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National Center for Alternative and Complementary Medicine (National Institutes of Health): http://nccam.nih.gov

Self Help UK (online database of over 1000 self-help groups and support groups in the UK): http://www.self-help.org.uk

Self-Help Group Sourcebook Online (USA): http://mentalhelp.net/selfhelp

World Health Statistics 2005 (World Health Organization): http://www3.who.int/statistics

5

Doctor–patient interactions

Doctors and their patients, even if they come from the same social and cultural background, view ill health in very different ways. Their perspectives are based on very different premises, employ a different system of proof, and assess the efficacy of treatment in a different way. Each has its strengths, as well as its weaknesses. The problem is how to ensure some *communication* between them in the clinical encounter between doctor and patient. In order to illustrate this problem, the differences between medical and lay views of ill health – between, that is, 'disease' and 'illness' – will be described in some detail.

'DISEASE' – THE DOCTOR'S PERSPECTIVE

As described in the previous chapter, those who practice modern scientific medicine form a group apart, with their own values, theories of disease, rules of behaviour and organization into a hierarchy of specialized roles. The medical profession can be seen as a healing 'subculture', with its own particular world view. In the process of medical education, students undergo a form of *enculturation* whereby they gradually acquire a perspective on ill health that will last throughout their professional life. They also acquire a high social status, high earning power and the socially legitimized role of healer, which carries with it certain rights and obligations. Some of the basic premises of this medical perspective are:

1 Humanitarian outlook.
2 Scientific rationality.
3 The emphasis on objective, numerical measurement.
4 The emphasis on physicochemical data.
5 Mind–body dualism.
6 The view of diseases as entities.
7 Reductionism.
8 The emphasis on the individual patient, rather than on the family or community.

Since ancient times, medicine's core approach has been *humanitarian*: that is, its main concern has been to treat illness, improve human welfare, and alleviate human suffering and pain, by all the means at its disposal. In order to achieve this, modern medicine is based on *scientific rationality*, whereby all its assumptions and hypotheses must be capable of being tested and verified under objective, empirical and controlled conditions. Phenomena relating to health and sickness only then become 'real' when they can be *objectively* observed and measured under these conditions. Once they have been observed, and often quantified, they become clinical 'facts', the cause and effect of which must then be discovered. All 'facts' have a cause, and the task of a clinician is to discover the logical chain of causal influences that led up to this particular fact. For example, iron-deficiency anaemia may result from loss of blood, which may be the result of a bleeding stomach tumour, which may have been caused by certain carcinogens in the diet. Where a specific causal influence cannot be isolated, the clinical fact is labelled 'idiopathic' – that is, it *has* got a cause, but that cause has yet to be discovered. Where a phenomenon cannot be objectively observed or measured, for example a person's beliefs about what caused an illness, it is somehow less 'real' than, say, the level of the patient's blood pressure or white cell count. Because blood pressure and white cell count can be measured and agreed upon by several observers, they form the sorts of clinical 'facts' upon which diagnosis and treatment will be based.

These 'facts', therefore, arise from a *consensus* among the observers, whose measurements are carried out in accordance with certain agreed guidelines. The assumptions underlying these guidelines that determine which phenomena are to be looked for, and how they are to be verified and measured provide what is termed a conceptual *model*. As Eisenberg[1] points out, models 'are ways of constructing reality, of imposing meaning on the chaos of the phenomenal world' and 'once in place, models act to generate their own verification by excluding phenomena outside the frame of reference the user employs'. The model of modern medicine is mainly directed towards discovering and quantifying physicochemical information about the patient, rather than less measurable social and emotional factors. According to Kleinman and colleagues,[2] the modern Western doctor's view of clinical reality 'assumes that biologic concerns are more basic, "real", clinically significant, and interesting than psychological and sociocultural issues'.

This emphasis on physiological facts means that a doctor confronted with a patient's symptoms tries first of all to relate these to some underlying physical process. For example, if a patient complains of a certain type of chest pain, the doctor's approach is likely to involve a number of examinations or tests to try to identify the physical cause of the pain – perhaps coronary heart disease. If no physical cause can be found after exhaustive investigation the symptom might be labelled 'psychogenic' or 'psychosomatic', but this diagnosis is usually only made by excluding a physical cause. Subjective symptoms, therefore, become more 'real' when they can be explained by objective, physical changes. As the Goods[3] describe it: 'Symptoms achieve their *meaning* in relation to physiological states, which are interpreted as the referents of the symptoms. Somatic lesions or dysfunctions produce discomfort and behavioural changes, communicated in a patient's complaints. The critical task of the physician is to "decode" a patient's discourse by relating symptoms to their biological referents in order to diagnose a disease entity'. These somatic or biological referents are discovered by the doctor's examination and sometimes by the use of specialized tests, often using diagnostic technology.

As described in the previous chapter, Feinstein[4] has pointed out the shift in recent years in how doctors collect information about underlying disease processes. The traditional method was by listening to the patient's symptoms and how they developed (the history), and then searching for objective physical signs (the examination). Increasingly, though, modern medicine has come to rely on diagnostic technology to collect and measure clinical facts. This implies a shift from the *subjective* (the patient's subjective symptoms, the physician's subjective interpretation of the physical signs) towards the notionally *objective* forms of diagnosis. The underlying pathological processes are now firmly identified by blood tests, X-rays, scans and other investigations, usually carried out in specialized laboratories or clinics (see Chapter 4). One result of this is the increasing use of *numerical* definitions of health and disease. Health or normality are defined by reference to certain physical and biochemical parameters, such as weight, height, circumference, blood count, haemoglobin level, levels of electrolytes or hormones, blood pressure, heart rate, respiratory rate, heart size or visual acuity. For each measurement there is a numerical range – the 'normal value' – within which the individual is considered normal

and 'healthy'. Above or below this range is 'abnormal', and indicates the presence of 'disease'. Disease, then, is seen as a deviation from these normal values, accompanied by abnormalities in the structure or function of body organs or systems. For example, lower than the normal value of thyroid hormone in the blood is *hypo*thyroidism, above it is *hyper*thyroidism; between the two the thyroid is functioning normally.

Diseases

The medical definition of ill health, therefore, is largely based on objectively demonstrable physical changes in the body's structure or function, which can be quantified by reference to 'normal' physiological measurements. These abnormal changes, or *diseases*, are seen as 'entities', each with their own unique 'personality' of symptoms and signs. Each disease's personality is made up of a characteristic cause, clinical picture (symptoms and signs), results of hospital investigations, natural history, prognosis and appropriate treatment. For example, tuberculosis is known to be caused by a particular bacillus, to reveal itself by certain characteristic symptoms, to display certain physical signs on examination, to show up in a particular way on chest radiographs and sputum tests, and to have a likely natural history, depending on whether it is treated or not. As Fabrega and Silver[5] point out, the medical perspective assumes that diseases are 'universal in form, progress, and content', and that they have a recurring identity; that is, it is assumed that tuberculosis will be the same disease in whatever culture or society it appears. It will always have the same cause, clinical picture, treatment, and so on. However, this perspective does not include the social, cultural and psychological dimensions of ill health, and the context in which it appears, which determine the *meaning* of the disease for the individual patients and those around them. Because medicine focuses more on the physical dimensions of illness, factors such as the personality, religious belief, culture and socioeconomic status of the patient are often considered largely irrelevant in making the diagnosis or prescribing treatment. Engel[6] sees this approach as further evidence of 'mind–body dualism', a medical way of thinking that focuses on identifying physical abnormalities while often ignoring 'the patient and his attributes as a person, a human being'. Reducing him, that is, to a set of abnormal physiological parameters. This conceptual dualism can be traced back at least to Descartes in the seventeenth century, who divided man into 'body' (to be studied only by science), and 'mind' or 'soul' (to be studied by philosophy and religion). In more recent times, 'mind' has been handed over to psychiatrists and behavioural scientists to study (rather than priests), while 'body' – seen increasingly as an animated machine – has been handed over to medical science and its diagnostic technology. Thus, in modern medicine the basic dualism still remains.

Reductionism

A further point is that modern medicine is often very reductionist in its approach. With the exception of the specialties of public health and family medicine, its focus is mainly on the individual patient, rather than on their families, communities or wider society. In some cases, that focus has moved beyond the individual, to concentrate instead on a particular diseased organ, system, group of cells or region within their body. This development has been made possible by advances in equipment and diagnostic technology, which can now reveal changes at the cellular, biochemical or even molecular levels, and can exactly localize the site of pathology. In recent years, there has also been a growing emphasis on the human genome (see Chapter 14), and on genetic abnormalities as indicators, or predictors of hereditary diseases. As mentioned in the previous chapter, advances in diagnostic technology have led to the development of a new group of 'patients' produced by that technology, such as X-ray plates, scans, printouts of blood test results or the strips of paper from an electrocardiogram. The development of these 'paper patients' as a growing feature of clinical consultations, case conferences and hospital grand

Figure 5.1 Advances in diagnostic technology have helped shift medicine towards an increased focus on *physical* abnormalities – rather than on the patient's symptoms, their psychological state, or their social and cultural background. (Source: © Corbis MED 028. Reproduced with permission.)

rounds is a further step towards medical reductionism. Furthermore, many doctors now diagnose and treat abnormalities of only a small part of the human body. Their professional aim is, in a sense, to know more and more about less and less (and often this results in knowing less and less about more and more). In modern medicine these hyper-specialists tend to have a higher status and a higher income than many generalists, such as general practitioners. In addition, those specialists, who are publicly seen to 'cure', have a higher status than those who merely 'care'. Treating a small area of the body in a relatively short period of time and with a clearly defined outcome has a much higher status than dealing with those conditions where no short-term cure is evident or even possible. Thus surgeons generally have a higher status than doctors working in geriatrics, psychiatry, physical disability, terminal illness, chronic disease or preventive medicine. Even within surgery there is a hierarchy of prestige, depending on the symbolic value our society gives to different parts of the body. This applies especially to the brain and the heart, so that brain surgeons and heart surgeons have a much higher prestige than, say, rectal or gynecological surgeons.

THE RANGE OF MEDICAL MODELS

The medical model should not, therefore, be seen as homogeneous and consistent. In understanding doctor–patient interactions, one should always ask: '*which* doctor?', or perhaps 'which *type* of doctor?' There is really no such thing as a uniform 'Western' or 'scientific' medicine; as illustrated in Chapter 4. Although it is now international, there are enormous variations in how Western medicine is practiced in different parts of the world. This applies in different Western industrialized countries, and even within those countries themselves. Furthermore, the medical model is always to a large extent culture-bound, and varies greatly, depending on the context in which it appears. Even within the same society, huge differences in perspective exist between different branches of medicine and the different specialties – between, say, the perspectives of surgeons,[7] psychiatrists, epidemiologists, general practitioners and public health specialists. In some cases, their approach to a particular case may be quite incompatible: an example of a professional 'culture-clash'. They may concentrate on different aspects of the patient's condition, but ignore others. Some may focus only on a small area of the body, others mainly on the patient's state of mind, or on relationships with their families and communities. This type of clash of perspectives is often seen also in the relationships between doctors and nurses.

When a particular doctor trained in modern scientific medicine makes a diagnosis, he or she usually employs a number of *different* models or perspectives, each of which looks at the problem in a particular way. As the Goods[3] note, 'any physician or medical discipline has a repertoire of interpretative models – biochemical, immunological, viral, genetic, environmental, psychodynamic, family interactionist and so on', each with its own unique perspective on the disease. In some cases these perspectives, or models, might be very different from one another. In psychiatry, for example, Eisenberg[1] points out that 'multiple and manifestly contradictory models' are used by different psychiatrists in explaining the psychoses. These include:

1 The *organic* model, which emphasizes physical and biochemical changes in the brain.
2 The *psychodynamic* model, which concentrates on developmental and experiential factors.
3 The *behavioural* model, where psychosis is maintained by environmental contingencies.
4 The *social* model, with its emphasis on disorders in role performance.

Whatever specialty they choose to work in, it should be noted that physicians themselves are also part of the 'folk' world for most of their lives – both before and after graduating from medical school. Both as individuals and as members of a particular family, community, religion or social class, they bring with them a specific set of ideas, assumptions, experiences, prejudices and inherited folklore, and this can greatly influence their medical practice. When they impose (often unconsciously) their own cultural values, assumptions and expectations on their patients, that phenomenon – using psychoanalytic imagery – could be seen as an example of what I would term *cultural counter-transference*.

All medical and psychiatric models tend to change over time as new concepts are developed and new discoveries are made. Disease entities such as hypertension, cancer or coronary heart disease are continuously being re-examined or reworked as new theories of aetiology are advanced and new techniques of diagnosis and treatment are invented. The different models used by clinicians in different specialties also means that they might perceive and diagnose the *same* episode of ill health in very different ways, if an ill person consults with each of them over a period of time.

