Disease versus illness in general practice

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SUMMARY. Two different, though interrelated, conceptions of ill-health—disease and illness—are described. Recent literature on this disease/illness model is reviewed, and the value of this approach to general practice is shown.

Introduction

The terms 'disease' and 'illness' are used by medical anthropologists to describe the different views of ill-health held by doctors and their patients. The analytical distinction between the two terms has been made by a number of authors (Fox, 1968; Fabrega, 1973, 1975; Eisenberg, 1977; Cassell, 1978; Kleinman et al., 1978; Kleinman, 1980), yet they are not separate entities, but rather explanatory concepts or models which to some extent overlap. As Eisenberg notes, such models are ways of constructing reality, of imposing meaning on the chaos of the phenomenological world. In the case of ill-health, the explanatory models that patients use to explain what has happened, and which determine their behaviour, may bear little relation to those of the medical profession (Snow and Johnson, 1977; Helman, 1978, 1980; Kleinman et al., 1978; Snow et al., 1978; Blaxter and Paterson, 1980); this may have important clinical implications.

Disease

In the scientific paradigm of modern medicine, disease refers to abnormalities of the structure and function of body organs and systems (Eisenberg, 1977). Diseases are the named pathological entities that make up the medical model of ill-health, such as diabetes or tuberculosis, and which can be specifically identified and described by reference to certain biological, chemical or other evidence. In a sense, diseases are seen as abstract 'things' or independent entities which have specific properties and a recurring identity in whichever setting they appear. That is, they are assumed to be universal in their form, progress and content. Their aetiology, symptoms and signs, natural history, treatment and prognoses are considered to be similar in whatever individual, culture or group they occur (Fabrega, 1973; Eisenberg, 1977; Cassell, 1978; Kleinman, 1980). The universality of the form of a disease is related to the medical model's definitions of health and normality. In many cases, it is assumed that normality can be defined by reference to certain physical and biochemical parameters such as weight, height, haemoglobin level, blood counts, levels of electrolytes or hormones, blood pressure, heart rate and so on. For each measurement, there is a numerical range within which the individual is healthy and normal. Disease is often seen as a deviation from these normal values, and accompanied by abnormalities in the structure or function of body organs or systems. Aspects of personality, such as intelligence, can also be quantified within a numerical range of normality, for instance in IQ tests. For example, the disease model assumes that diabetes in a Manchester patient is the same as diabetes in a New Guinea tribesman. While their blood glucose levels may be identical, the meaning of the disease to the patients, and the strategies they adopt to deal with it, may be very different in the two cases. The disease model cannot deal with such personal, cultural and social factors in ill-health, which are better viewed from the perspective of illness.

Illness

Cassell (1978) uses illness to mean "what the patient feels when he goes to the doctor", and disease to mean "what he has on the way home from the doctor's office. Disease, then, is something an organ has; illness is something a man has." Illness refers to the subjective response of the patient to being unwell; how he, and those around him, perceive the origin and significance of this event; how it effects his behaviour or relationships with other people; and the steps he takes to remedy this situation (Eisenberg, 1977; Kleinman et al., 1978, 1980). It includes not only his experience of ill-health, but the meaning he gives to that experience.

Illness, therefore, is the patient's perspective on his ill-health, a perspective which is very different from that...
of the disease model. It depends on a number of factors. Fox (1968) has noted that: “the particularities and nuances of the emotional meaning of an illness to an individual and the nature of his affective response to his state and symptoms are profoundly influenced by his social and cultural background as well as by his personality traits.” Even responses to physical symptoms, such as pain, can be influenced by social and cultural factors (Zborowski, 1952); these factors can in turn affect the presentation of the symptoms and the behaviour of the patient and his family (Guttmacher and Elinson, 1971; Chrisman, 1977).

Folk models of illness

Folk theories about the causes of ill-health are part of much wider conceptual models used to explain misfortune in general (Fabrega, 1973; Helman, 1980). Illness is only a specialized form of misfortune or bad luck within this wider model. It therefore shares the psychological, moral and social dimensions associated with other forms of adversity, especially in answering the question “Why has it happened to me?”.

Faced with an episode of ill-health, patients try to explain what has happened, why it has happened and decide what to do about it. The shaping of the illness and the behaviour of the patient—and of those around him—will depend on the answers to six questions:

1. What has happened?
2. Why has it happened?
3. Why to me?
4. Why now?
5. What would happen if nothing was done about it?
6. What should I do about it—or whom should I consult for further help?

