15

THE ILLNESS EXPERIENCE: LAY PERSPECTIVES, DISABILITY, AND CHRONIC ILLNESS

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Overview

- How is illness understood and experienced by individuals?
- What are the strategies used by individuals to cope with the experience of illness?
- How does the experience of illness influence interactions with health professionals and health care systems?

Key terms

acute illness
biographical disruption
biomedicine/biomedical model
chronic illness
class (or social class)
contested illnesses
deinstitutionalisation
disability
gender/sex
illness trajectory
lay concepts of health and illness
lay epidemiology
medical gaze
narrative reconstruction
social construction/constructionism
social determinants of health (SDOH)
social exclusion
social model of disability
socio-economic status (SES)
stigma/stigmatisation

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DOES LYME DISEASE EXIST IN AUSTRALIA?

Queenslander Emily Muldoon is a Pilates instructor, who hoped to one day become a professional dancer. When she was 14 years old, she began to experience debilitating symptoms of a sore back, intense fatigue and swollen glands but it was 10 years before her diagnosis was confirmed. Extensive and expensive testing overseas eventually found she was suffering from Lyme disease, a tick-borne illness with symptoms that include fatigue, fever, severe muscular pain, headaches and skin rashes. In an interview with the *Courier Mail* Emily said:

> I was in so much pain but some (doctors) wouldn't believe me. They said, 'You've got depression, it's all in your head, the blood tests are coming back clear' because they were testing me for MS and Parkinsons. (Le Messurier 2017)

One of the reasons the doctors had so much difficulty identifying Emily's disease is that the Australian medical and research community say the tick carrying Lyme disease is not present here (Collignon, Lum & Robson 2016). Consequently, the medical profession does not recognise the disease can be contracted in this country (Commonwealth Department of Health 2016). Despite this, the Lyme Disease Association of Australia say over 2000 Australians have the illness and that many of these people have never been overseas (Lyme Disease Association of Australia 2017). In 2016, partly in response to public pressure, a Senate Inquiry into the disease concluded that although many sufferers are told 'it's all in your head' … 'there are too many people presenting with tangible symptoms for this assessment to be accurate' and called for more research into the presence of the disease in Australia (Parliament of Australia 2016).

BIOMEDICINE/ BIOMEDICAL MODEL
The conventional approach to medicine in Western societies, based on the diagnosis and explanation of illness as a malfunction of the body's biological mechanisms. This approach underpins most health professions and health services, which focus on treating individuals with little attention to the social origins of illness and its potential prevention.

SOCIAL CONSTRUCTION/ CONSTRUCTIONISM
The socially created, yet often enduring characteristics of human life, based on the idea that people actively construct reality in a way that then reacts back on their day-to-day lives. Social categorisations are neither 'natural', inevitable nor entirely relative or meaningless. Instead, notions of normality/ abnormality, right/ wrong, and health/ illness are subjective human creations, though creations with considerable consequences, that should not be taken for granted.

Introduction

Biomedical constructions of health focus on disease as a deviation from a biological norm. **Social constructions** explore the interaction between the self, society, and the body. Understanding how illness is subjectively experienced and interpreted provides valuable insights into this interaction. This chapter examines the illness experience by first considering lay understandings of health and illness, and aspects of **chronic illness** and **disability**. These foundational ideas are then used to examine how people experience chronic illness and the coping strategies they develop. The chapter concludes with a review of the contribution these understandings make to improvements in health care provision.

A sociological approach to the understanding of health involves drawing a distinction between disease and illness. Disease is the theoretical construction of a condition by a specialist. Illness is the way individuals experience and make sense of bodily conditions (Kleinman 1988). How patients understand illness is influenced by cultural and interpersonal factors derived from a wide range of sources. These include the expert knowledge of health professionals as well as popular accounts. Social variables such as gender, age, and ethnicity contribute to the patterning of these understandings within the general population. This is

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reflected in the saying: ‘women get sicker but men die quicker’. This observation is based on perceptions that women visit their GPs frequently and that men are generally reluctant to pay attention to signs of bodily dysfunction. This saying also reveals the close association that exists between the experience of illness and patient interactions with the health care system.

How disease is experienced is intertwined with self-understandings about the meaning of embodied experience and the social relationships that surround this. Interactions with friends and family, and with work colleagues and health professionals, as well as broader cultural constructions through the media and other sources, shape responses to illness. The manner in which symptoms are perceived, and the meanings given to illness, influence coping strategies and responses to treatment. In traditional Chinese medicine, for example, bronchial asthma in children is understood to result from an imbalance between the life forces of yin and yang, which may be caused by the mother taking too much ‘cold’ food during pregnancy. Treatment with inhalers is seen as undesirable because of the belief that children get addicted to them. Instead, cures involve avoiding fruits, vegetables, and icy water (Arif & Beng 2006).

Health promotion initiatives are based on models about how people will respond to guidance about self-care and self-monitoring. Understanding how different groups receive health messages is essential to their success. In the US, the unsubstantiated belief among some African Americans that HIV/AIDS was deliberately created by the Federal Government to kill and wipe out black people was associated with negative attitudes and inconsistent condom use. This meant governments and public health organisations aiming to reduce the incidence of HIV/AIDS, needed to understand how and why these beliefs exist. Research found that these concerns were based on the US’s long history of racial discrimination so that an effective campaign could only be established if trust within black communities was first addressed by reducing discrimination within the American health care system (Bogart & Thorburn 2005).