MEDICINE AS A SYSTEM OF MORALITY

A final issue is that, with the decline in organized religion in many Western societies, the moral concerns of the contemporary age are increasingly being expressed in medical rather than religious terms. Medicine has always been more than a system of scientific ideas and practices; it has also been a *symbolic* system, expressing some of the basic underlying values, beliefs and moral concerns of the wider society. In a more secularized age, religious ideas of sin or immorality often seem to be replaced by ideas of health and disease. Today, medical metaphors have become part of the daily discourse, for example a 'sick society', an 'epidemic of crime', an 'ailing economy', 'the plague of terrorism'. Whereas a few generations ago religion spoke out against a 'sinful life', medicine now condemns the 'unhealthy lifestyle', but the punishments occur in this world, rather than in the world to come. The ancient Deadly Sins of 'gluttony' and 'sloth' have been reconceptualized as 'overeating' and 'lack of exercise'. Because so much moral discourse is now couched in medical terms, the definitions of certain behaviours – alcoholism, illegitimacy, truancy, drug abuse and criminality – have shifted from being bad or sinful to being in some way in the domain of medicine or psychiatry.

A related phenomenon in most industrialized societies is the growth of the *insurance* industry. While it penalizes those of its clients who have an unhealthy lifestyle (who smoke or drink, for example), it compensates individuals for unexpected illness, accident or other misfortune – events that, in previous generations (and elsewhere in the world), were dealt with by the religious system. Arguably, in those societies where organized religion is weak, the insurance industry (like the medical system itself) provides some people with a rational, secularized way of responding to misfortune and of diminishing its effects. However, both approaches focus much less on moral responsibility than does religion; despite medicine's enhanced social role, its main focus is still on the *consequences* of illness, accident or misfortune, rather than on their cause.

Despite these changes in the social and symbolic role of medicine in modern society, and variations within the medical model itself, its predominant approach in clinical practice still remains the search for *physical* evidence of disease or dysfunction and the use of physical treatments (such as drugs, surgery, or radiation) in correcting these underlying abnormalities.

'ILLNESS' – THE PATIENT'S PERSPECTIVE

Cassell[8] uses the word 'illness' to represent 'what the patient feels when he goes to the doctor', and 'disease' for 'what he has on the way home from the doctor's office'. He concludes: 'Disease, then, is something an organ has; illness is something a man has'. *Illness* is the subjective response of an individual and of those around him to his being unwell – particularly how he and they interpret the origin and significance of this event, how it affects his behaviour and his relationship with other people, and the various steps he takes to remedy the situation. It not only includes his experience of ill health, but also the *meaning* he gives to that experience. For example, people who suddenly fall ill might ask themselves 'why has it happened to *me*?', 'why *now*?', 'have I done anything wrong to deserve this?' or even, in some societies, 'has anyone *caused* me to be ill?'. Both the meaning given to the symptoms and their emotional response to them are influenced by their own background and personality, as well as the cultural, social and economic context in which the symptoms appear. In other words, the same 'disease' (such as tuberculosis) or symptom (such as pain) may be interpreted completely differently by two individuals from different cultures or social backgrounds and in different contexts. This will also affect their subsequent behaviour, and the sorts of treatment they will seek out.

The patient's perspective on ill health is usually part of a much wider conceptual model used to explain misfortune in general; within this model, illness is only a specialized form of adversity. For example, in many societies *all* forms of misfortune are ascribed to the same range of causes; a high fever, a crop failure, the theft of one's property or a roof collapsing might all be blamed on witchcraft or on divine punishment for some moral transgression. In the last case, they may cause similar emotions of shame or guilt and call for similar types of treatment, such as prayer or penitence. 'Illness' therefore often shares the psychological, moral and social dimensions associated with other forms of adversity, within a particular culture. It is a wider though more diffuse concept than 'disease' and should be taken into account in understanding how people interpret their ill health and suffering, and how they respond to it.

BECOMING ILL AND DEFINITIONS OF 'HEALTH'

Definitions of what constitutes both 'health' and 'illness' vary between individuals, families, cultural groups and social classes. In most cases, *health* is seen as much more than just an absence of unpleasant physical symptoms. The World Health Organization (WHO),[9] for example, defined it in 1946 as 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity'. 'Health' is really a *multi-dimensional* and holistic concept, which includes physical health, psychological health, social health, and spiritual health. A disturbance of any one of these, such as a major conflict with a spouse or close relative, unsettling dreams, or a sense of being 'bewitched, may be seen as a form of 'illness', especially if it interferes with daily life and activities. That is because in many non-industrialized societies, health is conceived of as a balanced *relationship* between people, between people and nature, and between people and the supernatural world. It is also seen as an internal balance, both physical and emotional. A disturbance of any of these dimensions proves that one is not 'healthy', especially as this imbalance may manifest itself by physical or emotional symptoms. Among Western communities, definitions of health tend to be rather less all-embracing, owing to Western biomedicine's over-emphasis on physical abnormalities *within* the body, but they almost always include some physical, psychological and behavioural aspects. In modern discourse, some traces of the 'balance' idea still remains, in phrases such as 'a well-balanced person', 'to be mentally unbalanced', 'to eat a balanced diet' and 'everything in proportion'.

Definitions of 'health' also vary between social classes. For example, Fox[10] quotes a classic 1960s study of 'Regionville', a town in upper New York State where members of the highest socio-economic class usually reported a persistent backache to their physician as an abnormal symptom, while members of the poorer socioeconomic class regarded it as 'an inevitable and innocuous part of life and thus as inappropriate for referral to a doctor'. Similarly, in Blaxter and Paterson's 1981 study[11] in Aberdeen, Scotland, working-class mothers did not define their children as ill, even if they had abnormal physical symptoms, provided that they continued to walk around and play normally. This functional definition of health, common among poorer people, is probably based on the (economic) need to keep working regardless of what they feel, as well as on low expectations of medical care. These lay definitions of health can obviously differ from those of the medical profession, as will be described.

On an individual level, the process of defining oneself as being 'ill' can be based on one's own perceptions, on the perceptions of others, or on both. Defining oneself as being ill usually follows a number of subjective experiences including:

- perceived changes in bodily appearance, such as loss of weight, changes in skin colour, or hair falling out
- changes in regular bodily functions, such as urinary frequency, heavy menstrual periods, irregular heart beats
- unusual bodily emissions, such as blood in the urine, sputum or stools
- changes in the functions of limbs, such as paralysis, clumsiness or tremor
- changes in the five major senses, such as deafness, blindness, lack of smell, numbness or loss of taste sensation
- unpleasant physical symptoms, such as pain, headache, abdominal discomfort, fever or shivering
- excessive or unusual emotional states, such as anxiety, depression, guilt, nightmares or exaggerated fears
- behavioural changes in relation to others, such as marital or work disharmony
- certain spiritual experiences such as visions or dreams, or the sense of having being punished by the deity, or of being bewitched, or 'possessed' by a malevolent spirit

Most people experience some of these abnormal changes in their daily lives, though usually in a mild form, and this has been demonstrated in several studies. In Dunnell and Cartwright's study[12] in 1972, 91 per cent of a sample of adults had experienced one or more abnormal symptoms in the 2 weeks preceding the study (while only 16 per cent had consulted a doctor during this time). Having one or more abnormal changes of symptoms may therefore not be enough to label oneself as being 'ill'. For example, in Apple's study[13] of middle-class Americans, abnormal symptoms were only considered an illness if they interfered with the usual daily activities, were recent in onset and were ambiguous – that is, difficult for a layman to diagnose.

Other people can also define one as being ill, even in the absence of abnormal subjective experience, by statements such as 'You look pale today, you must be ill' or 'You've been acting very strangely recently'. In the absence of behavioural changes, cultures vary as to whether a particular form of behaviour is defined as illness or not. In Guttmacher and Elinson's[14] 1971 study, different social and ethnic groups in New York City were asked whether certain types of socially deviant behaviour (such as transvestism, homosexuality or getting into fights) were evidence of illness. The Puerto Rican group was found to be less likely to describe these as illness than other groups such as Irish, Italian, Jewish or Black. In most cases, though, a person is defined as being 'ill' when there is agreement between his perceptions of impaired wellbeing and the perceptions of those around him. In that sense, becoming ill is always a *social* process that involves other people in addition to the patient. Their cooperation is needed in order for him to adopt the rights and benefits of the 'sick role' – that is, of the socially acceptable role of an 'ill person'. People who are so defined are temporarily able to avoid their obligations towards the social groups to which they belong, such as family, friends, workmates or religious groups. At the same time, these groups often feel obligated to care for their sick members while they are ill. The sick role therefore provides, as Fox[10] pointed out, 'a semi-legitimate channel of withdrawal from adult responsibilities and a basis of eligibility for care by others'. In most cases this role is most potent when validated by a doctor or some other health professional. This care usually takes place within the popular sector of health care, and especially within the family, where the patient's symptoms are discussed and evaluated and decisions made about whether they are ill or not and, if so, how they should be treated.

The process of 'becoming ill' involves, therefore, both subjective experiences of physical or emotional changes and, except in the very isolated, the confirmation of these changes by other people. In order for this confirmation to take place there must be a *consensus* among all concerned about what constitutes health and abnormal symptoms and signs. There must also be a standardized way in which an ill person can draw attention to these abnormal changes so as to mobilize care and support. According to Lewis,[15] 'in every society there are some conventions about how people should behave when they are ill... in most illness there is some interplay of voluntary and involuntary responses in the expression of illness. The patient has some control of the way in which he shows his illness and what he does about it'.

Both the presentation of illness and others' response to it are largely determined by socio-cultural factors. Each culture (and to some extent each gender, social class, region and even family) has its own *language of distress*, which bridges the gap between subjective experiences of impaired wellbeing and social acknowledgement of them. Cultural factors determine *which* symptoms or signs are perceived of as abnormal; they also help *shape* these diffuse emotional and physical changes into a pattern that is recognizable to both the sufferer and those around him. The resultant pattern of symptoms and signs may be termed an 'illness entity', and represents the first stage of becoming ill.

THE EXPLANATORY MODEL

Kleinman[16] has suggested a way of looking at the process by which illness is patterned, interpreted and treated, which he terms the *Explanatory Model* (EM). Although there are limitations to this model, it can be useful on occasion. The EM is defined as 'the notions about an episode of sickness and its treatment that are employed by all those engaged in the clinical process'. Explanatory models are held by both patients and practitioners, and they 'offer explanations of sickness and treatment to guide choices among available therapies and therapists and to cast personal and social meaning on the experience of sickness'. In particular, they provide explanations for five aspects of illness:

1 The aetiology or cause of the condition.
2 The timing and mode of onset of symptoms.
3 The pathophysiological processes involved.
4 The natural history and severity of the illness.
5 The appropriate treatments for the condition.

These models are marshalled in response to a particular episode of illness, and are not identical to the general beliefs about illness that are held by that society. According to Kleinman, lay EMs tend to be 'idiosyncratic and changeable, and to be heavily influenced by both personality and cultural factors. They are partly conscious and partly outside of awareness, and are characterized by vagueness, multiplicity of meanings, frequent changes, and lack of sharp boundaries between ideas and experience'. He contrasts this with physicians' EMs, which are also marshalled to deal with a particular illness episode but are mostly based on 'single causal trains of scientific logic'. Explanatory models, therefore, are used by individuals to explain, organize and manage particular episodes of impaired wellbeing. Consultations with a doctor are actually transactions between lay and medical EMs of a particular illness.[17]

Another way of looking at lay explanations of ill health is to examine the sorts of questions that people may ask themselves when they perceive themselves as being ill[17] (or when they suffer from any other misfortune), and how they weave the answers to these questions into the story or *narrative* of their ill health. These questions include:

1 *What has happened?* This includes organizing the symptoms and signs into a recognizable pattern, and giving it a name or identity.
2 *Why has it happened?* This explains the aetiology or cause of the condition.
3 *Why has it happened to me?* This tries to relate the illness to aspects of the patient, such as behaviour, diet, body build, personality or heredity.
4 *Why now?* This concerns the timing of the illness and its mode of onset, sudden or slow.
5 *What would happen to me if nothing were done about it?* This considers its likely course, outcome, prognosis and dangers.
6 *What are its likely effects on other people (family, friends, employers, workmates) if nothing is done about it?* This includes loss of income or of employment, or a strain on family relationships.
7 *What should I do about it – or to whom should I turn for further help?* This includes strategies for treating the condition, including self-medication, consultation with friends or family, or going to see a doctor.

For example, someone suffering from a 'head cold' might answer these questions as: 'I've picked up a cold. It's because I went out into the rain on a cold day, directly after a hot bath, when I was feeling low. If I leave it, it may go down to my chest and make me more ill. Then I might have to stay at home for a long time, and lose a lot of money. I'd better go see the doctor, and get some medicine for it'. Before these questions can be asked or answered, the patients must see their symptoms or signs – such as muscular aches, shivering or a runny nose – as 'abnormal', before grouping them into the recognizable pattern of 'a cold'. This implies a fairly widespread belief in the patient's community about what 'a cold' is and how it can be recognized, although the EM of a particular cold is likely to have personal, idiosyncratic elements. Where many people in a culture or community agree about a pattern of symptoms and signs, and its origin, significance and treatment, it becomes an 'illness entity' or *folk illness*, with a recurring identity. This identity is more loosely defined than medical 'diseases', and is greatly influenced by the socio-cultural context in which it appears.

