03) 8640 5683
Mental Illness Fellowship Australia (MIFA)	A national network of community-based organisations that provide a range of services to people living with mental illness, their carers and the community	www.mifa.org.au

of awareness of the connection between mental disorders and other health conditions are likely contributing factors. Mental illnesses may interact to increase risk for communicable diseases (e.g. alcohol and other drugs for HIV/AIDS), non-communicable diseases (e.g. depression and coronary heart disease), and intentional and unintentional injuries (e.g. alcohol as a risk factor in traffic accidents). Conversely, many health conditions may increase the risk of mental illness (e.g. depression subsequent to debilitating chronic illness).

The prediction of the WHO is that the burden of mental disorders will increase even more by the year 2020, because global mental health resources remain low, and improvements in the past few decades have been minimal. Moreover, the impacts of rapid technological development, widespread civil disturbance, terrorism and climate change will likely contribute to an increasing risk of mental illness. It is also possible to identify groups of people whose life circumstances make them especially vulnerable to developing mental illness. In many cases this vulnerability stems from sociocultural dislocation, disadvantage or exposure to violence. Some of these groups are included in Table 1.2 ■. Clearly, mental illness is one of global health's greatest challenges (Patel & Prince, 2011), which is unlikely to be adequately addressed unless nurses play a leading role.

Throughout this text, we will continue to remind you of these serious concerns. We will remind you of the humanity

Table 1.2 ■ Sociocultural dislocation, violence and mental illness

People exposed to bullying

Bullying is associated with youth violence, but can occur with adults, too. Bullying is defined as unwanted repeated aggressive behaviour towards others, involving power imbalance, and can be physical, verbal or relational in nature. Cyber-bullying is bullying through information communication technology. Bullying is a major, modifiable risk factor for mental illness, and can contribute to depression, anxiety, sleep disturbance and poor school adjustment (Kozlowska & Durheim, 2013).

See: www.cdc.gov/violenceprevention

People subjected to intimate partner violence

Intimate partner violence refers to behaviour within an intimate relationship that causes physical, psychological or sexual harm to those in the relationship. Such physical violence, psychological abuse and controlling behaviour is often associated with harmful levels of alcohol consumption, and is most often perpetrated by men. Exposure to intimate partner violence significantly increases the risk of depression, anxiety, suicide and drug and alcohol abuse. Public policy responses include awareness-raising campaigns, reporting of cases, and advocacy to protect survivors and bring perpetrators to justice.

See: www.who.int/violence_injury_prevention/violence/world_report/factsheets/ft_intimate.pdf

People living with disability

Disability is the interaction between individuals with a health condition and personal and environmental factors. Worldwide, a billion people have some form of disability, many with mental illness. There is high unmet need for health care among people living with disability, especially among people living with mental illness: in developed countries, 35–50 per cent of those affected do not receive any form of help; in developing countries, this can be as high as 76–85 per cent. Policy responses include: awareness-raising campaigns; accurate data collection and dissemination; capacity building within health and social care services; and strategies to ensure that people living with disabilities are knowledgeable about their health conditions.

See: http://www.who.int/mediacentre/factsheets/fs352/en/

Child maltreatment

Up to a quarter of adults report having been physically abused when they were children, with females (1 in 5) being at higher risk than males (1 in 13). Child maltreatment includes: physical and/or emotional ill-treatment, sexual abuse, neglect and commercial exploitation. The consequences of child maltreatment include severe physical and mental health problems that may persist for life. Approaches to prevention include supporting parents and teaching parenting skills through home visits to provide support and education, and group-based effective parenting courses. In many countries, child protection checks and reporting of actual or suspected cases are mandatory for health and social care professionals and students.

See: www.who.int/mediacentre/factsheets/fs150/en/

The mental health of indigenous people

Worldwide, there are about 370 million indigenous peoples living in more than 70 countries. They represent a rich diversity of cultures, religions, languages and traditions; however, many are socially and politically marginalised, and as a population group have much poorer health than their non-indigenous counterparts. Human rights and social justice concerns often underpin poor health, and this is especially so for indigenous peoples: they are at higher risk of poor living conditions, alcohol and substance misuse and suicide. Interventions include: improved health data collection and dissemination; improved access to housing, social services, education and employment; and the development of culturally appropriate health services.

See: www.who.int/mediacentre/factsheets/fs326/en/

The mental health of people during and after emergencies

People can develop a wide range of mental health problems during and long after being involved in emergency situations. The likelihood of recovery is improved if people feel safe and remain connected, calm and hopeful. With access to social, physical and emotional support, many will find ways to help themselves. Intervention involves the provision of basic services through to services that are highly specialised, to help match community needs to required levels of expertise. Despite their adverse effects on mental health, humanitarian crises and emergency situations are also opportunities to build better mental health systems; as individuals, communities and countries recover, resilience increases.