CHRONIC ILLNESS
A long-term or permanent illness condition that has no known cure (for example, diabetes).

DISABILITY
A socially constructed and contested term (for which the definition has varied over time and between cultures) that broadly refers to physical and/or mental limitations, restrictions, or impairments that can be **chronic** or last for a sustained period of time.

Lay concepts of health and illness

While expert conceptualisations of health undoubtedly form the dominant paradigm for understanding health and illness within Western cultures, they are not the only paradigms. How people actually experience and interpret illness is usually influenced by these understandings, but they do not preclude alternative interpretations that overlap, contradict, and supplement them. The meanings people give to experiences of illness, referred to as **lay concepts of health and illness**, are derived from multiple sources, including their individual experience of their own and others’ illness, and knowledge that is passed down within families and accessed through the media and the internet. Both mainstream and alternative understandings of health exist within the broader culture. The plurality of interpretations is especially prevalent in a globalised culture where multiculturalism and electronic media expose people to many different frameworks for explaining bodily experiences.

LAY CONCEPTS OF HEALTH AND ILLNESS
Personal and non-expert explanations of health attainment and illness causation and treatment.

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The terms 'lay' and 'expert' models of illness denote the distinction between the popular models of illness employed by ordinary people and the expert models employed by health professionals. The term 'lay expert' is also used to signal the overlap between these two models that results from the incorporation of expert interpretations into lay models of illness. It also points to the development of a well-informed public as a result of widespread access to 'previously obscure and inaccessible medical information' through the internet and the creation of a new struggle over expertise in health that is transforming the relationship between health professionals and their clients. Whereas in the past, illness was largely privatised, with the most important relationship being between patient and doctor (Kivits 2006), today social media and search engines such as Google, have made the experience of illness a far more public experience (Conrad, Bandini & Vasquez 2016).

LAY EPIDEMIOLOGY
Refers to people's everyday understanding of health risks, which may or may not be supported by the research evidence.

Lay models of health influence many aspects of health behaviour including compliance and help seeking. The term **lay epidemiology** refers to the processes by which people understand and interpret health risks. How people understand the health messages conveyed in public campaigns is mediated by their existing frameworks. This mix can produce undesirable effects. A study of a campaign to reduce the incidence of heart disease in the UK found that how people talked about illness and death influenced the explanations they derived about their causes, sometimes producing contradictory effects (Davison et al. 1991). The campaign sought to encourage a rational approach to health management, but because people observed that who did and did not get sick did not always fit the model, they developed a notion of a 'coronary candidate'. This had the undesirable effect of supporting fatalistic views about health risks. Similar results were found in a recent study on lay notions of cancer risks. This found that non-smokers rejected the notion of 'candidacy' for this disease, but smokers maintained it. Lay understandings overall were that cancer was random and unpredictable, resulting in a lack of adherence to health messages due to self-discounting beliefs (Macdonald, Watt & Macleod 2012).

Chronic illness

Much of the work on the illness experience has been conducted in relation to chronic diseases. Chronic illness is the most common form of illness in the Western world and accounts for the bulk of the burden of disease. In 2014–15, almost half the Australian population (1.1 million people) had at least one chronic disease such as asthma or a mental health condition (AIHW 2016, p. 73). Eight chronic diseases are responsible for over 60 per cent of the total burden of disease in Australia (AIHW 2016, p. 75). The prevalence of chronic illness is increasing partly due to structural ageing as the proportion of older individuals in the total population increases relative to the proportion of younger individuals and partly due to improvements in treatment and prevention. For example, between 1982 and 2016 the age-standardised incidence rate for all cancers increased by 22 per cent (AIHW 2016, p. 83). At the same time, prevalence rates are declining for some diseases due to improvement in prevention, early detection and treatment. Declines in chronic obstructive pulmonary disease and lung cancer have declined alongside declines in levels of smoking while the use of statins has reduced the rate of chronic heart disease (AIHW 2016, p. 71). Many of those

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experiencing chronic illness have co-morbid conditions; for example, 63 per cent of those with diabetes also have cardiovascular disease (AIHW 2016, p.80).

Chronic diseases can be defined as conditions that 'tend to be long-lasting and persistent in their symptoms or development' (AIHW 2016, p. 446). A wide diversity of conditions is covered by the term. Chronic diseases cross the spectrum of physical and mental disease, as well as injury-related conditions. They include asthma, arthritis, high blood pressure, depression, kidney disorders, and lung cancer, as well as acquired brain injury. Their symptomatology, prognosis, and impact on social and physical functioning are therefore equally wide ranging. For example, chronic fatigue syndrome is a far more contested condition than diabetes, less easily diagnosed and managed, affecting different population groups, and with a different risk of premature mortality. The uncertainty surrounding chronic fatigue syndrome is also associated with a degree of **stigma** that is absent from diabetes.

STIGMA/STIGMATISATION
A physical or social trait, such as a disability or a criminal record, that results in negative social reactions such as discrimination and exclusion.

Despite this diversity, the concept of chronic disease is important, providing an important distinction from the characteristics of **acute illness** on which medical models of treatment are based. In acute illness, the individual progresses from illness to wellness, but in chronic illness the condition is prolonged and characterised by constant or intermittent ill-health. The uncertainty of recovery means that the idea of progression is also absent. People can have a chronic illness and still live a relatively normal life, but it is also true that chronic diseases and conditions are the leading cause of premature mortality:

ACUTE ILLNESS
Illness with a rapid onset, short duration, and needing urgent attention.