The context of explanatory models

Explanatory models, however, do not ever exist in isolation. They are not concrete, unchanging 'things' that are somehow separate from the unique circumstances of a particular human life. Unlike some biomedical tests, they are not a type of 'diagnostic test' of someone's worldview, or psychological condition, but only a reflection of how, at that particular moment in time, they explain what has happened to them, and how it should be dealt with. Furthermore, EMs can only be fully understood by examining the specific *context* in which they are employed, since this usually has a major influence upon them.

Because EMs are strongly shaped by context, explanations for the *same* illness event may vary, depending on when and where they are given, by whom, and to whom. Ill people may give different explanations for their illness to themselves, to their family, and to their doctor. In turn, each of these parties may view the illness in a completely different way. The wider context of an EM also includes the social and economic organization and dominant ideology (or religion) of the society in which a particular individual got ill, and in which they consulted a doctor or other health professional. It can depend also on the particular social and economic circumstances of someone's life at that time. For example, an ill person's assessment of how serious an illness is (and how it will affect their life) may depend not only on their explanation of the origin of their condition, but also on whether they are able to afford to miss work, whether they can afford private health insurance, and whether the state will provide them with free health care and disability payments while they remain unfit to work. A broken leg will have different economic implications for a manual labourer or farm worker than for a computer programmer, and their EMs of the same condition will thus be very different. The social and economic context will also influence the types of treatment that patients can afford for their illness, and whether these take place mainly in the popular, folk or professional sectors. Finally, the gender, age group and stage of the life cycle of different individuals will greatly influence the EMs that they employ: those of children, the elderly, new mothers and family bread-winners are all likely to be very different from one another.

The ways that lay and medical EMs interact in the clinical consultation are influenced not only by the physical context in which they occur (such as a hospital ward, or doctor's office),[18] but also by the social class, gender and age of the two parties involved. The *power* invested in clinicians by virtue of their background and training (as well as gender or social class) may allow them to mould the patient's EM to make it fit into the medical model of disease, rather than allowing the patient's own perspective on illness to emerge.

FOLK ILLNESSES

As mentioned above, folk illnesses can be regarded as EMs *shared* by a group of people. Rubel[19] has defined them as 'syndromes from which members of a particular group claim to suffer and for which their culture provides an aetiology, a diagnosis, preventive measures and regimens of healing'. Anthropologists have described dozens of these folk illnesses from around the world, each with its own unique configuration of symptoms, signs and behavioural changes. Some examples are: *susto* throughout Latin America; *amok* in Malaysia; *windigo* in north-eastern America; *narahatiye qalb* ('heart distress') in Iran; *dil ghirda hai* ('sinking heart') in the Punjab, India; *koro* in China; *brain fag* in parts of Africa; *tabanka* in Trinidad; *nervios* in much of Latin America; *vapid unmada* in Sri Lanka; *crise de foie* in France; *high blood* in the USA; and *colds* and *chills* in much of the English-speaking world. Each of these is a 'culture-bound syndrome' (see Chapter 10) in the sense that it is a unique disorder, recognized mainly by members of a particular culture, and treated by them in a culturally specific way. One is dealing with a culture-bound folk illness when, as Rubel puts it, 'symptoms regularly cohere in any specified population, and members of that population respond to such manifestations in similarly patterned ways'.

Folk illnesses are more than specific clusterings of symptoms and physical signs. They also have a range of *symbolic* meanings – moral, social or psychological – for those that suffer from them. In some cases they link the suffering of the individual to changes in the natural environment, or to the workings of supernatural forces. In other cases, the clinical picture of the illness is a way of expressing, in a culturally standardized way, that the sufferer is involved in social conflicts, such as disharmony with family, friends or neighbours.

The following case studies are two examples of folk-illness, described by anthropologists.

Case study: 'Heart distress' in Maragheh, Iran

Good[20] in 1977 described an example of this type of folk illness, *narahatiye qalb* or 'heart distress' in Maragheh, Iran. This is a complex folk illness that usually manifests itself in physical symptoms, such as trembling, fluttering or pounding of the heart, and feelings of anxiety or unhappiness, also associated with the heart ('my heart is uneasy'). This illness is 'a complex which includes and links together both physical sensations of abnormality in the heartbeat and feelings of anxiety, sadness, or anger'. The abnormal heartbeat is linked both to unpleasant affective states and to experiences of social stress. It is more frequent among Iranian women, and expresses some of the strains and conflicts of their lives. 'Heart distress' often follows quarrels or conflict within the family, the deaths of close relatives, pregnancy, childbirth, infertility and the use of the contraceptive pill (which is seen as a threat to fertility and lactation). It is primarily a self-labelled folk illness that expresses a wide range of physical, psychological and social problems at the same time. The label 'heart distress' is an image that draws together a network of symbols, situations, motives, feelings and stresses that are rooted in the structural setting in which the people of Maragheh live. The basic presentation of this illness, however, is in the form of common physical symptoms associated with the heart.

Case study: 'Sinking heart' among Punjabis in Bedford, UK

Krause[21] in 1989 described a similar syndrome among both Hindu and Sikh Punjabis living in Bedford, England. The image of *dil ghirda hai* ('sinking heart') links together physical sensation, emotions and certain social experiences into one illness complex, which has specific meanings for the community. 'Sinking heart' – certain physical sensations in the chest – can happen repeatedly to the same individual, and may eventually result in heart 'weakness', heart attacks or even death. Among its many causes are: excessive heat from food or climate or from excessive emotions (such as anger) that make the body 'hot'; other emotional states such as shame, pride, arrogance or worry about one's fate, which are all seen as evidence of self-centredness; and hunger, exhaustion, old age and poverty, which all make people 'weak' and therefore unable to fulfil their moral obligations and may in turn result in worry and sadness. 'Sinking heart' is thus especially linked to 'a profound fear of social failure', and to cultural values that stress the importance of carrying out social obligations, being able to control one's personal emotions, being altruistic and not too worried and self-absorbed and, for men, being able to control the sexuality of their female relatives. Failure in any of these – for example, being unable to prevent the disrespectful and promiscuous behaviour of one's daughters – may result in a loss of *izzat* (honour or respect) in the community, and in *dil ghirda hai*. Like many folk illnesses, therefore, the syndrome blends together physical, emotional and social experiences into a single image or metaphor.

Somatization

A feature of many folk illnesses is that of somatization (see Chapter 10), which Kleinman[22] defines as 'the substitution of somatic preoccupation for dysphoric affect in the form of complaints of physical symptoms and even illness'. That is, unpleasant emotional states (such as depression) or the experience of various social stresses is mainly expressed in the form of physical symptoms. In Taiwan, for example, Kleinman[22] describes how depression is commonly presented in the form of physical symptoms and signs. In Taiwanese culture mental illness is heavily stigmatized, as is the use of psychotherapy, and therefore stress from family problems or financial difficulties is often expressed by physical symptoms. Although these symptoms do not necessarily appear in a standardized form, they are more easily recognized by Chinese folk healers (who are more familiar with this mode of presenting personal problems and conflicts) than by Western-trained physicians.

Folk illnesses can be 'learnt', in the sense that a child growing up in a particular culture learns how to respond to, and express, a range of physical or emotional symptoms or social stresses in a culturally patterned way. Children see relatives or friends suffering from a condition and gradually learn to identify its characteristic features, both in themselves and in others. Frankenberg[23] notes how people's experience of a particular form of ill health is also shaped by much wider cultural and social forces, such as television, advertisements, newspapers and novels (and, increasingly, the Internet), as well as by the dominant ideology and social structure of the society in which they live.

A health professional working in any culture or society should therefore be aware how folk illnesses are generated, how they are acquired and displayed, and how this may affect patients' behaviour and the diagnosis of ill health.

METAPHORS OF ILLNESS

In most of the industrialized world a large number of folk illnesses still persist, many of them largely untouched by the medical model and still rooted in traditional folklore. In addition, certain serious and life-threatening diseases, such as cancer, heart disease or acquired immune deficiency syndrome (AIDS), have also become folk illnesses, though of a particular and powerful type. Often these conditions are linked in the public imagination with traditional beliefs about the moral nature of health, illness and human suffering. These diseases (especially those that are difficult to treat, explain, predict or control) come to symbolize many of the more general anxieties that some people have, such as a fear of the breakdown of ordered society, of invasion or of divine punishment. In the minds of many of the population these diseases become more than just a clinical condition; they become *metaphors* for many of the terrors of daily life. Some of the metaphors associated with AIDS, at least in the early years of the epidemic, are described in Chapter 16.

Metaphors of cancer

Susan Sontag[24] has described how, historically, certain serious diseases, especially those whose origin was not understood and whose treatment was not very successful, became metaphors for all that was 'unnatural' and socially or morally wrong with society. In the Middle Ages, epidemic diseases such as plague were metaphors for social disorder and the breakdown of the religious and moral order. In the last two centuries, syphilis, tuberculosis and cancer have all been used as contemporary metaphors for evil. In the twentieth century in particular, cancer has been described (in the media, literature and popular discourse) as if it were a type of unrestrained and chaotic evil force, unique to the modern world, and which is composed of 'primitive', 'atavistic', 'chaotic' and 'energetic' cells that behave completely without inhibitions and always destroy the natural order of the body (and of society). According to Sontag, a result of this moral model of cancer is that, for many sufferers, the disease is 'often experienced as a form of demonic possession – tumours are "malignant" or "benign", like forces – and many terrified cancer patients are disposed to seek out faith healers, to be exorcised'. In the media too, crime, terrorism, drug abuse, strikes, immigration and even political dissent have all been described as 'a cancer', a demonic force gradually destroying the very fabric of society. One result of this, as Lupton[25] notes, is the widespread use of 'invasion', 'battle' and 'war' metaphors in cancer treatment. An example of this was President Nixon's declaration in 1971 of a 'War on Cancer'.

Metaphors, as Kirmayer[26] notes, are creative of meaning. Their use 'involves a process of discovery or invention'. They are, in a sense, *new* ways of viewing and experiencing the world we live in. In the case of serious conditions such as cancer, these metaphors carry with them a range of symbolic associations that can have serious effects both on how sufferers perceive their own condition, and how other people behave towards them. For example, Peters-Golden[27] described how the stigma associated with breast cancer can cause other people to avoid the sick person and withdraw their social support from her. In her study in the USA of 100 women with breast cancer, 72 per cent of the sample said that other people treated them differently after they knew the diagnosis; 52 per cent found they were avoided or feared, 14 per cent felt they were pitied and only 3 per cent thought people were nicer to them than they had previously been. One reason for this may be the fear that cancer is, in some way, 'contagious'. Similarly, Herzlich and Pierret[28], in their study of French illness beliefs, also found evidence for this. For example, one woman with breast cancer asked her doctor whether it was 'contagious', and whether she could cause any harm to her daughter by sharing her plate.

Similarly, Gordon's study[29] in Italy found that many women described breast cancer as an epidemic or a 'plague' – a malevolent force that somehow invaded them from outside. To one woman 'it is a thing in the air... It plants itself in a part of the body, then begins to eat the whole person', to another 'I see it as something that comes from outside that disturbs something perfect that is inside of me...'. Others saw it as 'an animal', 'a beast' or 'a monster' that invades and then devours the woman's body. Seeing cancer as something originating outside the body – an idea that draws on more ancient imagery of the plague, or of possession by malevolent spirits – inevitably reinforces the sense of it being dangerous, or contagious, to those in contact with one of its victims.

Hunt's study[30] in southern Mexico showed further how women with cancer struggled to deny this sense that the disease was arbitrary. To try to restore the 'sense of a general orderliness to life', they blamed it on previous events in their personal lives. These included emotional upsets, worrying too much, improper sexual behaviour, infidelity by a spouse, failure to reproduce, or a physical blow (*golpe*) to the body, as well as environmental pollution. Thus, 'the illness did not just happen, it happened for a reason'. Similar findings have been reported in the USA by Chavez and colleagues,[31] among Mexican and Salvadorean immigrants. These lay explanations for cancer may imply, therefore, that the disease has a moral element, and that responsible behaviour can somehow avert it.

Metaphors for cancer are not static, however, and may change considerably over time. Also, different types of cancer seem to attract different types of metaphor, depending on the part of the body affected, the duration of the condition, and the speed of onset.

Comparison of illness metaphors

Weiss[32], in a study in Israel, compared the metaphors used for cancer, AIDS and heart disease. Cancer metaphors were those of flux and transformation, of the destruction of boundaries both within the body and beyond it. As in the examples above, the disease was described as an alien 'thing' – an 'amoeba', 'octopus', 'spider', 'worm' or 'parasite' – that 'eats up' the victim's body from within ('Cancer eats up your body... It eats whatever it comes across. It has an open mouth with teeth and it bites off everything'). Yet although it was alien, it somehow originated within the person. In contrast, AIDS (see Chapter 16) was not seen as an isolated 'thing', but an all-embracing part of the self ('it's his whole body that's infected, not a single discernible organ of it'). Unlike cancer, it was seen as originating completely outside the individual ('AIDS attacks you from without... Cancer, from within'), and was linked to notions of outside pollution. Metaphors of both cancer and AIDS suggested 'an entity beyond culture'; a sense of something that belongs 'outside' yet somehow has become incorporated 'inside' both body and self (and society) and is now destroying it. Conversely, the metaphors for heart disease were much less dramatic. They described it in less symbolic but more familiar and mechanical terms. It was seen as essentially 'a problem in plumbing', and heart attacks as simply a 'pump' that suddenly fails.