See: www.int/mediacentre/factsheets/fs/383/en/

Refugees and asylum seekers

Cultural factors may influence the presentation, assessment and treatment of mental illness. Escape from conflict zones, the experience of long and often dangerous journeys, and the uncertainty and distress of potentially long-term (onshore and offshore) immigration detention contribute to the high rates of mental illness among refugees seeking to enter Australia. Psychiatric–mental health nurses and other practitioners must be aware of how individual refugees and family groups understand and respond to mental illness, and how such understandings are likely to influence the expression of distress, patterns of (non-) help-seeking and (non-) adherence to treatment. Working with refugees and asylum seekers involves: understanding how cultural beliefs may present as psychiatric symptoms; communicating effectively using (telephone and face-to-face) interpreters; establishing rapport with people distrustful of government officials and services; managing the possibility that symptoms might be feigned to gain support to stay in Australia from treating staff; recognising and responding to the psychological and emotional impact of prolonged immigration detention. Galletly and colleagues (2016, pp. 451–452) have outlined cultural considerations in the treatment of psychoses in refugee and asylum-seeker populations. Box 1.2 outlines questions that may be used on assessing people from refugee and immigrant backgrounds.

Box 1.2 Questions for assessing people from refugee and immigrant backgrounds

- Can you tell me about what brought you here? What do you call_____? [Use the person's words for their problem]
- When do you think it started, and why did it start then?
- What are the main problems it is causing you?
- What have you done to try to stop/manage _____ to make it go away or make it better?
- How would you usually manage _____ in your own culture, or make it go away or make it better?
- How have you been coping so far with _____?
- In your culture, is your _____ considered 'severe'? What is the worst problem _____ could cause you?
- What type of help would you be seeking from me/our service?
- Are there people in your community who are aware that you have this condition?
- What do they think or believe caused _____? Are they doing anything to help you?

Source: Galletly et al. (2016, 451, citing Procter [2007]).

of people living with mental illness—of the family and friends we love, the neighbours we know, and celebrities we hear about. We will also continue to remind you that the lived experience of mental illness not only has distressing effects on the lives of those affected, but also can encourage extraordinary clarity, insight and creative potential.

FAMILIES, FRIENDS AND CARERS OF PEOPLE LIVING WITH MENTAL ILLNESS

Your work as a nurse is also likely to bring you into contact with members of another very important group of stakeholders—the carers of people living with mental illness. The number of informal carers in Australia is estimated to be 2.7 million (12 per cent of the population). Of these, just under one-third are primary carers, providing the majority of help and support for the person being cared for. More than two-thirds of primary carers are women caring for a close relative, such as a partner, parent or child (Hughes, 2007; Pirkis et al., 2010; ABS, 2016).

Carers are essential to the effective working of mental health care in Australia, and the replacement value of informal caregiving is likely to be in the tens of billions of dollars. Carers provide a range of emotional and practical supports to close relatives living with mental illness, including help in crisis situations, supervision with medications, financial support, and support to attend medical appointments. It is important to recognise the considerable burdens that may accompany caregiving—worry, anxiety, depression and the pressure of caring-associated financial costs (Pirkis et al., 2010). Caregiving is itself a risk factor for mental illness.

Carers are important stakeholders in the mental health system. It is important that mental health nurses and other health professionals acknowledge and value the very important role they play in supporting people living with mental illness. Carers Australia (www.carersaustralia.com.au) and ARAFMI Mental Health Carers of Australia (www.arafmi.australia.asn.au) are two national organisations that provide advocacy on behalf of carers.

HISTORICAL PERSPECTIVES

People who have been called 'mentally ill' have been with us throughout history—to be feared, marvelled at, ignored, banished, laughed at, pitied or tortured. A historical review of mental illness and the people who have lived with these experiences shows that societies have 'understood' and reacted to the phenomenon differently over time:

- Dominant social attitudes as well as religious and philosophical viewpoints have influenced the understanding of, approach to, and treatment of mental illness throughout recorded history, and probably before.
- Ideas that may be considered contemporary at one time often have roots in earlier centuries.
- The modern medical concept of 'madness' as an illness is open to the same scrutiny as interpretations of the past, such as beliefs about witchcraft or mysticism.

The timeline in Figure 1.2 ■ illustrates the shifting approaches to mental disorder throughout history.