The social determinants of chronic disease are similar to those for illness generally, with variables including age, gender, ethnicity, place, education, and income. Many of these relate to socio-economic disadvantage:

- Aboriginal and Torres Strait Islander people experience high rates of cardiovascular disease, mental disorders, diabetes, and kidney disease resulting in high rates of disability, low quality of life, and high mortality rates. There is a 10-year difference between the life expectancy of Indigenous people and that of the non-Indigenous population. Compared with the non-Indigenous population, rates of disability are 1.5 times as high, and levels of severe or profound disability twice as high (AIHW 2016, p. 15). They are also more than four times as likely to be in the advanced stages of chronic kidney disease. Rates of co-morbidity are also high, with diabetes, cardiovascular disease and chronic kidney disease often occurring together in the same individual (ABS 2014).
- People living in areas of low socio-economic status experience higher rates of chronic illness than those living in high **socio-economic statuses (SES)** areas. Diseases include depression, diabetes, chronic respiratory disease, and cardiovascular disease).
- People living outside major cities in rural and remote areas have a high burden of disease, especially in regard to injuries, cancer, mental illness, cardiovascular disease, and diabetes (AIHW 2017, p. 73).

SOCIO-ECONOMIC STATUS (SES)
A statistical measure of relative inequality that classifies individuals, households, or families into one of three categories—low SES, middle SES, or high SES—derived from a combination of income, occupation, and education.

The reasons for this distribution are complex and interrelated, including biomedical and behavioural factors as well as access to health care and other services. A critical part of the

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SOCIAL DETERMINANTS OF HEALTH (SDOH)
The social, cultural, political and economic factors that impact living and working conditions, which directly and indirectly influence individual and population health.

explanation is the impact of the **social determinants of health** which are the conditions where people are born, grow up, live and work, as well as the wider forces that shape everyday life (WHO 2017), such as low income, gender and ethnicity and the effects of intergenerational disadvantage (AIHW 2016, pp. 127-141). One study found that if the inequalities influencing the prevalence of chronic disease across the population were addressed, then around half a million Australians in the 25–64 age group would be free from chronic illness, with an enormous cost-saving to the health system (Brown et al. 2012, p. ix).

The onset of chronic illness is often slow and insidious, and people tend to have little understanding that their experience represents an ongoing condition. What appears at first as an everyday problem, requiring a commonsense solution, is gradually reframed as a health issue that requires expert help and medical investigation. The effects of chronic illness are often long term, and involve various degrees of suffering and functional limitation. While chronic illness may be popularly understood as a static condition, change is a key characteristic, and while this may often be in an undesirable direction, there are some conditions where people are able to live normal lives (Monaghan & Gabe 2015).

When people initially seek medical help for a condition that turns out to be chronic, they often have no idea that it will be a semi-permanent state and may not even have identified that they have an illness. Diagnosis is often lengthy and lacking in clarity and certainty. The stress of the illness is therefore compounded by poor interaction with health professionals, and uncertainty of diagnosis and prospects of recovery. Further, patients may not always be provided with adequate information about what is known about their illness.

CONTESTED ILLNESSES
Conditions with an indefinite constellation of symptoms that are not easily or formally recognised by the public and medical professionals under a specific diagnosis.

These social aspects of the experience of illness and diagnosis are particularly relevant in cases of **contested illness**. These illnesses—which have included chronic fatigue symptom, occupational over-use syndrome (OOS) (or repetition strain injury (RSI) as it used to be called), and fibromyalgia—involve symptoms that do not fit well within established social and medical definitions of illness. Symptoms are often unobservable leading to questions about the legitimacy of the illness, especially when their existence is linked to other conditions, which is often the case (Conrad & Barker 2010). Until recently, individuals experiencing OOS faced disbelief over the severity and existence of their condition and were often seen as malingering (Reid et al. 1991). The disparity between patient reports of symptoms and objective evidence of organic causes means patients have to negotiate a pathway with medical practitioners to having their illness and suffering recognised. They may also experience difficulty in accessing treatment, since the uncertain diagnosis means treatment regimes are open to dispute. Contested illnesses are especially strong examples of how subjective experiences of illness interact with medical institutions and cultures, with sufferers often having actively to defend their symptoms against stigmatised classifications of mental ill-health (Conrad, Bandini & Vasquez 2016).

Disability

Although most people living with chronic illness function very well, chronic diseases such as asthma and arthritis make up a significant proportion of disability groups (AIHW 2016). Long years of living with an impairment or restriction can be a common feature of chronic

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illness. According to the Australian Bureau of Statistics (ABS), disability refers to any person with a limitation, restriction, or impairment, which has lasted, or is likely to last, for at least six months and restricts everyday activities. Over 4 million Australians—that is, 18.3 per cent of the population—fit this description, with almost 6 per cent of these having a severe or profound limitation (ABS 2015a). This means that they sometimes or always required help or supervision with self-care, mobility, or communication.

Although the number of years people can expect to live without disability is increasing, increased life expectancy and medical advances are changing the extent and significance of disability within the population, creating new health system challenges as the age and number of people living with a disability increases. Women are disproportionately affected because their greater life expectancy translates to increased years of disability. Current estimates suggest that men can expect to live 62.4 years without disability and 17.5 years with some form of disability, while women can expect to live 64.5 years without disability and 19.8 years with some form of disability (AIHW 2016, p. 9).