A fuller discussion of the metaphors associated with human immunodeficiency virus (HIV) and AIDS, is given in Chapter 16.

All these illness metaphors are not just phenomena of language. They are also, in a sense, *embodied* or internalized by those that use them. They become part of the way that individuals experience events – both within their own bodies and beyond it – and the meanings that they give to those experiences. Metaphors often come into play at times of vulnerability caused by illness, pain, anxiety or other forms of suffering. Such metaphors are often a feature, as Becker[33] noted, of 'disrupted lives' – of sudden, traumatic events that interrupt the normal flow of human events. Under these circumstances, therefore, some of the metaphors of severe illness may well contribute towards the *nocebo* effect (see Chapter 8), with damaging consequences for the physical or mental health of the person concerned, as well for as those around them.[34]

Therefore, as the examples of cancer, AIDS and other conditions illustrate, under some circumstances certain serious medical *diseases* can also become forms of *folk illness*, and this can seriously impair the recognition, diagnosis, management and control of these conditions.

LAY THEORIES OF ILLNESS CAUSATION

As noted above, lay theories about illness are part of wider concepts about the origin of misfortune in general. They are also based on beliefs about the structure and function of the body and the ways in which it can malfunction. Even if based on scientifically incorrect premises, these lay models frequently have an internal logic and consistency, which often helps the victim of illness 'make sense' of what has happened and why. In most cultures they are part of a complex body of inherited folklore, which is increasingly influenced – especially in industrialized countries – by concepts borrowed from the media, the Internet and the medical model.

In general, lay theories of illness place the aetiology or causation of ill health in one of the following sites, or in combinations of them:

1 Within the individual.
2 In the natural world.
3 In the social world.
4 In the supernatural world.

This is illustrated in Figure 5.2. In many cases, illness is ascribed to combinations of two or more causes, or to interactions between these various worlds.

As a very broad generalization, social and supernatural aetiologies tend to be a feature of some communities in the non-industrialized world (especially those in rural areas), while natural or patient-centred explanations of illness are more common in the Western industrialized world, though the division is by no means absolute. For example, Chrisman[35] described eight groups of lay aetiologies that are most commonly reported among patients in the USA. They are:

1 Debilitation.
2 Degeneration.
3 Invasion.
4 Imbalance.
5 Stress.
6 Mechanical causes.
7 Environmental irritants.
8 Hereditary proneness.

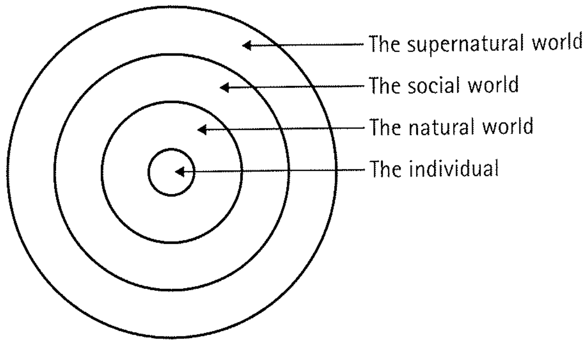

Figure 5.2 Sites of illness aetiology.

As in other Western countries, most of these aetiologies are patient-centred and do not invoke either supernatural or social explanations of why people get ill.[36] In practice, these aetiologies tend to overlap, since many lay explanations for illness are *multicausal*. For example, a person might blame their illness on 'stress' at work, which has caused some 'imbalance' in their life, resulting in weakness ('debilitation') and 'reduced resistance, and therefore making them more prone to 'invasion' by a virus or other microbe.

The lay concept of 'stress' is discussed in Chapter 11, the notion of 'hereditary proneness' in Chapter 14, while the other lay aetiologies will be discussed in more detail below.

The individual

Lay theories that locate the origin of ill health within the individual deal mainly with malfunctions within the body, sometimes related to changes in diet or behaviour. Here the *responsibility* for illness falls mainly (though not completely) on the patients themselves.[36] This belief is especially common in the Western world (where it is often encouraged by government health education campaigns), and where ill health is increasingly blamed on not taking care of one's diet, dress, hygiene, lifestyle, relationships, sexual behaviour, smoking and drinking habits, and physical exercise. Ill health is therefore evidence of such carelessness, and the sufferer should feel guilty for causing it. This applies especially to stigmatized conditions such as obesity, alcoholism, sexually transmitted diseases and, as mentioned earlier, to some extent to AIDS. Other more common conditions are also ascribed to incorrect behaviour; in the UK, colds and chills can be caused by 'doing something abnormal' such as 'going outdoors when you have a fever', 'sitting in a draught after a hot bath', or 'walking barefoot on a cold floor'. Wrong diet can also cause ill health; for example, as described in Chapter 2, 'low blood' and low blood pressure in the southern USA are thought to result from eating too many acid or astringent foods, such as lemons, vinegar, pickles, olives and sauerkraut, while 'high blood' results from eating too much rich food, especially red meat.[37] In another study,[38] one-quarter of the women interviewed believed one should eat differently during menstruation so as to avoid causing ill health. For example, sweets were said to keep the menstrual flow 'going longer', while other foods caused it to stop, resulting in menstrual cramps, sterility, strokes or 'quick TB'. Similar dietary prohibitions applied to pregnant women. Other examples of personal responsibility for ill health are some traumatic injuries (also ascribed to carelessness), or injuries that are clearly self-inflicted, such as unsuccessful attempts at suicide. Finally, one's moods, feelings and emotional state can be blamed for ill health, and the responsibility of the individual is to avoid worry, sadness and despair[28] and cultivate feelings of happiness and contentment. As one French woman put it, 'I have the impression it is because I am happy that I am no longer ill'.[28]

Whether people perceive ill health as resulting from their own behaviour, diet or emotions depends on a number of factors. Pill and Stott[39] in their 1982 study of 41 working-class mothers in Cardiff, UK, found that the extent to which people believed their health was determined by their own actions (as opposed to luck, chance or powerful external forces) correlated with socioeconomic variables such as education and home ownership. Those people who had most economic *control* over their own lives accepted more responsibility for ill health causation than those who perceived themselves as socially and economically powerless. In this latter group, illness was believed to result from external forces over which the victim had no control, and for which he or she felt no responsibility.

Other aetiological factors are believed to lie within the body but to be outside the victim's conscious control. This includes notions of personal *vulnerability* – psychological, physical or hereditary. Personality factors include the 'type of person one is', especially if overanxious or easily worried. In Pill and Stott's study,[39] this is illustrated in quotes like: 'Well, I think something you bring on yourself, like nerves or anything like that, it's partly down to you, I would think – to what sort of person you are. Like I'm a little bit highly strung, you know'. Physical vulnerability is based on lay notions of *resistance* and *weakness*. Some people in the sample were believed to be more resistant to illness than others ('I think some people have a better body resistance than somebody else. I don't really know why – whether it's to do with the blood grouping').[39] This resistance could be strengthened by proper diet, clothing, tonics and so on, but was often seen as being inherited and constitutional ('Some people are born resistant to colds and things'). Similarly 'weakness' can be inherited or acquired; in the UK, some 'weaknesses' are thought to 'run in families' ('all our family have weak chests'), but people who have been severely penetrated by environmental cold may also retain a permanent weakness or gap in their defences in that part of their body ('a weakness of the chest'). Similarly, in Chrisman's[35] classification, *debilitation* – a weakness of the body which results from overworking, being 'run down', a chronic disease or a 'weak spot' in the body – was a common lay aetiology. There was also *hereditary proneness*, which is the genetic transmission of a particular illness, quality or trait, which includes 'weakness' (see Chapter 14). In addition he describes *degeneration* in the structure or function of body tissues or organs, such as occurs in the process of aging, and *invasion*, which in the USA spans the 'individual' and 'natural' zones of aetiology. Here, illness is caused either by external invasion by a 'germ' or other object, or internal spread from an existing problem such as cancer. The other common 'individual' aetiologies are: *imbalance*, perceived as a state of disequilibrium (excess or depletion) within the body, such as 'vitamin deficiency' or 'a lack in the blood'. Imbalance may also result from eating the wrong foods, and in the wrong proportions, especially in a culture with a 'hot-cold' classification of foodstuffs (Chapter 3); and *mechanical causes* include abnormal functioning of organs or systems ('bad circulation'), damage to parts of the body such as a fracture or wound, 'blockage' of internal organs or blood vessels, and 'pressure' inside organs or parts of the body.

Explanations for ill health that are individual-centred are thus important in determining whether people take responsibility for their health, or whether they see the origin and curing of ill health as lying largely outside their own control.

The natural world

This includes aspects of the natural environment, both living and inanimate, which are thought to cause ill health. Common in this group are climatic conditions such as excess cold, heat, sunlight, wind, rain, snow or dampness. In the UK, for example, areas of environmental cold are believed to cause colds or chills if allowed to penetrate the boundary of skin; cold draughts on the back cause a 'chill on the kidneys', cold rain on the head causes 'a head cold'. In Morocco, excess environmental heat (as in sun-stroke) can enter the body and expand the blood vessels to cause a fullness and throbbing in the head – 'the blood has risen to my head', and, as in the UK, cold air, cold draught and getting wet are thought of as the cause of 'colds' (*berd*) or 'chills' (*bruda*).[40] Other climatic conditions include natural disasters such as cyclones, tornadoes or severe storms.

The supposed influences on health of the moon, sun and planetary bodies, which is a common feature of societies where astrology is practised, could be included here – and astrological birth signs can also be seen as a form of hereditary proneness to health or illness. Other 'natural' aetiologies include injuries caused by animals or birds and, at least in the Western world, infections caused by microorganisms. In the UK, infectious 'fevers' are commonly ascribed to penetration of the body by living entities called, interchangeably, 'germs', 'bugs' or 'viruses', which are commonly thought of as being 'insect-like' ('a tummy bug'). In some cases, as noted above, cancer is conceived of as invasion of the body by an external living entity, which then grows and 'eats up' the body from within. Parasitic infestations, such as round- or threadworms, also form part of this group, as do accidental injuries. In Chrisman's classification, *environmental irritants* such as allergens, pollens, poisons, food additives, smoke, fumes and other forms of pollution were commonly ascribed causes of illness in the USA. In France, Herzlich and Pierret[28] found that the 'air, climate and seasons' were all blamed for causing ill health, and that modern notions of environmental pollution were, in many cases, a return to more traditional theories of *miasmas*, or 'dirty air', as a cause of disease.

The social world

Blaming other people for one's ill health is a common feature of smaller-scale societies, where interpersonal conflicts are frequent. In some non-industrialized societies, the commonest forms of these are witchcraft, sorcery and the 'evil eye'. In all three, illness (and other forms of misfortune) is ascribed to interpersonal malevolence, whether conscious or unconscious. In *witchcraft* beliefs, which are particularly common in Africa and the Caribbean, certain people (usually women) are believed to possess a mystical power to harm others. As Landy[41] points out, this power is usually an intrinsic one, and is inherited either genetically or by membership of a particular kinship group. Witches are usually 'different' from other people, either in appearance or behaviour; often they are ugly, disabled or socially isolated. They are usually the deviants or outcasts of a society, on whom all the negative, frightening aspects of the culture are projected. Their malevolent power, however, is often unconsciously practised, and not all 'witches' are observably deviant.

Anthropologists have pointed out that witchcraft accusations are more common at times of social change, uncertainty and social conflict. Competing factions within a society, for example, may accuse each other of causing their misfortunes by practising witchcraft. Under these circumstances, the identity of the witch may need to be exposed in divinatory ritual and its negative effect exorcised. Witchcraft beliefs were common in Europe in the Middle Ages; in England, illness was often ascribed to a witch's *maleficium*, and thousands of women were condemned as witches in the sixteenth and seventeenth centuries. This belief system has largely disappeared, but traces of interpersonal conflicts causing ill health still persist in the language – 'He broke her heart' or 'She caused him much pain' – and in modern psychiatric concepts such as the 'schizophrenogenic mother'.

Sorcery, defined by Landy[45] as 'the power to manipulate and alter natural and supernatural events with the proper magical knowledge and performance of ritual', is different from witchcraft. It is also extremely common in some non-Western societies. The sorcerer exerts his or her power consciously, usually for reasons of envy or malice. He causes illness by certain spells, potions or rituals. For example, in a 1976 study[42] of health beliefs among low-income African-Americans, ill health was often ascribed to sorcery, known variously as 'voodoo', 'hoodoo', 'crossing up', 'fixing', 'hexing' or 'witchcraft'. Sorcery is often practised among the social world of friends, family or neighbours, and is often based on envy; as one of Snow's informants declared 'Put on a few little clothes and some people get begrudged-hearted'. The daughter of another informant had been 'killed by sorcery' practised by her in-laws, who were jealous of her pretty face, attentive husband and nice home'. In other cases sorcery was used to control the behaviour of others, such as a wife using spells to prevent her husband leaving her. Illnesses that were ascribed to sorcery included a range of gastrointestinal conditions, as well as general changes such as anorexia or weight loss. Sorcery beliefs of this type usually occur in groups whose lives are characterized by poverty, insecurity, danger, apprehension and a feeling of inadequacy and powerlessness.