IMPORTANT DATES IN THE SHIFTING APPROACHES TO MENTAL DISORDER

Era of magico–religious explanations

It is thought that in preliterate cultures the causes of mental and physical suffering were not differentiated. Both were attributed to forces acting outside the body. Consequently, no distinctions were made between magic, medicine and religion. Primitive healers quite logically dealt with the 'spirits of torment' with appeal, reverence, prayer, bribery, intimidation, appeasement, confession, punishment, exorcism, magical ritual and incantation. In some cultures, beliefs and practices similar to these continue today, and are directed towards 'banishing' the mental illness.

Behaviour considered to be a mental illness by modern Western cultures was attributed in preliterate cultures to the violation of taboos, the neglect of ritual obligations, the loss of a vital substance from the body (such as the soul), the introduction of a foreign and harmful substance into the body (such as evil spirits), or witchcraft.

Era of organic explanations

In the 4th century BCE, Hippocrates proposed a medical concept to explain mental suffering. He rejected demonology, and proposed that mental illnesses were caused mainly by imbalances in body humours: blood, black bile, yellow bile and phlegm. For example, an excess of black bile was thought to cause melancholy (Wallace & Gach, 2011).

One important consequence of these beliefs was that emotional suffering came within the realm of medical practice, to include words (interpretation of dreams and talking) and medical treatments (purging, bloodletting and ritual purification).

Era of alienation

At the height of their civilisation, the citizens of ancient Greece found their inner security in knowledge and reason. The Romans adopted the intellectual heritage of Greece, but placed greater reliance on their social institutions and the rational organisation of society, supported by law and military might. When these institutions disintegrated and the Roman Empire went into a decline, fear tore apart the fabric of society.

The collapse of Rome signalled a general return to the magic, mysticism and demonology from which people had retreated during the age of Greek rationality. During the Middle Ages, the period between approximately 400CE and the Renaissance (1300–1600CE), madness was seen as a dramatic encounter with secret powers. Troubled minds were thought to be influenced by the moon (see Figure 1.3 ■). *Lunacy* literally means a disorder caused by the moon.

In the Arab world, people who were insane were believed to be divinely inspired and not victims of demons. An asylum for people with mental illness was built in Fez, Morocco, early in the 8th century. Other asylums were soon established in Baghdad, Cairo and Damascus. The care in these asylums was usually benevolent and kindly. Contrary to the pejorative meanings often associated with 'mental asylum', the term 'asylum' literally means 'a place of safety'.

The first European hospital devoted entirely to people with mental illness was built in 1409 in Valencia, Spain. The problems of the mind, however, remained the domain of theologians. A book called *Malleus maleficarum* (translated as *The witches' hammer;* Institoris, H. & Sprenger, J. [1970; original ed. 1498]) became the basis for witch hunts. The *Malleus* details the destruction of dissenters, heretics and the 'mentally ill', most of whom were women, and all of whom were labelled *witches*. Theological rationalisations and magical explanations were used to justify burning witches at the stake.

People considered to be the 'violent insane' were shackled in prisons. In Europe, the belief developed that people who had mental illness could be sent on voyages of symbolic importance to find their reason (sanity). While the existence of actual boatloads of 'ships of fools' is now disputed, the idea persisted for centuries and possibly contributed to the social abandonment of people with mental illness.

Era of confinement

Unlike the Middle Ages, when people with mental illness were generally driven out of, or excluded from, community life, during the Renaissance they were confined. Tamed, retained and maintained, 'madness' was reduced to silence through a system of mutual obligation between the afflicted and society. People with mental illness—known as 'mad' persons—had the right to be fed, but were morally constrained and physically confined.

Seventeenth-century society created enormous houses of confinement. In these establishments, society incarcerated the mad, the poor and people who were considered deviants. A landmark date is 1656, when by decree the Hôpital Général in Paris was founded. It was not a medical establishment, but rather a threatening institution, complete with stakes, irons and dungeons. The 'insane' were completely under the jurisdiction of the institution, and had no recourse to appeal their incarceration. The Hôpital Général and other, similar institutions were primarily established to maintain social order. In London, the hospital of St Mary of Bethlehem became famous as *Bedlam*, illustrated in Figure 1.4 ■, where, for the entertainment of onlookers on a Sunday afternoon outing, mad persons were publicly beaten and tortured.

Those chained to cell walls were no longer considered people who had lost their reason or sick persons, but rather beasts seized by frenzy. During this period, it was believed that madness could be overcome only by discipline and brutality.