The widespread nature of disability means that most people can expect to experience it either directly, or indirectly as carers. Despite this, disability continues to be socially constructed as an out-of-the-ordinary experience. People whose physical or mental abilities challenge normative expectations have historically experienced discrimination and abuse, often behind locked doors. Prior to the 1970s disabled people in Western nations were segregated from mainstream society, treated in special institutions, and subjected to techniques of control with little opportunity to control their own lives.

The disempowerment and marginalisation of disability groups form the historical context for understanding contemporary models for disability treatment and care. These emphasise the normality of disability and the extent to which the social environment shapes the degree to which a physical or mental condition is disabling. The **social model of disability** distinguishes between impairment and disability. Impairment refers to the physical or mental condition that affects functioning, while disability is how that impairment is treated by society. If the environment is designed to provide for wheelchairs, for example, then the disabling aspects of mobility limitations may be minimal. The impact of cerebral palsy on a person's capacity to live a fulfilled life is similarly mediated by social factors such as the availability of support, opportunities for carer respite, accessible education and work opportunities, and the level of discrimination within the community.

The social model of disability is located within a human rights framework arguing that different physical or mental capability and functioning do not justify different treatment. People living with impairment are as entitled as the rest of the population to a fulfilled life and the opportunity to contribute to society. This model has been associated with the **deinstitutionalisation** of disability services and the closure of the large institutions that provided treatment and care. Yet, while the mainstreaming of disability services has been in existence for over two decades, disability advocates argue that a form of 'social apartheid' remains, even though people with disabilities are no longer physically segregated from the rest of the population. There remain many symbolic, physical, and social barriers that create isolation and **social exclusion**, preventing a normal existence. This is reflected in a range of negative outcomes, including low incomes, poor health, difficulties in establishing

SOCIAL MODEL OF DISABILITY
An approach that views society as 'disabling' and thus focuses on the rights of disabled people so as to address cultural and structural discrimination and ensure similar treatment and opportunities afforded to able-bodied people.

THEORY LINK
See Chapters 13 and 14 for more on deinstitutionalisation.

DEINSTITUTIONALISATION
A trend in mental health treatment whereby individuals are admitted for short periods of time, rather than undergoing lifetime hospitalisation. In theory, such policies are meant to be supported by extensive community resources, to 'break down the barriers' and integrate the mentally ill into the community; however, in practice, this has not occurred on a wide scale because of the lack of funding of community services.

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SOCIAL EXCLUSION
A broad term used to encompass individuals and groups who experience persistent social disadvantage from a range of causes (poverty, unemployment, poor housing, social isolation etc.), preventing participation in social institutions and political processes.

intimate relationships and friendships, and weak labour market participation. Levels of employment have remained relatively stable, despite the efforts of governments, and the advocacy efforts of disability groups. In the two decades between 1993 and 2012, the labour force participation rate for working-age people with a disability remained broadly similar at a little over 50 per cent (52.8 per cent in 2012), while the comparable figure for working-age people without disability increased from 76.9 per cent to 82.5 per cent (ABS 2015b).

A major development in the Australian state's response to disability has been the introduction of a National Disability Insurance Scheme (NDIS), which aims to enhance independence and choice for people living with disability through improved access to high-quality care and support. The NDIS provides three tiers of support. The first provides all Australians with disability insurance, ensuring they will have access to needed services should they ever experience disability. The second provides information and referral services to individuals affected by disability. The third tier provides individualised packages of high-quality care and support to all Australians with significant and ongoing disability. An estimated 410,000 Australians will benefit from these. The scheme has been welcomed by disability advocates not least because the insurance model provides universal care that distinguishes it from paternalistic charity-based schemes; however, critics suggest that the focus on individual packages of care does not fit within a social model of disability and reflects liberal/market principles rather than human rights perspectives (O'Connor 2014; Fawcett & Plath 2014; Foster et al. 2016). This means that performance of the NDIS is dependent on the quality and responsiveness of the care market and is vulnerable to changes in the capacity of the sector over time (Foster et al. 2016).

Experiencing illness

The experience of serious illness can have life-changing effects on how patients see the world and their place within it. It often challenges taken-for-granted certainties and creates new dynamics in interpersonal relationships. Experiences of weakness, pain, and dependence lead to questions about the self and interpersonal relationships. It can also provide opportunities for new insights. This is especially the case with chronic illness due to its prolonged nature, its effects on daily functioning, and its association with impairment. Accounts of the subjective aspects of illness focus on how the experience of illness influences self-identity and the implications of this for relationships with family members, health professionals, and the broader health system.

ILLNESS TRAJECTORY
The changing nature of a person's experience of illness over time and how this is influenced by the actions of the patients and their interactions with health professionals, family, and friends.

The illness trajectory

Sociologist Anselm Strauss and nursing academic Juliet Corbin (Corbin & Strauss 1988) interviewed patients and carers about how they managed the changing course of illness. They saw that managing diseases such as Alzheimer's, stroke, and kidney disease involves the establishment of management regimes that affect social interaction. The changing course of illness, often in a deteriorating direction, also affects self-identity and this requires biographical adjustment. They employed the idea of the **illness trajectory**

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to analyse the biographical work associated with this as patients made efforts to control and adjust to their changing health status and the new requirements and arrangements associated with this. This involved both inner reflection and negotiations with friends, families, and professionals. The idea was further developed by sociologist Michael Bury's (1982) concept of illness as **biographical disruption**.

BIOGRAPHICAL DISRUPTION
The effect of chronic illness on a person's self-identity, such as loss of control and certainty, that influences how the person deals with the illness experience.