How the questions are answered, and the behaviour that follows, constitutes a ‘folk model of illness’.

There is not one folk model, but many. In a sense, each patient has his own lay model of sickness and what to do about it, though a particular folk model may be shared by a family, an area or a large group of people (Snow and Johnson, 1977; Helman, 1978). Chrisman (1977) and Dingwall (1977) point out that such folk models—even if based on scientifically false premises—can have an internal logic and coherence and should be taken seriously by the clinician as they are the patients’ ways of trying to make sense of, and deal with, their ill-health in terms of their own view of reality. The answers to the six questions determine how that ill-health is interpreted, and how it is dealt with. For example:

1. What has happened? ‘I’ve picked up a cold.’ This includes naming the condition, or giving it an identity within the lay frame of reference and couched in its own vocabulary. Even if terms borrowed from the medical model (such as ‘a virus’) are used by patients, they may be conceptualized in a different way (Helman, 1978).

2, 3 and 4. Why has it happened? Why to me? Why now? “Because I went out into the rain after a hot bath, when I was feeling low.” This embodies lay theories of aetiology, based on beliefs about illness causation and of the structure and function of the human body. Fisher (1968) and Snow and Johnson (1977) have noted that folk beliefs about the body may bear little relation to those of the medical profession. Chrisman (1977) sees four common categories of aetiology within folk models of illness:

a) Invasion, such as ‘a germ’, ‘cancer’, ‘something I’ve eaten’ or object intrusions.
b) Degeneration, such as ‘being run down’ or accumulation of ‘toxins’.
c) Mechanical, such as ‘blockage’ of gastro-intestinal tract or blood vessels.
d) Balance, such as maintaining ‘a proper diet’, ‘enough vitamins’, ‘enough sleep’, as well as maintenance of harmony in the patient’s life and relationships.

These four aetiological categories tend to overlap. There is usually a continuum in lay beliefs from more traditional beliefs to more scientific ones derived from the medical model.

5. What would happen if nothing was done about it? “It might go down to my chest.” This includes folk beliefs about the significance, prognosis and probable natural history of the condition.

6. What should I do about it—or whom should I consult for further help? “Take an aspirin” or “Call the doctor.” This strategy, or health behaviour, follows logically from the previous model. Based on these premises, patients may act in a number of ways:

a) Self-medication. Several studies show that most symptoms are never brought to any medical agency but are dealt with by the patients, or their families, in terms of their own folk model of illness. Levitt (1976) estimated that in Britain about 75 per cent of symptoms are treated by patients themselves. Much of this is by self-medication. Patients who feel ill frequently resort to tonics, ‘bitters’ or aspirins purchased from pharmacies (Claridge, 1970); pharmacists are frequently consulted for a wide range of conditions, from skin complaints to haemorrhoids (Sharpe, 1979). Jeffers and colleagues (1960) and Dunnell and Cartwright (1972) found that between two thirds and three quarters of patients interviewed had taken some self-medication, especially analgesics, in the few weeks preceding their interviews. Lay use of self-prescribed medication—whether modern or traditional remedies—follows logically from patients’ beliefs about the nature of these preparations and the conditions in which they are useful.

b) Consultation with others. Except in the very isolated, illness is a social event. It involves people other
than the patient, as it “disrupts his participation in those collectivities in which he holds membership” (Dingwall, 1977). These collectivities include family and friendship networks as well as work and other organizations. A patient who labels himself as ill is able to adopt the sick role and therefore remove himself temporarily from many of the obligations of daily life. Self-labelling, however, is often not sufficient to allow a patient to adopt the sick role and reap its benefits, especially as it appears that most people are ill in some way most of the time. In Dunnell and Cartwright’s (1972) study, 91 per cent of adults in a random interview reported that they had had one or more abnormal symptoms in the two weeks preceding the interview. Most of these symptoms are dealt with by patients, and by those around them, in terms of their folk beliefs about the causation and treatment of illness.