Era of moral treatment

The 18th and early 19th centuries were an era characterised by internal contradictions. Although people with mental illness were unchained, the medical treatment they received consisted of what amounted to torture with special paraphernalia. To grasp the incredible inhumanity with which people with mental illness were treated in what became known as 'the era of enlightenment', consider the following:

- The nature of mental illness could not be explained by any of the prevailing concepts—black humours could not be seen, demons or animal spirits could not be observed, and knowledge of anatomy could not be applied to the workings of the mind.
- Because mental illness could not be satisfactorily explained, the deeply felt dread of the insane could not be dispelled.
- Mental illness was believed to be incurable and mad persons were thought to be dangerous.

Even the most sensitive physicians did not try to understand the sources of mental suffering. Because they had no way to explain or understand mental illness, they developed and focused on elaborate and detailed systems of classification (see Chapter 5).

During this period, a general spirit of reform and humanitarianism swept Western Europe and the United States. Social reform and moral enrichment saw people released from their chains, systematised brutality with chains and whips was abolished, nourishing foods were provided, and the importance of treating people with kindness was acknowledged. This movement was first led by Philippe Pinel (1745–1826) (see Figure 1.5 ■) in France, and the Quakers in England under William Tuke (1732–1822).

Moral treatment in the United States—associated with Benjamin Franklin, Benjamin Rush (called 'the father of American psychiatry', 1745–1813), and others—was an alternative to mere confinement. Despite his association with humanitarianism and moral treatment, Rush was a major follower of the ideas of Scotland's William Cullen (1710–1790). Cullen believed that mental illness was due to decay, either of the intellect or of the involuntary nervous system; that is, a matter of disordered physiology. Rush advocated bloodletting, the restraining chair illustrated in Figure 1.6 ■, the gyrating chair and other devices that we now consider inhumane.

Important dates in the shifting approaches to mental disorder

Preliterate times

Era of magico-religious explanations

- Mental and physical suffering not differentiated.
- 'Spirits of torment' acting outside the body are responsible for ills.
- No distinctions made between medicine, magic and religion.
- Primitive healers address spirits by appeal, prayer, bribery, intimidation, appeasement, punishment.
- Healing methods include exorcism, magical ritual, incantation.

Early civilisation

Era of organic explanations

- Hippocrates (460–370) rejects demonology and proposes that psychiatric illnesses are caused by imbalances in 'body humours': blood, black bile, yellow bile, and phlegm.
- Psychiatric suffering comes within the realm of medical practice.
- Imbalances in body humors often corrected by bloodletting.

The medieval period

Era of alienation

- Return to the magic, mysticism and demonology of preliterate times.
- Madness viewed as dramatic encounter with secret powers and influenced by the moon (lunacy).

- *Malleus Maleficarum* (The Witches' Hammer) by Dominican monks Johann Sprenger and Heinrich Kraemer, published in 1487, rationalised mental illness in terms of magical explanation.
- Violent insane shackled in prisons or sent to sea 'in search of reason'.

Early 20th century

Era of psychoanalysis

- Emil Kraepelin (1856–1926) creates system of distinct disease entities and differentiates biopolar disorder from schizophrenia.
- Sigmund Freud (1856–1939) explains human behaviour in psychological terms and demonstrates that behaviour can be changed through psychoanalysis.

- Pavlov's discovery of the conditioned response forms the basis for modern-day cognitive behavioural therapy.

Mid 20th century

Era of ideological expansion

- From the mid-1940s to mid-1950s, a strong rift between biological orientation and dynamic orientation develops.
- By the early 1950s, several drugs for the treatment of mental disorder were in common use.
- Harry Stack Sullivan developed the interpersonal theory of psychiatry, Erik Erikson formulated his psychosocial theory of development, and Abraham Maslow proposed an order, or hierarchy, of basic human needs leading to self-actualisation.

- Group therapy, family therapy and short-term therapy recognised as options to costly long-term therapy.
- Milieu therapy developed by Maxwell Jones in England.

Late 20th century

Deinstitutionalisation and the community mental health movement

- By the early 1960s, a shift from institutional to community-based care and toward preventive services, consumer participation and the development of community mental health centres began.
- Between 1955 and 1975, the number of people resident in state mental hospitals decreased substantially as the community mental health movement gained in influence.
- By the 1960s, family therapy had become both a diagnostic tool and a mode of treatment.
- Politicians and the public become more aware of the difficulties the mentally ill face.

FIGURE 1.2 ■ *Photo source top to bottom by column:* SZ Photo/Scheri/Alamy; Photo Researchers, Inc.; Maslow, Abraham H./ Frager, Robert D./Fadiman, James, *Motivation and Personality*, 3rd Ed., ©1987. Reprinted and electronically reproduced by permission of Pearson Education, Inc., Upper Saddle River, New Jersey; Philosophical Library; Photo Researchers, Inc.; Photo Researchers, Inc.; Philosophical Library; Philosophical Library; ajt/Shutterstock.