Illness as biographical disruption

In his writings on self-identity, Anthony Giddens (1991) points out that our sense of who we are is not automatically given but involves an ongoing, creative act of reflexive self-awareness. Through this act we establish a sense of safety, or ontological security, the taken-for-granted nature of which shields us from the reality of the uncertainty of existence. It establishes a feeling of living in a stable world in which the contours are familiar and which we know how to negotiate. This anchoring of the self is assisted by the predictable nature of our world and the fit between anticipation and experience. The experience of serious illness ruptures this predictability because it places a question mark over the future, threatens relationships, and dislocates existing arrangements.

Kathy Charmaz (1983) characterises the loss of self as a kind of suffering not recognised by biomedical explanations of illness. Chronic illnesses are often life-limiting, and can contribute to the personal agonies of social isolation or, conversely, dependence on others. Some conditions are also discredited by others, or are experienced as deeply discrediting to a previous identity or role, which is eroded and often not replaced with new positive self-images. Certainty is replaced by uncertainty and feelings of risk, presenting a profound challenge to ontological security.

This understanding of the effects of chronic illness on individual subjectivities is captured by Bury's notion of biographical disruption. This concept highlights how chronic illness 'disrupts the structures of everyday life and the forms of knowledge which underpin them' (Bury 1982, p. 169). Using semi-structured interviews with 30 rheumatoid arthritis patients in England, Bury explores how chronic illness raises questions about 'what is going on here?' that challenge plans and expectations for the future, disrupt routine explanatory systems, and have wider implications for the 'normal rules of reciprocity and mutual support' on which individuals normally depend (Bury 1982, p. 169). He describes how what at first appears to be an everyday pain is slowly understood as a serious, long-term, and disabling condition. This recognition involves a biographical shift from a perceived normal trajectory to one fundamentally abnormal and inwardly damaging (Bury 1982).

The notion of a disruption has been found to be less relevant to older people and those with existing conditions where the illness may be experienced as continuous with established notions of the self (Larsson & Grassman 2012). Further, those living with bodily limitations may develop strategies to adapt to, redefine, and accommodate impairments, so that rather than experiencing an identity crisis or loss, people 'revise their identity goals' by continually reassessing what is possible for them as their condition changes (Charmaz 1995).

The limited medical knowledge that commonly characterises chronic illness means that diagnosis is often followed by a prolonged feeling of uncertainty, further adding to the shock

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of the experience. As people search for answers to the questions 'Why me? Why now?', they draw on medical knowledge, but the uncertain nature of their health status means they also draw on their personal biography, finding meaning in past incidents or family history in order to adjust to the new reality. Adjustment also involves the mobilisation of other resources, with the internet playing a prominent role in efforts to understand symptoms, diagnosis and treatment regimes and also to establish support networks (Ziebland & Wyke 2012; Conrad, Bandini & Vasquez 2016). Access to strong friendship networks or wealth assist with adjustment, so some groups—such as women and the middle and upper classes—are better placed than others to respond to the challenges of illness. The disruptive effects of illness are therefore mediated by social variables such as **gender**, age, and **class**, as well as the seriousness of the illness.

GENDER/SEX
Refers to the social practices by which the biological reproductive distinction of fe/male is enacted in the making of social differences and power relations among people, inclusive of femininity, masculinity, and LGBTIQ (lesbian, gay, bisexual, transsexual, intersex, and queer).

CLASS (OR SOCIAL CLASS)
A position in a system of structured inequality based on the unequal distribution of power, wealth, income, and status. People who share a class position typically share similar **life chances**.

Moral dimensions of illness: shame, stigma, discrimination, and the medical gaze

Historically, chronic illness and disability have been associated with discrimination and rejection within the broader community; research suggests that stigmatisation continues to be associated with some physical and mental conditions. Illness, by definition, involves the departure from some socially constructed ideal or expectation of bodily appearance or function, and its association with a judgment of moral worth is therefore unsurprising. In *Stigma: Notes on the Management of Spoiled Identity* (1963), sociologist Erving Goffman suggests that when people deviate from established social expectations it often leads to the imposition of a spoiled identity, because possession of the undesirable characteristic is seen as a mark of moral failure. The existence of a single imperfection becomes associated with a range of other features so that the whole person is judged as morally problematic. In this way, the person is no longer perceived by others as an individual but becomes the illness. The stigmatised individual then becomes vulnerable to social condemnation and categorisation as somehow 'less than human' (1963, p. 5). This tainted identity can become the basis of prejudice and formal and informal discrimination, including the withholding of legal privileges.

While Goffman (1963) recognises the internalisation of stigma, he sees it as an imposed identity of which the origins lie in the negative reaction of others. This has been described as 'enacted stigma' (Scambler & Hopkins 1986). Yet self-stigmatisation, or 'felt stigma' (Scambler & Hopkins 1986), can also occur among people experiencing debilitating mental and physical conditions such as epilepsy, multiple sclerosis, or Parkinson's disease. Feelings of inadequacy or shame as a result of an embarrassing condition or appearance, or limited mobility, for example, can lead to people questioning their self-worth regardless of whether their situation is visible to others or not. Such judgments can make it even more difficult to participate in normal social activities, thereby further deepening the sense of social isolation. This may be especially acute in contested medical conditions such as chronic

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fatigue syndrome or post-traumatic stress disorders (PTSD), where there exist perceptions that personal inadequacy, incompetence, or psychological weakness are implicated in the aetiology. It may also extend beyond the ill individual to care givers and other family members in a ripple effect that has repercussions in many areas of life (Wasow 1995).