The *evil eye* as a cause of illness has been reported throughout Europe, the Middle East and

North Africa. In Italy it is the *mal occhia*, in Hispanic cultures it is *mal de ojo*, in Greece the *mati*, in Turkey the *nazar*, in Arabic cultures the *ayn*, in Hebrew the *ayin ha-rah*, and in Iran the *cašm-e šur*. It is also known as 'the narrow eye', 'the bad eye', 'the wounding eye' or simply as 'the look'. Spooner[43] describes how it is found in the Middle East among all the communities there, whether Islamic, Jewish, Christian or Zoroastrian. He defines the main features of the evil eye as 'it relates to the fear of envy in the eye of the beholder, and [that] its influence is avoided or counteracted by means of devices calculated to distract its attention, and by practices of sympathetic magic. Jealousy can kill via a look'. It can also cause several types of ill health. The possessor of the evil eye usually harms unintentionally, is often unaware of his or her powers and is unable to control them. In their study of Yemen, the Underwoods[44] point out that such a person 'is usually either a stranger or a local person whose social activity, appearance, attitudes or behaviour is to some degree unorthodox or different', especially a person who 'stares' rather than speaks. In this type of society, therefore, a tourist or health worker from overseas might be thought of as a source of illness, whatever their good intentions, especially if they were seen staring at a child and complimenting its appearance just before it got ill.

The social aetiology of illness also includes physical injuries, such as poisoning or battle wounds, inflicted by other people. In many non-industrialized societies, though, other people usually cause illness by magical means, such as witchcraft, sorcery or the evil eye. In Western society, lay notions of *stress* (see Chapter 11) often play the same role, placing the origin of ill health within other people – for example, blaming illness on spouses, children, family, friends, employers or workmates; 'I usually get a migraine if I have a row with the family' or 'I get ill whenever my boss gives me stress'. Infections can also be blamed on other people, as in 'He gave me his cold' or 'I caught his germ', or in the case of sexually transmitted diseases. It could also be argued that overuse of *litigation*, especially in the USA, is analogous to witchcraft accusations, since it displaces the blame for accidents, suffering or misfortune away from oneself and onto the malevolence or carelessness of other people.

In general, though, the widespread blaming of other individuals for one's own ill health is generally more commonly a feature of smaller and preindustrialized societies, mainly in rural areas rather than in more urban, Western societies. However, it should be noted that very similar beliefs are found in many different settings, in many different parts of the world, both rich and poor.

The supernatural world

Here illness is ascribed to the direct actions of supernatural entities, such as *gods*, *spirits* or *ancestral shades*. In the study by Snow[42] quoted above, illness was often described as a 'reminder' from God for some behavioural lapse, such as neglecting to go to Church regularly, not saying one's prayers or not thanking God for daily blessings. Illness was a *whuppin*, a divine punishment for sinful behaviour. On this basis, neither home remedies nor a physician were considered useful in treating the condition. A cure involves acknowledgment of sin, sorrow for having committed it, and a vow to improve one's behaviour. Here, as described by Snow,[42] 'Prayer and repentance, not penicillin, cure sin'. Similar approaches that link ill health to divine disapproval of one's behaviour have also been described among middle-class suburban Americans.

In other societies, illness is ascribed to invasion by capricious, malevolent spirits. These have been described by Lewis[45] in some African communities, where 'disease-bearing spirits' strike unexpectedly, causing a variety of symptoms in their victims. Their invasion is unrelated to the individual's behaviour, and he or she is therefore considered blameless and worthy of sympathetic help from others. Like germs or viruses in the Western world, these pathogenic spirits reveal their identity by the particular symptoms they cause, and can only be treated by driving them out of the body. A similar form of spirit possession – the *jinn* or *ginn* – is common in the Islamic world. In the Underwoods' description,[44] they are ubiquitous and capricious spirits that are 'semihuman rather than supernatural', and can also cause ill health. Another form of 'spirit possession', described by Lewis,[45] occurs when individuals are invaded and made ill by the spirits of their ancestors whom they have offended. This happens when the victim is guilty of immoral, blasphemous or antisocial behaviour. Diagnosis takes place in a divinatory séance, where illness is seen as punishment for these transgressions, and the moral values of the group are reaffirmed. While such supernatural explanations for illness as divine punishment or spirit possession are less common in the industrialized world, the main equivalent is blaming ill health on bad luck, fate, the stars, or 'an act of God'. However, among many Western religious communities illness is blamed on moral error, on not thinking or acting in a spiritual enough way. As one American Christian Scientist explained to McGuire:[46] 'The medical way they don't heal anyone. They just don't heal, because our sense of it is if someone is ill, it's a product of his thinking. And [doctors] don't correct thinking'.

In most cases, as noted above, these lay theories of illness aetiology (like medical explanations) are *multicausal* – that is, they postulate several causes acting together. This means that individual, natural, social and supernatural causes are not mutually exclusive but are usually linked together in a particular case. For example, careless or immoral behaviour may predispose to natural illnesses, divine anger or spirit possession, or an ostentatious lifestyle may attract sorcery or the evil eye. In a study in Emilia-Romagna, Italy, for example, Whitaker[47] found that, in understanding what caused ill-health, people used a combination of traditional models and modern scientific theory: the body was seen as vulnerable to 'germs', but most especially when it was not 'in balance', in terms of the symbolic qualities of 'hot' and 'cold'.

In understanding any specific type of illness, lay EMs within a community often vary in how they explain its aetiology; Blaxter's[48] study of working-class women in Aberdeen, UK, for example, found variation in how some common conditions were explained. Of the 30 working-class women interviewed, eight attributed bronchitis to environmental factors, two attributed it to behaviour, four to heredity, three to 'susceptibility', 10 to being secondary to other conditions and three as the consequence of pregnancy or childbirth. While these were seen as discrete categories in this study, most EMs see illness as multicausal, with elements of several types of aetiology involved in a particular episode of ill health.

CLASSIFICATION OF ILLNESS AETIOLOGIES

Foster and Anderson[49] proposed an alternative way of classifying lay illness aetiologies, especially in non-Western societies. They differentiate between *personalistic* and *naturalistic* systems. In the former, illness is caused by the purposeful active intervention of an agent, such as a supernatural being (a god), a non-human being (ghost, ancestral spirit or capricious spirits) or human being (witch or sorcerer). One could also include modern notions of 'germs' in this category, especially those causing 'fevers'. In naturalistic systems, illness is explained in impersonal, systemic terms. It can be caused by natural forces or conditions such as cold, wind or damp, or by disequilibrium within the individual or the social environment. Included in this 'disequilibrium' group are systems of illness explanation such as humoral or 'hot–cold' systems in Latin America, Ayurvedic medicine in India, and the Yin–Yang system of traditional Chinese medicine. The 'colds' and 'chills' caused by environmental cold could also be included here.

Young[50] classified belief systems about ill health as either *externalizing* or *internalizing*. Externalizing belief systems concentrate mainly on the aetiology of the illness, which is believed to arise *outside* the sick person's body, especially in their social world. Thus, in trying to identify a cause for the individual's illness, people closely examine the circumstances and social events of his life before he fell ill – such as tracing the cause of an illness from a grudge between two people, which led to feelings of resentment, then to some pathogenic act (such as witchcraft or sorcery), which then led on to the illness itself. Many of the lay models of illness aetiology from different parts of the world and described in this chapter can therefore be described as externalizing types of explanations.

In contrast, internalizing belief systems concentrate less on aetiological explanations and more on events that occur (and arise) *inside* the individual's body, and they always emphasize physiological and pathological processes as explanations for how and why some people get ill. This is the perspective of the modern scientific medical model. Its strength lies in its detailed perception of physiological events within the individual body, but its weakness lies in ignoring the social and psychological events that preceded the onset of symptoms – while the reverse is true of the externalizing systems.

Narratives of illness and misfortune

A feature of externalizing explanations for ill health is that they often take the form of a *narrative* or story about how and why that person got ill[51]. In each case the story is presented in a specific *language of distress*, either verbal or non-verbal. A verbal story might include events from the sufferer's life and even events that preceded their birth, such as 'I inherited my weak chest from my father's family'. As Brody[52] pointed out, telling such 'stories of sickness' is a way of giving *meaning* to the experience of ill health, of placing it in the context of the individual's life history. It also relates it to the wider themes of the culture and society in which they live. A narrative is thus a basic way of organizing an experience, especially a traumatic one; of 'making sense of it', and giving it meaning.

Narratives of personal suffering are not only personal. They also draw on the repertoire of language, idiom, metaphors, imagery, myths and legends provided by the culture in which that suffering took place.[51] In that sense they are usually *culture-bound* to some extent – that is, the way people tell the story of their suffering in one culture may be very different from how they tell it in another. Narratives are thus, as Becker[53] describes them, 'cultural documents'. She points out that they come into being at times of unexpected disruption in the flow of everyday life. This implies a concept of an earlier state of 'normality', which may in turn be defined largely in cultural terms. At times of illness or misfortune, therefore, narratives are usually highly personal stories, but expressed in a culturally specific way.

Many narratives are created with the help of other people – with the members of a family, for example, or of a healing cult or a self-help group. In particular, healers of every sort take a major role in helping to construct their clients' narratives. Helping to reveal and then to shape these narratives of misfortune is characteristic not only of medical care but also of most forms of symbolic healing, from shamanism to psychoanalysis (see Chapter 10), and of most religious traditions. In each case, the healer aims to impose a sense of coherent order on the chaos of the patient's symptoms and feelings. Usually, this places individual suffering in a much wider context of time and place, and employs cultural, religious or scientific concepts of cause and effect. In many cases, the new form of the narrative is negotiated between healer and client during the consultation. This shared, syncretic creation is then carried back home, as a sort of 'gift' from the healer to the client. In terms of symbolic healing, the healer's explanation of what has happened and why is often more important to clients than the herbs, prescriptions or other forms of physical treatment that they have been given.

Western medicine is unique in the type of narrative structure that it seeks to impose on its patients. Usually this takes a *linear* form, in keeping with pervasive Western notions of monochronic time (see Chapter 2). This seeks to organize a patient's story – their history – into a linear form, with a clear beginning for events, a sense of duration and an ending at the present time. Questions such as 'When did the pain begin?', 'What happened next?', 'Where did it move to then?', 'What did you do then?' and 'What has happened since I gave you the medicine?' all impose such a linear narrative form, sometimes inappropriately, on patients' experience. Patients who fail to produce a clear oral history are often branded a 'poor historian'. In Western medicine, the doctor's narrative of the patient's experience now takes a standardized form, found in every medical journal, where it is known as the 'case history'.

Unlike in many traditional societies, the patient in Western medicine, as in psychoanalysis, does most of the talking, with the healer asking only the occasional question for clarification. In traditional healing systems, however, the situation is often reversed. The patient offers the healer only a small amount of information – their date and time of birth, for example, or the content of a particular dream – and the healer does most of the talking. In these systems, therefore, the sign of a good healer is one who quickly 'knows' the diagnosis, sometimes with the aid of divination. Their diagnosis is made without having to ask numerous questions, or eliciting a lengthy narrative from the client. To people from these communities, therefore, the sign of a good doctor may be someone who asks very *few* questions – since they should already sense or 'know' the diagnosis by other means.

Non-verbal narratives

Many narratives of suffering are *non-verbal*. Personal suffering may be acted out in terms of a specific pattern of behaviour – for example, withdrawal, silence, self-neglect, changes in clothing, fasting, substance abuse or even violence – over a period of time. Often this performance aspect of narrative is played out more as a mime than as a spoken play. It may take the form of behaviour changes, such as too-frequent consultations with a doctor, constantly missing medical appointments, losing prescriptions, or always taking the wrong dose of medication – all of which can only be 'decoded' over time. In some societies narratives are commonly acted out in the form of a standardized, sometimes very theatrical 'culture-bound syndrome' (see Chapter 10), its meaning clearly understood by other members of the group, but often not by outsiders. In clinical and psychotherapeutic practice, narratives often take the form of particular patterns of physical symptoms revealed over time – especially in the case of *somatization* found in some psychosomatic disorders. In many cultures depression, too, presents mainly as somatic symptoms, rather than as the emotional states of sadness or despair. Part of the task of the clinician then is to understand both the personal and the cultural meanings hidden within these patterns of symptoms. That is, to decode the somatic language in which the narrative of illness may be couched.

Thus, whatever the form they appear in, whether verbal or non-verbal, understanding narratives is an intrinsic part of understanding the nature of human suffering and the many dimensions of illness.

In the following case studies, two folk illnesses, one from the USA and one from the UK, are briefly described. In both cases the folk illness is a cluster of symptoms and signs that are subject to individual and contextual variations, including changes over time.