The renaissance

Era of confinement

- In 1656, Hôpital Général in Paris founded to confine the mad, poor and various deviants.
- The 'insane' have no recourse to appeal.
- Madness not linked to medicine; could only be mastered by discipline and brutality.
- Radical physicians like Johann Weyer (1515–1588) believed that 'those illnesses whose origins are attributed to witches come from natural causes'.

The 18th and early 19th centuries

Era of moral treatment

- Physicians classify symptoms of mental disorders without understanding the sources of mental suffering.
- In 1794, Philippe Pinel (1745–1826) treated inmates in the French institutions Bicêtre and Salpêtrière with humanity and was thus considered mad.

- In England, William Tuke (1732–1822) focused on 'moral treatment' in a humane milieu called the York Retreat, to counter conditions in settings such as 'Bedlam.'
- In America, Benjamin Rush (1746–1813) focused on moral treatment and humanitarianism at the Pennsylvania Hospital.

Late 19th and early 20th centuries

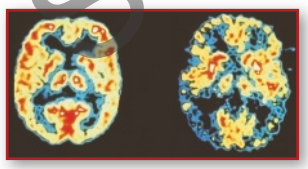
Era of public mental hospitals

- Dorothea L. Dix (1802–1887) founds or enlarges over 30 mental hospitals.
- Moral treatment replaced by custodial care.
- Clifford Beers (1876–1943) published his book describing his own intense suffering and mental anguish, leading to the development of preventive psychiatry and the formation of child guidance clinics.

The 1990s

The decade of the brain

- The primary innovation of the 1990s is the 'biological revolution': collaboration of science and technology to expand concepts of mental disorder proposed by psychological, behavioural and psychoanalytic theories.
- The gains made in research-based knowledge about the epidemiology, diagnosis, treatment and prevention of major mental illnesses constitute substantial progress in understanding of the brain.



- Consumer advocacy groups welcome psychiatry's shift toward psychosocial rehabilitation for consumer self-care.

The new millennium

Era of health care reform

- Reform of psychiatric care has decreased length of stay and increased consumer acuity.
- Developments in neuroscience have reshaped our conception of the bases of mental disorders.
- Innovations in technology have informed diagnostic practices such as brain imaging.

- The range of available psychopharmacological treatments continues to expand.
- Populations of people with mental illnesses include growing numbers of older people, more people with co-existing substance use disorders, more comorbidities with chronic illnesses and expanding cultural diversity.
- The study of genomes and the biology of the brain touch ethical, moral and political nerves.

FIGURE 1.3 ■ Moonstruck women dancing in a 17th-century square. This activity is the source for the word 'lunatic'.
Photo courtesy of Philosophical Library.

FIGURE 1.4 ■ A ward in Bethlehem Hospital, about 1745. A patient is being chained in the foreground, and in the background are two Sunday visitors on an entertainment outing.
Photo courtesy of Philosophical Library.

FIGURE 1.5 ■ A landmark event—Philippe Pinel unchaining the insane in the Bicêtre Hospital in Paris.
Photo courtesy of Charles Ciccione/Photo Researchers, Inc.

FIGURE 1.6 ■ Benjamin Rush, the 'father of American psychiatry' and an idealist and humanitarian, nevertheless favoured physical theories such as 'excitement of the brain' to explain mental illness. He was preoccupied with somatic treatments, such as bleeding and purging, and developed the tranquilising chair to quieten the insane.
Photo courtesy of Philosophical Library.

Era of psychoanalysis

During the late 19th and early 20th centuries, the number of mental hospitals, both private and government-run, grew. Beliefs about mental illness began to change again. Mental illness was linked to faulty life habits, and treated with new forms of physical or somatic therapies. Some clinicians were inclined towards an organic, neurophysiological explanation of mental illness. The emphasis on the classification of distinct disease entities continued.

These developments formed the background for the work of one of the most influential figures in the history of psychiatry, Sigmund Freud (1856–1939). He succeeded in explaining human behaviour in psychological terms. Freud's contributions to psychiatry are discussed in greater detail in Chapter 5.

Contemporary developments

By the mid-20th century, psychiatric thinking was expanding and moving towards an emphasis on the importance of the

social dimension. Dissatisfaction with psychoanalytic explanations for mental illness became more common, and pharmacological treatments for mental illness were being developed in the early 1950s. Research into chemotherapy and the aetiology of mental illness increased.