THEORY LINK
See Chapters 13 and 14 for more on Erving Goffman.

The HIV/AIDS pandemic provides an illustration of the kind of moral panic that can be associated with a stigmatised disease. Researchers Jeffrey Huber and Mary Gillaspy argue that those population groups associated with HIV and AIDS were subjected to extreme rejection, prejudice, and formal and informal discrimination (1998). The stigmatised status of the disease was associated with a range of biomedical and non-biomedical factors including physical aspects of the illness, its association with homosexuality and intravenous drug use, and fear of its transmission through everyday contact. The imposition of shame on those directly and indirectly affected by HIV and AIDS was so extreme that denial of its occurrence was common and it was sometimes not acknowledged as a cause of death. Fear of the disease was closely tied to misinformation about the science surrounding the condition. It became associated with metaphors such as the 'body turns nasty on itself', which linked it with notions of pollution and contamination (Alonza & Reynolds 1995). False ideas about its causes, transmission, and effects were common and formed a further source of popular anxiety, which fuelled negative stereotypes about the kind of person likely to become infected.

While the idea of stigma has been valuable in drawing attention to the de-legitimating effects of embarrassment at, and fear of, bodily difference, it has also been critiqued. Theoretically the concept is so general that it can apply to any process of negative labelling and therefore has limited analytical value. It also tends to deny the extent to which people resist labels and redefine situations to their advantage. Neville Millen and Christine Walker, for example, found that people experiencing chronic illness actively seek to influence the health agenda in their favour through the formation of consumer and self-help groups (2003). By this means they exchange their illness status for 'political activist status'. This can be seen in the 'fat acceptance' movement where resistance to 'fat shaming' and the construction of obesity as always problematic has resulted in efforts by health professionals to remove blame and destigmatise obesity (Clair, Daniel & Lamont 2016).

This idea of moral categories of disease has some similarities with French philosopher Michel Foucault's concept of the **medical gaze**. In *The Birth of the Clinic* (1963/2003) Foucault describes the increasing dominance of the medical profession over the course of the eighteenth and nineteenth centuries. He uses the term the 'medical gaze' to refer to the power of doctors to use their biomedical knowledge to objectify, categorise, and judge bodies in ways that can be dehumanising for patients. Foucault writes: 'The medical gaze was also organised in a new way … It was no longer the gaze of any observer, but that of a doctor supported and justified by an institution, that of a doctor endowed with the power of decision and intervention' (2003, p. 109). This provides a powerful way of understanding the potential disconnect between the subjective experience of patients experiencing chronic illness and the expert knowledge of the medical profession whose judgments may or may not accord with patients, yet are critical for diagnosis and treatment.

MEDICAL GAZE
The power of doctors to use their biomedical knowledge to objectify, categorise, and judge bodies in ways that can be dehumanising for patients.

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Coping with chronic illness

Adjusting to the disruptions to bodily and social integrity created by chronic illness generates a need for practical and emotional coping strategies designed to re-establish a sense of normality and control. External aspects of coping involve questions about how to complete essential tasks and obtain necessary support, while internal aspects involve dealing with the disturbances to self-identity. Questions such as how to manage informing people about the illness ('Whom and what do I tell?') and how to behave when bodily conditions are out of control generate social tensions as well as risks to identity and self-esteem. Adjusting to chronic illness therefore involves establishing strategies that mediate this tension between the public social identity and the private personal self (Kelly, cited in Pierret 2003).

Much of the work relating to the practical strategies for coping takes place within the home, where family relationships are critical. The demands of care may impact on other family members in ways that are as disruptive to them as they are to the patient themselves (Williams 2012). Women carry much of this responsibility, as part of normative expectations about their nurturing role. Health researcher Susan Gregory (2005) points out that as well as contributing to the monitoring and maintenance of health, domestic work is central to the illness experience because it establishes the routine activities around which normality and ontological security are established for family members. Illness is an unwelcome intrusion into family life, disturbing domestic routines in ways that can test family relationships. Clare Williams also argues that carers are 'disenfranchised care contractors' (Dow & McDonald 2007) who are relied on by the medical system to allow early discharge and care in the home, but who are inadequately recognised and supported (Williams 2012).

How people respond to chronic illness also involves cognitive strategies such as optimising the situation by saying it could be worse, reordering priorities and values, seeking information that validates personal experience, and minimising the struggles and adjustments made (Royer 1998). In managing social relationships, the question of how much information to provide about the illness becomes a central issue, mediated by factors such as its visibility. Goffman (1963) identifies two adaptive techniques for establishing normality in the face of the tensions created by difference. 'Passing' is when strategies to disguise signs of abnormality are employed, while 'covering' involves strategies to reduce the social obtrusiveness of the embarrassing condition. In covering, the aim is to reduce the tensions created by knowledge of the condition. In passing, the aim is to deny the existence of the condition, by, for example, engaging in normal activities despite physical limitations, or making extraordinary efforts to maintain a normal appearance (Royer 1995); however, research by Millen and Walker (2003) found that most respondents made little attempt to deny their situation and instead were more likely to express a desire to acknowledge it in order to seek government support for all people with chronic illnesses.

Social psychologists Alan Radley and Ruth Green (1987) propose a four-type model of adjustment to chronic illness. 'Accommodation' involves the integration of the illness into

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the person's life through the pursuit of modified goals. 'Secondary gain' occurs when other rewarding activities are established that compensate for the areas of inactivity imposed by the illness. 'Active denial' involves an attempt to ignore the illness and its implications by minimising symptoms and the retention of social activities. 'Resignation' is characterised by a feeling of being overwhelmed by the illness and associated loss of activities.