Case study: 'hyper-tension' in Seattle, USA

Blumhagen's study[54] in 1980, carried out in Seattle at the Veterans' Administration Medical Center, was on patients suffering from hypertension. He discovered a lay EM (explanatory model), held by many of the patients about their condition, termed 'hypertension'. The majority saw their condition as arising from stress or tension in their daily lives – hence hyper-*tension*. In 49 per cent of the sample, chronic external stresses such as overwork, unemployment, 'life's stresses and strains' and certain occupations were blamed for the condition;

14 per cent blamed chronic internal stress, such as psychological, interpersonal or family problems. Fifty-six per cent of the total sample thought that the condition could be precipitated by acute stress, such as anxiety, excitement or anger. In this model, 'hypertension' is characterized by subjective symptoms such as nervousness, fear, anxiety, worry, anger, upset, tenseness, overactivity, exhaustion and excitement. It is brought on by stress, which makes the individual susceptible to becoming 'hyper-tense'. In many cases, patients did not perceive that 'hyper-tension' was the same as high blood pressure, since their model emphasized the psychosocial origin and manifestations of the condition. A smaller number saw 'hyper-tension' as resulting from hereditary or physical factors, such as excess salt, water or fatty foods. Overall, though, 72 per cent believed that hypertension is 'a physical reflection of past social and environmental stressors, which are exacerbated by current stressful situations', and this allowed them to withdraw from familial, social or work obligations – which they saw as sources of tension. They also labelled themselves as 'hyper-tense', even in the absence of medical evidence for hypertension.

Case study: 'colds', 'chills' and 'fevers' in London, UK

The author's own research,[55,56] dealt with a set of commonly held beliefs about 'colds', 'chills' and 'fevers' held by people living in a London suburb, and how these have changed from the 1970s to the present day. In the late 1970s, 'Nature' was seen as a potential cause of disease. 'Colds' and 'chills' were caused by the penetration of the natural environment (particularly areas of cold or damp) across the boundary of skin and into the human body. In general, damp or rain (cold/wet environments) caused cold/wet conditions in the body, such as a 'runny nose' or a 'cold in the head', while cold winds or draughts (cold/dry environments) caused cold/dry conditions, such as a feeling of cold, shivering and muscular aches. Once they entered the body, these cold forces could move from place to place – from a 'head cold', for example, to a 'chest cold'. 'Chills' occurred mainly below the belt ('a bladder chill', 'a chill on the kidneys', 'a stomach chill'), and colds above it ('a head cold', 'a cold in the sinuses', 'a cold in the chest'). These conditions were caused by careless behaviour, by putting oneself in a position of risk *vis-à-vis* the natural environment – for example, by 'walking barefoot on a cold floor', 'washing your hair when you don't feel well' or 'sitting in a draught after a hot bath'. Temperatures intermediate between hot and cold; where the former gave way to the latter, such as going outdoors after a hot bath, or autumn, where hot summer is giving way to cold winter, were specially conducive to 'catching cold'. Because colds and chills were brought about primarily by one's own behaviour, they provoked little sympathy among other people; individuals were often expected to treat themselves by rest in a warm bed, eating warm food ('feed a cold, starve a fever') and drinking hot drinks.

By contrast, 'fevers' were caused by invisible beings called 'germs', 'bugs' or 'viruses', which penetrate the body through its orifices (mouth, nose, ears, anus, urethra and nostrils) and then cause a raised temperature and other symptoms. The causative agents were conceived of as unseen, amoral, malign entities, which existed in and among people, and which traveled between people through the air. Germ infection was therefore an inherent risk of all social relationships. Some of these germs, such as 'tummy bugs', were thought of as almost insect-like, though of a very small size. Germs also had 'personalities' of symptoms and signs, which revealed themselves over time ('I've got that germ, doctor, you know – the one that gives you the dry cough and the watery eyes'). Unlike with colds, the victims of a fever were blameless, and could mobilize a caring community around themselves. The germs responsible for these conditions could be flushed out by fluids (such as cough medicines), starved out by avoiding food or killed in the body by antibiotics, though in the latter case no differentiation is made between 'viruses' and 'germs'. These lay beliefs about the colds/chills/fevers range of illnesses could thus affect behaviour, self-medication and attitudes towards medical treatment in both adults and children.

Since the 1970s, the model has changed considerably.[56] Although in 2003 these beliefs were still held among many older people, there has been a significant shift in how younger people explain these minor respiratory infections. The two sets of opposites in the original 'feed a cold, starve a fever model' – colds, Nature, and self-blame on one side and fevers, social relationships ('Society') and innocence on the other – have now synthesized into a single, composite model. Now Nature is seen not as a source of infection, but as a positive, health-giving force – and one that is under threat from our modern, industrialized lifestyle. This shift is evident in the new vocabulary of 'natural' or 'organic' as positive qualities, especially in foods and in types of healing. It is now Society – that is, other people – that is now seen as potentially dangerous to the individual, and as a source of ill-health. Blaming illness on 'germs' from other people, rather than on the natural world, has now spread to cover almost all the common colds and chills (as well as fevers), as well as many other conditions. The effect of this shift is to make the ill people feel less guilty for their illness, and see themselves instead as the blameless victim of some external force. This shift in perception also matches several other ways that young people now increasingly blame their misfortunes on others, such as their parents, their teachers, their spouses, their employers, or the state. 'Colds' and 'chills' have thus become a much more *social* concept, an image which seems to express an underlying anxiety about the dangers inherent in all human relationships – especially in the over-crowded cities, apartment blocks, trains and subways of modern life.

Furthermore, this metaphor of invisible 'infection' from others causing illness and misfortune is increasingly used to explain many of the *other* aspects of modern life over which people feel they have no control (a cultural phenomenon I call 'germism').[57] Civil unrest, crime, inflation, terrorism, divorce are now often described in the media as reaching 'epidemic proportions', as if they were somehow caused by invisible, capricious pathogens, outside of their victims' control. Despite all the modern emphasis on individuality and autonomy, this passive model of misfortune seems often to apply at the individual level as well.[58]

CHILDREN'S PERCEPTION OF ILLNESS

Within any community, different groups – depending on age, gender, education, ethnicity, religion and social position – often have very different perceptions of illness. Recent research has focused on *children* and on how they perceive and experience illness and medical care.

The research suggests that, despite their age, children *do* have their own unique understandings of illness, what causes it and how it should be treated. Like adults, they speculate about why and how it has happened to them, and why at that particular time. Their EMs are usually a blend of ideas derived from personal experience and family influences, from school and the media. In most cases these perceptions of illness duplicate those of adults, but sometimes they are very different.

In Europe, a considerable amount of data on the subject has come from a large multinational study carried out between 1990 and 1993 on children aged 7–12 years, and funded by the European Union. Known as the COMAC Childhood and Medicines Project,[59,60] it examined children's experience of illness and medicines in nine European countries. The research methods included a drawing-interview, where the children were each asked to make a drawing of the last time that they were ill and then interviewed about the content and meaning of the drawing. The results showed interesting differences, but many similarities, between the different countries.

The most common symptoms described by the children were those associated with fever, headache, dizziness or rash. Their drawings portrayed themselves as the central figure in the drama of illness, often surrounded by familiar persons or objects. Trakas[61] pointed out that their drawings often give a sense of isolation or loneliness, or of boredom, anxiety or sadness. They show a solitary figure lying in bed, 'entirely alone, seemingly passively waiting for "something" to change their state'.[61] Unlike adults, however, the children's experience of illness was not all bad. Although they described a series of negative sensations (such as pain, or fever) associated with the illness, they also described many positive experiences (such as watching television or videos, getting sweets and toys, having visitors and getting a lot of attention). While visitors were generally welcome, too many caused anxiety, as they were seen as a sign that the illness was serious. In almost all cases, the children emphasized the key role of their mother as the main caregiver. In Botsis and Trakas's study[62] in Athens, Greece, for example, their mothers were drawn 'serving hot tea, asking if juice was wanted, holding thermometers in their hand, and bringing flowers'. In contrast, fathers were hardly ever portrayed (a similar finding to the Spanish study). However, the doctor – whether male or female – was a prominent figure in many of the drawings.

Like adults, the children theorized about why they got ill. Illness was seen as something sudden and unexpected, that 'just happens', often without any reason. Their explanations for its origin – often complex and multicausal – showed how many cultural models (such as the germ theory) they had already absorbed from the adult world around them. These included concepts of the role of 'germs', contagion, cold weather, diet, and their own lifestyle or behaviour. Social causes were only occasionally mentioned, although one girl in Athens speculated that she had got stomach ache because of a spoiled cheese pie given to her by an aunt who disliked her mother. Unlike adults, though, the children usually did not ascribe their illness to supernatural, religious or similar causes.[63]

Climate and the weather were often blamed for causing illness. In their study of 100 children in Spain (Madrid and Tenerife), Aramburuzabala and colleagues[64] found that cold weather was frequently seen as a cause of illness – especially after doing 'something wrong', such as 'walking without my shoes'. Ideas of contagion were also common, and terms such as 'germs' and 'viruses', and 'picking up a germ' were freely used: 'Someone coughs and he gives me his germs; when you breathe, germs get into your body through your nose and mouth; germs are little animals that get inside and make you sick ... colds and things like that'.

In Finland[63], the 7–10-year-olds interviewed in Jyväskylä also revealed how far they had adopted the adult microbiological model, often blaming their illness on contagion by invisible entities called 'bacteria', 'viruses' or 'bugs' – terms that they used interchangeably. One child described bacteria as 'such little things that we people do not see as they are too small'. Like other European children, they also related illness to their own behaviour ('staying too long out in the cold') as well as climatic conditions (cold, damp, rain, snow). Although illness was seen as an interruption in their normal social relationships, it also brought them closer to their parents and got them more attention.

In Holland (Amsterdam and Groningen), Gerrits and colleagues[65] also found close agreement between the views of schoolchildren and those of their parents. Both shared an emphasis on body temperature and the central role of fever in defining whether a child was ill or not and whether to call the doctor. However, the parents differed among themselves in what level was dangerous, the range varying between 38.5°C and 41°C (101.3–105.8°F).

Overall, Vaskilampi and colleagues[63] pointed out that the children's view of health is a holistic, multidimensional one, incorporating physical, psychological and social elements in it. For this reason they tended to see illness in functional terms: as not being able to *do* things.

The COMAC study revealed that childrens' attitudes to *medication*, both prescribed and over-the-counter, varies quite widely, although usually it is quite positive. As one Spanish child put it, 'Medicine advances and kills the microbes, which are bacteria. You get the bacteria and it harms your body; the medicine kills them'. The researchers believed that this attitude matches what, in their view, is the overuse of medication in many Spanish households.[64] Elsewhere in Europe, and especially in Holland,[65] some children were more sceptical about medication than their parents. Some thought taking medicines was less important for their recovery than resting, while others were afraid of their side effects ('A lot of medicines are not right. Something gets better, but at the same moment something else gets worse').

Reviewing the COMAC study, van der Geest[66] noted four themes common to most of the European studies:

1. Children's experiences of illness are expressed by how they describe the medicines they were prescribed. For example, they remember a sweet taste if their experience of illness was positive (such as being pampered and spoilt), but a bitter taste if they were bored and lonely.
2. In many of their accounts of their illness, children never mentioned that they were given medicines. Other aspects of treatment, such as rest and attention, are more important to them. Usually they see illness in *social* terms; as a time when they enjoy special care and attention from other people. Thus, unlike adults, they often welcome the increased dependency of ill health, which gets them more care than they are usually entitled to.
3. In illness, medicines communicate to children the powers that adults hold over them. As substances forbidden to children, except with adult supervision, they are ways of representing the boundary between child and grown-up – symbols of power and adulthood.
4. The thermometer, as a ritual symbolic object, plays an important part in marking the boundary between health and illness.

Other recent studies have indicated that a major difference between adults and children lies in the perception of *time*, since both experience life within very different timeframes. James and colleagues,[67] and others, have pointed out the many ways that adults impose their own timeframes on children and how, in the home, the temporal rhythms of the child are dictated by family routines, which impose mealtimes and bedtimes on them. Beyond that, there is also the annual cycle of birthdays, major family events, vacations, and national and religious festivals. Later on, numerous other rhythms will impose themselves on the child, often against his or her will. These include the cycle of childhood vaccinations, and then of school timetables, with their rigid control by linear (or monochronic)[68] clock time (see Chapter 2). Also, children's notions of the future and the past are very different from those of adults. One reason why health-promotion campaigns about not smoking, drinking or practising safe sex often have very little impact is because children's ideas of 'distant time' (when these 'bad behaviours' will begin to affect then) are so blurred that they have such little reality for them. Telling a child or adolescent that in 30 or 40 years' time they will develop lung cancer from smoking, or liver damage from alcohol abuse, is a meaningless concept, since they have not lived '30 or 40 years', and have no experience of what that feels like.

Illness therefore highlights these differences in the perception of time. Parents (and doctors) see illness in discrete timeframes, which they use as a way of measuring its danger and severity. These notions determine when to call the doctor if there is no improvement: 'take this aspirin, and let's see if you feel better in half an hour'. Conversely, 'young children's conception of sickness is ... primarily an experience without time limits; whether it is of short or long duration, it is the event of sickness itself, with its associated dramas, which is important'.[67] Because illness has an immediate effect, the child wants immediate relief. In some ways, this experience of illness time is similar to Hall's model[68] of 'polychronic' time (see Chapter 2), where time is experienced not in a linear monochronic way, but as a special point at which events and relationships converge.