The primary innovation of the 1990s—known as The Decade of the Brain—was the so-called biological revolution: the collaboration of science and technology to expand concepts of mental illness proposed by psychological and behavioural theories. During this period, considerable progress was made in understanding the brain. For example, research on brain function resulted in a major reconceptualisation of the diagnosis and treatment of several mental disorders. Researchers discovered a variety of disturbances of brain functions, including ventricular enlargement, cerebral atrophy and disturbances in neurotransmitters (discussed in Chapter 6).

This medical approach is reflected in contemporary psychiatric mental health nursing literature, including this text. Research in the 21st century is focused on such areas as:

- the bases of mental illness
- the continuing development of newer generations of medications with fewer side-effects
- the effects of various medications on the neurotransmitters in the brains of people living with mental illness
- the role of nutrients in brain function
- the influence on mood and behaviour of disruptions of biological rhythms
- the role of viruses in mental illness
- the influence of the endocrine system on the brain and behaviour
- the role of the brain in producing physical illnesses
- the identification of biological markers that might signify the onset of mental illness
- the interrelationship between genetics and mental illness
- the prevention of mental illness
- the lived experience of mental illness, learning directly from people who have a mental health condition.

We can expect that, as the result of contemporary research, health professional and societal conceptualisations of mental illness will continue to shift.

THE STIGMA OF MENTAL ILLNESS

One of the negative consequences of being diagnosed with a mental illness is stigmatisation. The **stigma** of mental illness is based on a societal perception that mental illness is a blemish of individual character (Cockerham, 2011). Stigmatisation of mental illness is a worldwide problem experienced in all segments of society, but is especially prevalent in deprived, marginalised and minority communities (Lamb, Bower, Rogers, Dowrick & Gask, 2011). In North America, the actor Glenn Close, whose sister is living with bipolar disorder, established a national anti-stigma campaign called Bring Change 2 Mind. SANE Australia also has an anti-stigma campaign called Say No to Stigma (www.sane.org/stigmawatch).

Stigma is about disrespect. It:

- hurts, punishes and diminishes people
- harms and undermines interpersonal relationships
- appears in behaviour, language, attitude and tone of voice
- causes others to keep their distance from someone who has an illness, and results in social isolation for the stigmatised person.

Stigma is an attitude that leads to prejudice and discrimination. It affects the judgments of family, friends, co-workers, health care providers, and others about the person who has a mental illness. SANE Australia has produced a detailed report on stigma entitled *A life without stigma*, which can be obtained from https://www.sane.org/images/stories/media/ALifeWithoutStigma_A_SANE_Report.pdf. Examples of inaccurate beliefs about mental illness that lead to or perpetuate stigma and discrimination against people living with mental illness are given in Box 1.3.

Box 1.3 Stigmatising beliefs about mental illness

- ***MYTH: People with a mental illness are dangerous and violent.*** *FACT: People with mental illness are not more violent than other people. They are more frequently the survivors of violence than the perpetrators.*
- ***MYTH: People with a mental illness have a low IQ.*** *FACT: People with mental illness have the same range of intelligence as the 'normal' population. They may have temporary difficulty performing at a 'normal' level. People with an intellectual disability may also have a mental illness.*
- ***MYTH: People with a mental illness cannot hold down a job.*** *FACT: People who live with a diagnosis of a mental illness not only hold down jobs but may excel at work. They often face discrimination when applying for jobs.*
- ***MYTH: People with a mental illness have nothing to contribute to society.*** *FACT: People with mental illness are contributing members of society. They are scientists, musicians, astronauts, sports stars, singers, actors and contribute to society in a wide range of areas.*
- ***MYTH: People with mental illness lack willpower.*** *FACT: People with mental illness can, and do, exert willpower and control in their daily lives. Most difficulties are due to the impacts of medication, discrimination and stigma, and not to a lack of willpower.*
- ***MYTH: People with mental illness come from low-income families.*** *FACT: People with mental illness come from any income bracket, race, religion, age and educational background. Mental illness is an equal-opportunity disorder.*
- ***MYTH: People with mental illness are lazy.*** *FACT: People with mental illness are not lazy. Their symptoms and the medications they take can sometimes make it hard to be active.*
- ***MYTH: People with mental illness cause their own problems.*** *FACT: People with mental illness have often experienced trauma, discrimination and stigma, which create disruptions in their thinking, feeling, mood, daily functioning, and an ability to relate to others.*
- ***MYTH: People with mental illness should just 'shape up'.*** *FACT: People with mental illness can shape up if they can choose the mental health 'gymnasiums' they know work.*
- ***MYTH: Mental illness does not exist.*** *FACT: This one is in dispute. Many people believe that what they are experiencing is a normal human reaction to extraordinary experience. The dominant medical model believes that people with mental illness have an actual illness that is every bit as factual as a physical illness.*