Making meaning of illness: narrative approaches

The reorientation of the self that is involved in adjusting to chronic illness has been widely conceptualised as a process of self-storying. In *The Illness Narratives* (1988) medical anthropologist Arthur Kleinman points out that making meaning of the experience of illness takes a narrative form that links life history with the chronic course, providing answers to the question about who one is, and how one came to be in the present situation. Through **narrative reconstruction**, biographical integrity is reasserted in the context of the ruptures between body, self, and the world that illness represents (Pierret 2003). As well as helping self-understanding and adjustment, story-telling is performative: it enables communication with others about what is happening and the practical and emotional effects of this (Williams 2000).

NARRATIVE RECONSTRUCTION
Individuals' beliefs about the causes and implications of their illness and how this shapes a redeveloped sense of self-identity.

A framework for analysing illness narratives in terms of three types of narrative form is offered by Bury (2001). Contingent narratives address beliefs about the origins of the disease, its initial causes, and its immediate effects. Ideas that the disease was caused by an especially stressful event or some predisposing medical condition fit within this type. Contingent narratives also involve how people story their attempts at normalisation, either through passing strategies or through the reframing of what it means to be normal in light of the changed lifestyle and circumstances that serious illness may bring.

Moral narratives are stories that help to establish the moral status of the patient in the context of the changes to person and identity that follow from illness. They introduce an evaluative element into the illness experience as part of an attempt to answer the questions 'Why me? Why now?' They bring together moral considerations, such as fatalism or self-discovery, as a way of connecting diverse aspects of the illness such as family history, coincidences of symptoms, biographical events, and the particular social contexts in which these have occurred (Bury 2001).

Core narratives form the last of Bury's narrative typologies. These connect experiences of illness with deeper cultural forms such as 'heroic, tragic, ironic and comic and regressive/progressive narratives' (2001, p. 263). These narratives provide a temporal ordering of illness experiences, which 'give expression to the changed relationship between body, self and society' (2001, p. 278).

In his analysis of people living with a diagnosis of HIV/AIDS, Douglas Ezzy (2000) argues that the narratives people use to make sense of their lives need to be understood as an ongoing process of self-understanding that changes over time as new conditions arise, such as the appearance of new forms of treatment.

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DOING HEALTH SOCIOLOGY 15.1

Chronic illness as biographical oscillation

Meniere's disease is a chronic, progressive illness that affects the hearing and eventually results in permanent sensorineural hearing loss. It is a debilitating illness, made worse by unpredictable symptoms of vertigo, tinnitus and distorted hearing. Researchers conducted interviews with 28 Meniere's disease patients, with the aim of understanding how it affected critical life transitions involving family members, such as becoming a parent or retiring (Bell, Tyrell & Phoenix 2016). They found the illness had a strong impact on these developments, sometimes making the changes more difficult to negotiate because it prevented their efforts to fulfil desired or expected social roles. 'Becky' described the anxiety caused by 'robotic' tinnitus symptoms at a time when she had just had a baby:

> I had what I think would be classed as post-natal anxiety. I wasn't at all depressed but just completely like on a white-knuckle ride, thinking 'I'm going to go deaf, I'm going to be a deaf mum, I don't know how to do this. I'm going to live with this awful tinnitus, everyone's going to sound like a robot forever' … I was like that for about six months, sweating, diarrhoea, lost loads of weight, couldn't sleep, just completely panicked.

The researchers describe how the illness gives rise to a lifetime of chronically disrupted normalities which affect how time is experienced. 'Cherished time' involves periods of remission when life becomes more 'normal'; 'anomalous time' involves anxiety about the return of symptoms which get in the way of taken-for-granted routines and identities, and 'turbulent time' occurs when everyday functioning is undermined by the effects of the illness and new challenges of living. These findings extend understanding of the notion of biographical disruption as something that occurs in the early years of illness, to one that may occur throughout life. They argue the impact of chronic illness should be reconceptualised as involving many 'biographical oscillations' that are experienced across continually changing life trajectories (Bell, Tyrell & Phoenix 2016).

- In the context of chronic illness, consider the notion of biographical disruption/oscillations, drawing on your own or others' experiences.

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Conclusion: health care systems and the patient experience

Illness experiences are situated within the institutional framework of health care systems and are profoundly shaped by this. Features such as how symptoms are understood within current disease paradigms, access to alternative sources of care, and relationships with local

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health care professionals impact both positively and negatively on patients and their health outcomes. The rise in the predominance of chronic illness over the past century has meant that management and care have become as, if not more, important to health care than treatment and cure (Bury 2001). With this has come a focus on the everyday experiences of illness and recognition of the need to account for lay understandings of health and illness and their practical and emotional effects. This shifts the health care model away from a biomedical approach to a more social model of the body, which locates it within a holistic framework of self and society. Understanding how illness impacts on home and work and how disabling conditions can be better managed necessitates a multidimensional approach to care, which takes account of where the patient sits in relation to such things as social networks and self-understanding.

An understanding of patient experiences also offers insights into the symbolic meanings of illness, especially in relation to its moral dimensions. The tendency to impose negative meanings on disease and related conditions, which extend to the personal character of the individual, has harmful consequences for patient self-esteem and coping. Understanding this is especially important for health professionals whose interactions with patients can sometimes be a contributing factor to patient experiences of stigmatisation and whose assumptions about the moral worth of patients can interfere with objective assessment.