Finally, other research indicates that children's perceptions of their doctors can be based on very idiosyncratic criteria. For example, one British study[69] found that children saw formally dressed paediatricians as competent but not friendly, but casually dressed paediatricians as friendly but not competent.

These and other studies therefore indicate that doctors and parents should acknowledge and respect children's views of their illness, even if these views are sometimes 'unexpected and amazing'.[61] Like adults, their ideas often have a very clear internal logic, even if they are not scientific. The studies indicate that, in general, children *are* able to recognize abnormal symptoms and understand much of what their doctors say to them. Children – even younger children – are not merely passive spectators of their own ill health. Where appropriate, it is important to give them explanations that make sense to them, in terms of their own unique frame of reference. As Trakas[61] concludes, 'Children who are able to communicate with their health-care providers will grow into adults who can do the same'.

THE DOCTOR–PATIENT CONSULTATION

Against this background of medical beliefs about disease, and lay beliefs about illness, three aspects of the doctor–patient interaction can be viewed:

1. Why do people decide (or not decide) to consult a doctor when ill?
2. What happens during the consultation?
3. What happens after the consultation?

REASONS FOR CONSULTING, OR NOT CONSULTING, A DOCTOR

Several studies have examined the reasons why some ill people consult a doctor while others with the same complaint do not. Often this is because people simply cannot afford to pay for medical care, or because medical care is not available to them. However, even when they *can* afford it there is often little correlation between the severity of a physical illness and the decision to seek medical help. In some cases this delay can have serious consequences for the person's health. Other studies have shown that abnormal symptoms are common in the population, but that only a small percentage of them are brought to the attention of doctors. There are therefore a number of *non*-physiological factors that influence what Zola[70] terms the 'pathways to the doctor'. These include:

1. The availability of medical care.
2. Whether the patient can afford it.
3. The failure or success of treatments within the popular or folk sectors.
4. How the patient perceives the problem.
5. How others around him or her perceive the problem.

Obviously the sparse availability of medical care in many parts of the world, and the inability to pay for what care there is (or for medications, special diets, or transport to a clinic), are crucial in determining whether people consult a doctor or not; as is the failure of non-medical care to cure or reassure the individual patient. In this section, however, only the last two points, and the relationship between them, will be discussed.

The process of becoming 'ill' has already been described, particularly the definition of some symptoms as abnormal by patients and their families. Zola[70] has pointed out that this definition depends on how common the symptom is in their society, and whether it fits with the major values of that society or group. A symptom that is very common may be considered normal (though not necessarily good or desirable) and therefore be accepted fatalistically; for example, Zola found that tiredness is often considered to be normal, even though it is sometimes a feature of severe illness.[70] In the study of 'Regionville' mentioned previously, backache was considered to be a normal part of life, at least by the lower socio-economic groups. The second point is that symptoms and signs must *fit* with society's view of what constitutes illness in order to gain sympathetic attention, and for treatment to be arranged. The same symptom or sign might be interpreted differently, therefore, by different groups of individuals, as illness in one or as normal in another. In both cases, the definition of ill health depends on the underlying concept of health, which, as noted earlier, often includes social, behavioural or emotional elements.

Zola[71] has also examined how this wider definition of health affects patients' decisions to consult a doctor. In the mid-1960s he interviewed more than 200 American patients from three ethnic groups – Irish-Americans, Italian-Americans and Anglo-Saxon Protestant Americans – attending outpatient clinics in two Boston hospitals. The study aimed to find out why they had decided to consult a doctor, and how they communicated their distress to him. It was found that there were two ways of perceiving and communicating one's bodily complaints: either 'restricting' or 'generalizing' them. The first was typical of the Irish, the second of the Italians. The Irish focused on a specific physical dysfunction (such as poor eyesight or ptosis), and restricted its effect to their physical functioning. The Italians displayed many more symptoms, and a more 'global malfunctioning' of many aspects of their body, appearance, energy level, emotions, and so on. In their perception, the physical symptoms (such as poor eyesight) interfered with their general mode of living, their social relationships and their occupations.

On this basis, Zola[71] was able to identify five non-physiological 'triggers' to the decision to seek medical aid:

1. An interpersonal crisis.
2. Perceived interference with personal relationships.
3. 'Sanctioning'; that is, one individual taking primary responsibility for the decision to seek medical aid for someone else (the patient).
4. Perceived interference with work or physical functioning.
5. The setting of external time criteria ('If it isn't better in three days ... then I'll take care of it').

The first two patterns draw attention to the symptom, by signifying that there is 'something wrong' in the patients' daily lives; this pattern was common among the Italians. The third pattern was common among the Irish, and illustrates the social dimensions of illness ('Well I tend to let things go but not my wife, so on the first day of my vacation my wife said, "Why don't you come, why don't you take care of it now?" So I did'). The functional definition (the fourth pattern) of health was common among both Irish and Anglo-Saxon groups (cf. Blaxter and Paterson).[11] The fifth pattern was common among all the groups, and echoes the adult perception of time described above.

This study illustrates that decisions to consult a doctor may be related to socio-cultural factors, such as wider definitions of health, rather than to an illness's severity. Zola noted that in any community unexplained epidemiological differences may result from the differential occurrence of these factors, which reflect the 'selectivity and attention which get people and their episodes into medical statistics, rather than to any true difference in the prevalence and incidence of a particular problem or disorder' (see Chapter 15).

Apple[13] pointed out the dangers of defining a symptom as illness only when it interferes with usual activities and is of fairly recent onset. It means that more chronic, insidious conditions, such as heart disease, hypertension, cancer or HIV infection, may not be defined as abnormal, provided that one can carry on with daily life. Other reasons for the delay in seeking medical advice have been studied at the Massachusetts General Hospital in Boston: Hackett and colleagues[72] examined the delay between the first sign or symptom of cancer and the search for medical help in 563 patients. Only 33.7 per cent were 'early responders' and consulted within the first 4 weeks, while two-thirds waited over a month; 8 per cent of the sample avoided medical help until they could no longer function independently, and only then did they 'yield to family or community pressure and receive medical help'. The role of emotional factors was important: people who worried more about cancer tended to delay seeking help more than non-worriers, and it was hypothesized that the reason for the delay might be to avoid hearing a fatal diagnosis. The label given to the illness also affected the delay; labelling it candidly as 'cancer' led to a quicker response. In general, patients from higher socio-economic levels delayed a shorter time than those from poorer classes, although 'there is little evidence that cancer education programmes *per se* can be credited for this difference'. In a similar study, Olin and Hackett[73] studied 32 patients with acute myocardial infarction; most had explained away their chest pain as resulting from less serious conditions, such as indigestion, lung trouble, pneumonia or ulcer, despite the fact that they were familiar with the symptoms of coronary heart disease. The immediate response was denial, which was 'the consequence of an emotional crisis induced by chest pain and the menacing associations it evokes'. In the majority of cases, only increasing incapacity or the persuasion of family or friends led them to seek medical help.

Whether medical care is utilized – provided, of course, that it is available and affordable – depends also on the perceived *cause* of the condition and whether it is believed to originate in the individual, or in the natural, social or supernatural worlds. Some groups consider medicine is better at treating symptoms than eliminating the cause, especially if it is supernatural. In a study[74] of five ethnic groups in Miami, for example, patients sought symptomatic relief from a medical doctor but expected a folk healer to explain the cause in culturally familiar terms (such as witchcraft), and then to treat it by mystical means.

In all the above cases, a number of non-physiological factors (social, cultural and emotional) influence whether ill people or their families seek medical help or not. These factors also influence how this illness is presented in the doctor–patient consultation.

THE PRESENTATION OF ILLNESS

The way in which different individuals, social and cultural groups, use different *languages of distress* in communicating their suffering to others, including to doctors, has been described earlier. A clinician who is unable to decode this language, which may be verbal or non-verbal, somatic or psychological, is in danger of making the wrong diagnosis and providing the wrong sort of treatment. For example, in Zola's study in 1966,[71] the Italian-Americans presented their illness in a more voluble, emotional and dramatic way, complaining of many more symptoms, and stressing its effect on their social circumstances. In contrast, the Irish tended to underplay their symptoms. Where no organic disease was found, the physicians tended to diagnose the Italians as having neurotic or psychological conditions, such as tension headaches, functional problems or personality disorders, while the Irish were given a neutral diagnosis such as 'nothing found on tests', without being labelled neurotic. At the same time, the Irish stoicism in the presentation of illness could lead to more serious conditions being missed. In an early paper by Zborowski,[75] the findings were similar: in his study of responses to pain by Irish-American, Italian-American and Jewish-American patients in New York he found that the more emotional the language of distress, the more likely the patient was to be wrongly labelled as 'neurotic' or 'overemotional'.

The presentation of illness may also be learned from doctors, as well as from the media, especially by patients with chronic diseases. They learn to display the typical clinical picture that the doctors are looking for. In the author's study[76], a man who was mistakenly diagnosed as having angina from 'heart trouble' developed psychosomatic chest pain, and this gradually came to resemble 'real' angina the more contact he had with clinicians, especially cardiologists. This 'symptom choice', in the absence of physical disease, has been described by Mechanic[77] in the case of 'medical students' disease', a form of hypochondria believed to afflict up to 70 per cent of medical students. As they learn about the various diseases, they frequently imagine they are suffering from them and even develop their typical symptoms and signs. This is because the stressful conditions of medical school cause many transient symptoms in the students, and those 'diffuse and ambiguous symptoms regarded as normal in the past may be reconceptualized within the context of newly acquired knowledge of disease'. This may influence the patterning and presentation of their symptomatology. This, then, is an example of the language of distress acquired from the medical profession – a situation that is becoming increasingly common as people become more knowledgeable about health issues.

PROBLEMS OF THE DOCTOR–PATIENT CONSULTATION

The clinical consultation, as Kleinman[16] has noted, is a transaction between lay and professional EMs. It is also, however, a transaction between two parties separated by differences in *power*, both social and symbolic. This power differential may be based on social class, ethnicity, age or gender, and is a crucial influence on any consultation.

Although the consultation is characterized by ritual and symbolic elements, its manifest functions are:

1 The presentation of 'illness' by the patient, both verbally and non-verbally.
2 The translation of these diffuse symptoms or signs into the named pathological entities of medicine; that is, converting 'illness' into 'disease'.
3 The prescription of a treatment regimen that is acceptable to both doctor and patient.

Some of its more latent functions, especially in relation to social control, have already been discussed in the previous chapter. In order for the consultation to be a success, there must be a *consensus* between the two parties about the cause, diagnostic label, physiological processes involved, prognosis and optimal treatment for the condition. The search for a consensus – an agreed interpretation of the patient's condition – has been called 'negotiation' by Stimson and Webb.[78] In this process, each tries to influence the other regarding the outcome of the consultation – the diagnosis given and the treatment prescribed. Patients may try to reduce the seriousness of a diagnosis, or the severity of a treatment regimen, for example. In particular, they may strive for diagnoses and treatments that make sense to them in terms of their lay view of ill health, such as the appeal for 'tonics' or vitamins in the UK, which have deep roots in traditional medicine. The consultation is also a social process, whereby the ill person acquires the social role of patient, with all the rights and obligations that this entails. It should always be remembered, however, that achieving a consensus between doctor and patient is no guarantee in itself that the diagnosis will be correct, or that the treatment offered will be effective.

Within the consultation, one can isolate a number of recurring problems that interfere with the development of consensus. These problems, many of which have already been described, include the following.

Differences in the definition of 'the patient'

Western medicine tends to focuses increasingly on the *individual* patient[36] (or even on an individual organ or body system), but it may be the family, the community or even the wider society that are pathological, and not the individual. An inappropriate focus only on the individual and his or her symptoms, while ignoring wider familial, social and economic issues, may make both a consensus and a solution to the problem difficult to achieve. Modern family therapy thus emphasizes the role of the family in causing, and maintaining, certain types of mental or behavioral disorders in children, and therefore that for a solution to this problem the family, as well as the child, also has to undergo treatment.

Misinterpretation of patients' 'languages of distress'

These are clearly illustrated in the studies of Zola,[71] Apple[13], Mechanic[77] and Zborowski[75], and in the case of many of the 'culture-bound syndromes'. This phenomenon is more likely if the doctor and patient come from different cultural or religious backgrounds, or socio-economic classes, though it can also arise if doctor and patient are of different age groups or gender. A common example is the misinterpretation of somatization (see Chapters 7 and 10) as evidence of physical disease, or hypochondria, or of an absence of psychological 'insight'.

Incompatibility of explanatory models

Medical and lay models may differ greatly in how they interpret a particular illness episode, especially its cause, diagnosis and appropriate treatment. For one thing, they are often based on different understandings of the structure and function of the body. For example, many Western-trained doctors working in a rural setting in the non-industrialized world may have difficulty in understanding supernatural and interpersonal explanations of ill health, or definitions of good health as moral or social 'balance'. The sometimes limited disease perspective of modern medicine, with its emphasis on quantifiable physical data, may ignore the many dimensions of meaning – psychological, moral or social – that characterize the illness perspective of the patient and those around him or her. Thus the doctor, who concentrates only on diagnosing and treating physical dysfunction, may not take emotional states such as guilt, shame, remorse or fear on the patient's part into account.