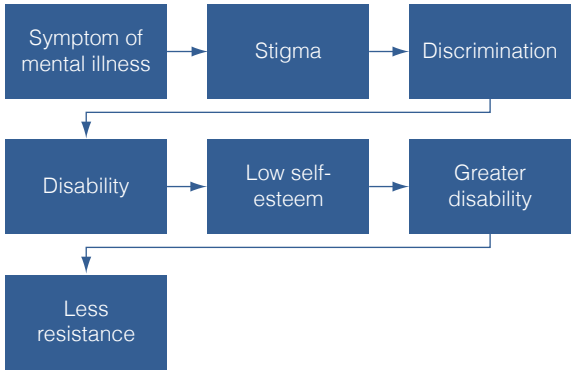


FIGURE 1.7 ■ The effect of stigma on recovery from mental illness. The person's symptom is the marker that leads to stigmatisation by society. Eventually, the effects of stigmatisation negatively influence the person's ability to recover from mental illness.

In his early classic work on stigma, the sociologist Erving Goffman (1963) equated stigma with having a *spoiled identity*. The person incorporates societal perceptions of not being normal, or right, or worthwhile, and comes to believe that they do indeed fall short of what they should be. This internalisation, or self-stigma, leads to feeling unworthy, having low self-esteem and losing hope—all characteristics that work against coping with, or recovering from, mental illness. This process is illustrated in Figure 1.7 ■.

Despite advances, stigma continues to grow around the globe, and is one of the main obstacles to better mental health care and quality of life for people living with mental illness, their families, communities and staff members who deal with mental health disorders.

According to the Programme against Stigma and Discrimination of the World Psychiatric Association (WPA), stigma extends to not only people living with mental illness and their families, but also to the medications used for treatment, the agencies that provide mental health treatment, staff members in those agencies (Sartorius et al., 2010), and even the sites on which they are located. Stigma affects everyone in the global mental health community.

Practice example

In Australia, job-seekers who tell a prospective employer about their mental illness risk not being hired. On the other hand, if they do not tell or have a relapse, they risk being fired despite the anti-discrimination laws. In India, people are reluctant to tell their neighbours about a mental illness, because it might hurt a child's or sibling's chances of being married. In Japan, people with mental illness are kept at home to do domestic chores, and out of the public eye. In China, mental illness is seen as a family problem that is hidden, and the responsibility for managing it is kept within the family. In all of these countries, stigmatisation is a significant motivating force.

LIVED EXPERIENCE

Simon Swinson

In my experience, internalising stigma is a very painful and almost unavoidable consequence of mental illness. Even before diagnosis, people turn away from you; people who have been close don't want to know you—schoolfriends, close friends, family members. However, I was fortunate in that my immediate family stood by me, including my sister-in-law. Things started to improve once I was well-established on medication. Self-confidence returned with time, some old friends reconnected and I have made new friends, many from within the mental health consumer movement.

Language matters

Although aberrant behaviour is a source of stigma, labels also reinforce stigma (Theurer, Jen-Paul, Cheyney, Koro-Ljungberg & Stevens, 2015). It would be nice if the old saying 'Sticks

MENTAL HEALTH IN THE MEDIA

The Snake Pit

In this 1948 classic film and exposé of the dire conditions at many state hospitals in the United States, Virginia Cunningham, played by Olivia de Havilland, is an inpatient in a state insane asylum (as mental health facilities were known then). *The Snake Pit* was an adaptation of a best-selling novel by Mary Jane Ward, who had been an inpatient in a mental hospital for more than eight months. Many of the characters were composites of the nurses, doctors and patients she met during her hospitalisation.

Prior to *The Snake Pit*, mental illness in the movies was either the butt of jokes in comedies or romanticised as a byproduct of tragic love. The film authentically portrayed the dehumanising conditions that existed at the time in large mental institutions—a fearful and insensitive staff focused on regimentation to control and manage the asylum's inmates, overcrowding, facilities designed like prisons, and typical treatments such as cold water hydrotherapy. Even so, the portrayals of psychoanalysis, hypnosis and the reasons behind the main character's mental illness were too simplistic to do justice to the complexities involved in living with a mental illness.

Nonetheless, the film had a significant impact on the conditions in psychiatric facilities in the United States. By 1949, journalists were keeping track of the number of states to institute reforms, and 20th Century Fox claimed that 26 of the 48 states had enacted reform legislation as a result of *The Snake Pit*.