The concern with patient subjectivities, which has accompanied the shift from acute to chronic illness, has to some degree changed the role of health professionals from one of 'medical dominance' (Willis 1989) to one of being a 'witness to suffering' and a source of practical advice and guidance (Bury 2001, p. 267). Performing this role necessitates a deeper and more empathetic understanding of patient and family stories. It reduces the authoritarian power of medicine by providing an alternative strand that acknowledges the self as well as the body as an object of medical investigation. In an information-rich age it also has potential to change the role of the patient from passive recipient of expert knowledge to that of lay expert and empowered consumer. The willingness of health care systems to pay attention to the voices of patients fits within a broader shift of the democratisation of society (Bury 2001). Patients no longer have to rely on the advice provided by a very limited number of professionals, but can research and investigate from a virtually unlimited source of knowledge and alternative perspectives.

There is also an alternative interpretation of how the emergence of the 'expert patient' might be used by health systems. Rather than opening the door to improved relationships between health care providers and patients, this may instead contribute to the reconstruction of the relationship between the state and its citizens. In this dystopian scenario, the state divests itself of its responsibilities for care for its citizens. Instead its patients and their families are expected to be active in monitoring and interpreting their health needs. From this perspective, the expert patient provides an opportunity for the state to reduce the costs of health care by increasing expectations that individuals will meet their own health needs.

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Summary of main points

- Understanding the meaning people give to illness is important for health professionals because of its influence on patient coping and interaction with health care systems.
- Lay concepts of health and illness are the commonsense understandings used by people to explain bodily conditions and their interaction with the social environment. This knowledge is derived from multiple sources including individual experience, family traditions, cultural norms, and biomedical constructs.
- Acute and chronic forms of illness differ in their longevity and the presence or absence of a cure. People experiencing chronic illness often have poor interactions with health professionals due to lengthy diagnoses and uncertainty of treatment and outcome.
- Chronic illness makes up a significant proportion of disability groups. Contemporary frameworks for understanding disability stress the role of the environment in shaping the degree to which a physical or mental condition is disabling.
- The experience of chronic illness may include negative moral judgments by others about the illness. These may extend to encompass the whole person. Patients may also experience self-generated feelings of failure and low self-esteem. Disability is especially associated with experiences of discrimination and exclusion.
- Chronic illness often has disruptive effects on individual biographies, necessitating coping strategies to deal with its practical effects and risks to personal and social identity. Narrative approaches shed light on how patients make sense of these experiences through stories that link personal biography with the changing experiences of illness and the social environment.

SOCIOLOGICAL REFLECTION

THE GP ENCOUNTER

Think about the last time you went to see a GP. Were there some things that you failed to disclose even though they might have been relevant to your health? What were the reasons for this? How might disclosure have assisted diagnosis or treatment? What could the GP have done to encourage you to provide this information? Alternatively, think about what kinds of situations or conditions might lead to reluctance to provide all potentially relevant information in a medical interaction.

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DISCUSSION QUESTIONS

1 Identify six ways in which an improved understanding of the experience of illness is important for health professionals.
2 Explain the meaning of the following terms: lay concepts of health and illness; biographical disruption; and stigmatisation of illness.
3 What impact is the internet having on the relationship between patients and the health system in terms of how illness is understood and experienced? How is this connected to broader changes within society?
4 What is narrative reconstruction and on what aspects of the illness experience does it shed light?
5 Review the vignette at the start of the chapter on Lyme disease. What aspects of the chapter does it highlight?
6 How do disability and chronic illness differ from acute illness? What is their impact on the health system?

FURTHER INVESTIGATION

1 What is stigma and why is it relevant to an understanding of experiences of health? Answer this question in relation to one of the following diseases: HIV/AIDS; chronic fatigue syndrome; or intellectual disability.
2 What is the social model of disability? How does it differ from earlier models of disability and what are its implications for treatment and care?

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WEB RESOURCES

Centre for Disability Studies (UK): <http://disability-studies.leeds.ac.uk>.

Centre for Disability Research and Policy, University of Sydney: <http://sydney.edu.au/health-sciences/cdrp/>.

Chronic Illness Alliance: <www.chronicillness.org.au>.

DIPEx: <www.dipexinternational.org/about-us/>.

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Sociology of Health and Illness (journal): <http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)1467-9566>.

Disability and Society (journal): <www.tandfonline.com/toc/cdso20/current?nav=tocList>.

DOCUMENTARIES/FILMS

Holding the Man (2015): 128 minutes.

This movie is based on a memoir by Timothy Conigrave and tells the story of his relationship with John, whom he first met as a fellow student at Xavier College in Melbourne, at a time when both homosexuality and HIV/AIDS were highly stigmatised.

50/50 (2011): 100 minutes.

Offbeat comedy about a young man diagnosed with a malignant spinal tumour and his efforts to negotiate his need for care while maintaining a normal life, and the difficulties experienced by carers.

Adam Hills: The Last Leg (2015): 40 minutes.

Broadcast by the ABC in Australia and hosted by Australian presenter Adam Hills, this Channel 4 (UK TV) late-night chat show originally focused on disability sport but has now become a 'para-documentary' of the day's events, often including an irreverent focus on disability.

The Intouchables (2011): 112 minutes.

A French comedy about a wealthy, white middle-aged quadriplegic who regains his zest for life as a result of the rapport he develops with his carer, a poor French-Algerian who's spent time in jail.

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