Disease without illness

This is an increasingly common phenomenon in modern medicine, with its emphasis on the use of diagnostic technology (see Chapter 4). Physical abnormalities of the body are found, often at the biochemical or cellular levels, but the patient does not feel ill. Examples of this are hypertension, raised blood cholesterol, cervical carcinoma *in situ*, or HIV infection, which are found on routine health screening programmes. People who are asymptomatic may not make use of these programmes, or may refuse treatment if an abnormality is found ('But I don't *feel* unwell'). This may also explain much of the reported non-compliance with prescribed medication; for example, a person prescribed a 1-week course of antibiotics may stop taking them after 2 or 3 days because they feel much better.

Illness without disease

Here the person feels that 'something is wrong' in their life – physically, emotionally, socially or even spiritually – but despite their subjective state they are told, after a physical examination and tests, that 'there is nothing wrong with you'. However, in many cases they continue to feel unwell or unhappy. Many of these people can be called the 'worried well'. Also included here are the many unpleasant emotions or physical sensations for which no physical cause can be found, many of them arising from the difficulties and strains of everyday life: the various 'psychosomatic' disorders (such as irritable colon, spasmodic torticollis, hyperventilation syndrome or Da Costa's syndrome); hypochondria (such as 'medical students' disease'); and the wide range of folk illnesses (such as 'spirit possession', *susto* or 'high blood'). In each of these cases the illness plays an important part in the patient's life and in the lives of their family, and reassurance that nothing is wrong physically may not be enough to treat it, as illustrated in the following case history.

Case study: illness without disease, London, UK

Balint[79] described the case of Mr U, aged 35 years, a skilled workman who was partly disabled as a result of having contracted polio in childhood. Nevertheless, he had managed to work, 'over-compensating his physical shortcomings by high efficiency'. One day he received a severe electric shock at work and was knocked unconscious; no organic damage was found at the hospital, and he was discharged. He then consulted his family doctor for pains in all parts of his body, which were getting worse and worse, and he 'thought that something had happened to him through the electric shock'. Despite exhaustive tests, no physical abnormality was found, but Mr U still experienced his symptoms: 'They seem to think I am imagining things: I know what I've got'. He still definitely felt ill and wanted to know what condition he could have causing all these pains. Despite more hospital tests that were negative, he still felt himself to be ill. In Balint's view, he was 'proposing an illness' to the doctor, but this was consistently rejected; the doctor's emphasis was not on the patient's pains, anxieties, fears and hopes for sympathy and understanding, but on the exclusion of an underlying physical abnormality.

Problems of terminology

Clinical consultations are usually conducted in a mixture of everyday language and medical jargon. However, the language of medicine itself has become more and more technical and esoteric over the past century or so,[80] and increasingly incomprehensible to the lay public. Where medical terms *are* used by either party, there is often a danger of mutual misunderstanding; the same term, for example, may have entirely different meanings for doctor and patient. In a study in 1970, Boyle[81] found that doctors and patients interpreted common medical terms such as stomach, heartburn, palpitations, flatulence or lungs in very different ways. The marked variations between the two groups could have important clinical implications, especially since many consultations include questions such as, 'Do you have pain in your stomach?' (which 58.8 per cent of the patients thought occupied their entire abdominal cavity). Similarly, a study by Pearson and Dudley[82] also showed major misunderstandings of terms such as gallbladder, stomach or liver. They pointed out that patients awaiting cholecystectomy could become extremely anxious if (like some of the sample) they believed that the gall-*bladder* was concerned with the storage of urine. Blumhagen's study[54] on lay beliefs about the meaning of 'hyper-tension' also found them to be different from medical definitions of hypertension. In the study of lay beliefs about 'germs' and 'viruses' quoted above, these bore little relation to their description in microbiology; both were considered vulnerable to antibiotics, and these drugs were demanded even if the diagnosis was of a 'viral infection'. The use of the same terminology by doctor and patient is *not*, therefore, a guarantee of mutual understanding as the terms, and their significance, may be conceptualized by both parties in entirely different ways.

Patients' use of specialized folk terminology may also confuse the clinician: statements such as 'I have been hexed' or 'a spirit has made me ill' may be incomprehensible to doctors unless they are aware of lay theories of illness causation. The same applies to self-labelled folk illnesses such as *susto*, 'heart distress' or 'brain fag', especially where the clinician comes from a different social or cultural background.

Questions in the consultation that are designed to uncover emotional distress may also involve problems of terminology. For example, Leff,[83] in a study in London, compared psychiatrists' and patients' concepts of unpleasant emotions. It was found that the psychiatrists clearly differentiated between anxiety, depression and irritability as discrete types of emotional distress, while the patients saw them as closely overlapping. To the patients, somatic symptoms such as palpitations, excessive perspiration or shakiness were considered to be as characteristic of 'depression' as of 'anxiety'. This would clearly influence how patients responded to specific questions such as, 'Do you feel depressed?' or 'Do you feel anxious?' Again, ignorance of how patients conceptualize and label ill health can lead to misinterpretation of symptoms during the consultation.

Problems of treatment

In order for medical treatment to be acceptable to patients, it must make sense in terms of their EMs. Consensus here about the form and purpose of treatment is as important as consensus about the diagnosis. This is particularly important if the treatment involves unpleasant physical sensations or side-effects, where it induces, in effect, a form of temporary 'illness'. This is the case in surgery, injections, radiotherapy, chemotherapy and certain diagnostic tests such as biopsies and sigmoidoscopy. Prescribed medication may not be taken if it is perceived to cause illness or, as in the case of asymptomatic hypertension, if the patient does not feel at all ill. A medication may also not be taken if relatives or friends have previously had side-effects from it. Another problem, mentioned elsewhere, is that the use of self-prescribed medicines is common in combination with the use of prescribed drugs; people may use both in ways that make sense to them in terms of their own view of ill health. The phenomenon of *non-compliance* has been estimated, in the UK, as 30 per cent or more.[84] In one UK study by Waters and colleagues[85] in 1976, out of 1611 prescriptions issued by general practitioners, 7 per cent were not even presented to pharmacists. The misuse of prescribed medication, based on specific lay beliefs, has been described by Harwood[86] among a group of Puerto Ricans in New York City (see Chapter 3). They divided all illnesses, foods and medicines into three groups: hot, cold and (sometimes) cool. Penicillin was regarded as a 'hot' drug, and was appropriate for prophylactic treatment in rheumatic heart disease (a 'cold' illness). If, however, an individual had diarrhoea or constipation ('hot' conditions), they would immediately break off penicillin treatment. In pregnancy, 'hot' foods or medications were also avoided in case they caused 'hot' illnesses, such as rashes or red skin, in the baby; because iron supplements or vitamins were 'hot', they might also be refused. Similar avoidance of certain foods or medicines classified as 'hot' have been found in many other communities elsewhere in the world.

The *success* of a treatment or medication is often evaluated very differently by doctors and their patients. The disappearance of an identifiable physical disease may not be accompanied by the disappearance of illness, though this situation can be reversed. For example, Cay and colleagues[87] examined patients' assessment of the results of surgery for peptic ulcers and compared these with the assessments of their surgeons, and found marked discrepancies between the two. Doctor-determined criteria of success, such as acid reduction, absence of diarrhoea, freedom from recurrence or completeness of antrectomy or vagotomy, differed from those of patients, who used quality of life criteria such as the effect on family life, social life, work, sex and sleeping habits. A successful operation in the eyes of the surgeon was sometimes seen as a failure by the patient, especially if it had interfered with any of these aspects of quality of life. That is, 'a bad result ... is determined more by psychosocial than physical evidence of failure'. Conversely, operations that the surgeons regarded as failures – owing to residual symptoms of diarrhoea, for example – were regarded as a success by patients, and the residual symptoms 'a price worth paying' for the absence of severe and unpredictable ulcer symptoms. In both cases an underlying functional definition of health can be hypothesized, against which the success of the operation was judged.

The role of context

A final but very important source of problems in the doctor–patient consultation is the role played by the *context* of the consultation itself. There are two aspects to this context, both of which play a crucial role in the doctor–patient relationship:

1. An *internal context* of the prior experience, expectations, cultural assumptions, explanatory models and prejudices (based on social, gender, religious or racial criteria) that each party brings to the clinical encounter.[88]
2. An *external context*, which includes the actual setting in which the encounter takes place (such as a hospital, clinic or doctor's office) and the wider social influences acting upon the two parties. These include the dominant ideology, religion and economic system of the society, as well as its divisions and social inequalities based on class, gender or ethnicity. All of these factors help to define who has power in the consultation and who does not. Of key importance here is the role of economic and social inequalities – particularly the differences in power between doctor and patient.

The sum of these two types of contexts can greatly influence the types of communication possible between doctor and patient, for they help to determine what is said in the consultation, how it is said, and how it is heard and interpreted.

THE DOCTOR–PATIENT RELATIONSHIP: STRATEGIES FOR IMPROVEMENT

This chapter has outlined some of the potential differences in medical and lay perspectives on ill health – between models of disease and those of illness – and some of the problems that this raises in the consultation. Six main strategies can be suggested to deal with these problems:

1. Understanding illness.
2. Improving communication.
3. Increasing reflexivity.
4. Treating illness *and* disease.
5. Respecting diversity.
6. Assessing the role of context.

UNDERSTANDING 'ILLNESS'

As well as searching for disease, the clinician should try to discover how patients and those around them view the origin, significance and prognosis of the condition, and also how it affects other aspects of their lives – such as their income or social relationships. The patient's emotional reactions to ill health (such as guilt, fear, shame, anger or uncertainty) are all as relevant to the clinical encounter as physiological data, and sometimes more so. The patient's EM of their ill health, and those of their family, should be elicited by obtaining answers to the seven questions listed in the The Explanatory Model section earlier in this chapter. Information should also be gathered about the patients' cultural, religious and social background, their economic status, previous experience of ill health and hopes and fears, and, if possible, their view of misfortune in general, in order to put their explanations for ill health in a wider context.

IMPROVING COMMUNICATION

The clinician should acquire knowledge of the specific language of distress used by the patient, especially the presentation of culturally specific folk illnesses. There should also be an awareness of the problems of terminology mentioned above, especially the misinterpretation of medical terms. The clinician's diagnosis and treatment must *make sense* to the patients, in terms of their lay view of ill health, and should acknowledge and respect the patients' experience and interpretation of their own condition. As stated by Mechanic[77], 'The efficacy of the doctor's interpretations of his patient's problems will depend on the extent to which they are credible in terms of the patient's experience and the extent to which he anticipates the patient's experiences and... the patient's reactions to symptoms and treatment'. However, as noted earlier, while good communication is essential, it does not in itself guarantee good medical care.

INCREASING REFLEXIVITY

Successful doctor–patient communication is not really possible without a heightened sense of self-awareness (or "reflexivity'),[89] on the doctor's part, in all clinical encounters. Whether in making a diagnosis or prescribing treatment, the clinician should always reflect on the role of his or her *own* social and personal background, especially culture, economic status, gender, religion, education, experiences, prejudices and professional power – in either improving or diminishing both communication with patients and effective health care. That is, they should be aware of, and where possible diminish, the possibility of *cultural counter-transference*. Doctors are not only the standardized products of medical schools and their disease perspective, their perceptions are personal, idiosyncratic and cultural as well as professional. For this reason it is important to emphasize that one cannot really understand other people's inner motivations and beliefs without, to some extent, understanding one's own.

TREATING ILLNESS AND DISEASE

Medical treatment should never deal solely with physical abnormalities or malfunctions. The many dimensions of illness – emotional, social, behavioural, religious – should also be treated by adequate explanation and reassurance in terms that make sense to the patients and those around them. Where necessary, treatment may have to be shared with a psychotherapist, counsellor, priest, alternative practitioner, social worker, self-help group, community organization, housing or employment agency or even, in some settings, with a culturally sanctioned folk healer. In this way *all* dimensions of the patient's illness can be treated, as well as any physical disease.

RESPECTING DIVERSITY

Clinicians need to acknowledge that the Western medical model of ill health is not the only valid one available. They have to recognize that there are many other ways, world-wide, of interpreting human suffering, and many different ways of relieving it. Furthermore, some of these have distinct advantages over the biomedical model, although others do not. This should imply a respect for the diversity of health beliefs and practices found in different countries, communities and individuals. It also involves seeing biomedicine in proportion – as just one part (albeit a very successful and important part) of a world-wide system of pluralistic health care.

ASSESSING THE ROLE OF CONTEXT

In order to understand any doctor–patient interaction, the role of both the internal and external *contexts* described above should always be assessed. It is particularly important to understand those external contexts – such as social and economic factors (including poverty, discrimination, deprivation, racism, unemployment, overcrowding and gender roles) and environmental factors (such as pollution, overpopulation, shortage of health-care facilities and contaminated water supplies) – that may contribute to the origin, presentation and prognosis of ill health. A consideration of context also helps the clinician to decide who is the real patient, and whether the focus of diagnosis and treatment should be on sick individuals, their family, their community, or the wider society in which they live.

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