Photo courtesy of Everett Collection.

and stones can break my bones, but words can never hurt me' was true. As it relates to stigma in mental health, words are powerful. Stigmatising language builds barriers to the understanding and treatment of persons with mental disorders.

Many terms have been used to describe aberrant behaviour or mental illness. You may have used some or all of these terms yourself, and you may hear them used in mental health settings and in the community at large. As you learn more about mental illness and the effects of stigma, you will gain a greater appreciation of the humanity of people living with mental illness, and find that you have edited demeaning, denigrating and stigmatising labels from your vocabulary.

In the earlier Practice Example on page 4, young people amused themselves by taunting 'Crazy Helen'. When used by people who do not identify as having a lived experience of mental illness, crazy is an informal, denigrating and stigmatising term that carries with it unfounded and negative implications. People probably described 'Crazy Helen' as having had a **nervous breakdown**—a general, non-specific term for an incapacitating but otherwise unspecified type of mental illness. Other stigmatising and denigrating terms are 'wacko', 'looney', 'psycho', 'lunatic', 'maniac', 'bananas', 'cuckoo', 'head case' and 'nuts'.

Many of the terms that society uses to describe aberrant behaviour have a convoluted history and have travelled over time and between languages, as shown in the historical perspectives section of this chapter. It is important that you not only educate those who use stigmatising language, and advocate for others to treat people living with mental illness respectfully and ethically, but also that you serve as a role model. The Nursing and Midwifery Board of Australia in its Code of Ethics for Nurses (2008), Code of Professional Conduct for Nurses in Australia (2008) and Registered Nurse Standards of Practice (2016) identifies respect for persons as a core principal integral to professional nursing. Respectful language is discussed in the Self-awareness feature. We also discuss the ethics of stigmatising labels in Chapter 11.

LIVED EXPERIENCE

Tim Heffernan

Driving to work today, a Tasmanian senator, who shall remain nameless, commented that people who believe that renewable energy can make a difference to climate change 'are deluded and should be locked up'. Politicians and the media use language about mental illness very carelessly, and in ways that reinforce and entrench stigma and marginalisation. It is essential that those who care for consumers when we are in distress and vulnerable use language for the opposite effect: to destigmatise, humanise, include and educate.

Language is most important within the therapeutic relationship, where two people are travelling together on a recovery journey. It is not just the words that are chosen that are important, but the tone and the context of delivery. Adult consumers experiencing psychological distress are not children, yet we frequently feel we are patronised when in inpatient care. Similarly, many of us have heard the language of 'deficits', where 'we can't do this, can't do that'. I am reminded of the lyrics of 'School' by Supertramp, a formative band of my youth, in which attempts to make the singer a good boy, by telling him what to do or not do, ends with the response 'do they know where it's at?'

Your language should be uplifting, positive and strengths-based. Really, you will only have partial knowledge of where a consumer is 'at', but you can choose, through your choice of words, the way you say them and when you say them, to either facilitate or undermine a consumer's journey to recovery.

The most difficult thing you will do, but you will have to do it, is to challenge inappropriate language in the workplace. How will you react when at handover you hear the language that seeks to dehumanise and oppress us? I don't need to write down examples, because unfortunately you will already have heard plenty.

It is an ethical issue for you; a human rights issue for us.

SELF-AWARENESS

Respectful language to combat stigma

You can help to combat stigma by using respectful language when you refer to mental illness or to people living with mental illness. This requires that you become aware of the language you use, and modify it, if necessary. The suggestions below are designed for your use. However, they can also be implemented in a psychoeducation teaching plan for people living with mental illness, family members, mental health staff and others in the community. Guidelines for recovery-oriented language in mental health can be obtained for the Mental Health Coordinating Council (MHCC) (mob.mhcc.org.au/media/5902/mhcc-recovery-oriented-language-guide-final-web.pdf). Following the MHCC Guideline, you can:

- Say *mental disorder, mental illness* or *psychiatric disability* (terms that show respect). Avoid saying *crazy, cuckoo, wacko, nuts, psycho, lunatic, bananas* or *head case* (terms that disrespect and stigmatise).
- Say *person with bipolar disorder, person who has schizophrenia, person who has cognitive difficulties* (terms that put people first, not their disabilities). Avoid saying *manic, bipolar, schizophrenic* or *demented* (terms that emphasise limitations and depersonalise).
- Say *person coping with, managing* or *recovering from depression* (terms that focus on positive abilities). Avoid saying *afflicted with, suffering from, victim of* (terms that sensationalise a disability).