A patient who feels ill follows a chain of advice and treatment—from self-medication to consultation first with his family, then with friends, neighbours, the local pharmacist and so on. The point at which these people acknowledge the patient’s ill-health, and confirm him in the sick role, varies between social and cultural groups. The family’s perception of the illness, for example, may be different from the patient’s (Dingwall, 1977; Kleinman et al., 1978), especially in the case of psychological disorders (Laing, 1967). Also, what is regarded as genuine illness (and therefore requiring treatment) in one society or cultural group, may not be regarded as such in other societies or groups (Fox, 1968). Certain types of illness, for example a germ infection, are more likely to mobilize a caring community around the patient—who is considered blameless for his or her condition—than others, where blame for the illness is ascribed to the patient’s irresponsible behaviour, for instance excessive alcohol intake or ‘going out into the rain after a hot bath’ (Helman, 1978).

Only when the patient and those around him feel unable to deal with the illness is it brought to the general practitioner, to be converted into disease. Providing a prescription or sick note confirms this change of paradigm and legitimizes the patient in the sick role.

c) After the consultation. Folk beliefs about illness affect patients’ attitudes and behaviour after the consultation, especially compliance with their doctors’ instructions (Stimson, 1974; Stimson and Webb, 1975; Eaton, 1980). Patients make decisions on whether to take prescribed medication, as well as how it should be taken, which are based on lay knowledge derived from family, friends, books, the media, personal experience and, to a lesser extent, from the general practitioner himself (Stimson and Webb, 1975; Eaton, 1980). Only if the prescribed treatments make sense to the patient will they be taken as directed. Viewing non-compliance from the perspec-
tive of the patient’s folk beliefs about illness can provide useful insights on the problem (Stimson, 1974).

Clinical implications of folk beliefs: some examples

1. Blaxter and Paterson (1980) studied the health beliefs and behaviour of two generations of working-class women in Aberdeen. In many cases the women had low expectations for their own and their families’ health. Health was defined in a functional, social sense, that is the ability to carry on with daily life despite the experience of illness. They therefore defined themselves as healthy despite medical evidence to the contrary; this obviously affected their attitude towards the need for medical care. Several of the young mothers ignored or delayed seeking help for children with chronic ear infections and other conditions that did not cause a disturbance of function; these were regarded as connected with the children’s general health rather than as symptoms of acute treatable illness. For example, “... but that’s not what you would call an illness—just a thing that’s happened. She has trouble with her ears, but that’s extra to health.”

2. Snow and colleagues (1978) studied lay beliefs about menstruation and pregnancy among women in an American city clinic. Many of these beliefs could have an adverse affect on their health and on the outcome of their pregnancies. For example, 16 per cent believed that the fetus could not be affected by its mother’s venereal disease as, during pregnancy, “the uterus is closed and germs cannot enter”. In a further study of menstrual beliefs (Snow and Johnson, 1977), many women believed they could get pregnant only before, during or just after the period when the uterus “is open”. It was reasoned that no contraception was required at other times of the month, as then the uterus was “tightly closed” and sperm could not enter.

3. Kleinman and colleagues (1978) report a case of a 60-year-old women with pulmonary oedema admitted to Massachusetts General Hospital. Told she had water in the lungs she began to act bizarrely, vomiting and urinating frequently in her bed. A psychiatric consultation revealed that the woman, the wife and daughter of plumbers, had a folk concept of the anatomy of the human body in which the chest was connected by pipes leading to the mouth and the urethra. She had been trying to remove as much of the water in the lungs as possible by vomiting and frequent micturition. After appropriate explanations of the structure and function of the body, her unusual behaviour immediately ended.

Relationship between disease and illness

Most cases of disease, though not all, are accompanied by illness, that is by a psychological, social and cultural reaction to the disease process. As mentioned, this reaction may vary between individuals, groups and
cultural units. Members of ethnic minority communities, for example, faced with similar episodes of disease may vary markedly in the symptoms they complain of and in how these are communicated to other people (Zborowski, 1952; MacCormack, 1980).

As Kleinman (1980) points out, there can be a circular relationship between illness and disease. For instance, in a chronic anxiety neurosis an episode of acute anxiety may be manifested by tachycardia (the disease process). The patient's perception of this physical symptom, and its significance, is part of his illness experience—in this case a feeling of over-anxiety about the symptom. This may, in turn, provoke more tachycardia, more anxiety and so on. This positive feedback loop, with a vicious circle of escalating disease and illness, is frequently seen in other cases of over-anxiety, such as asthma, hyperventilation and other psychosomatic complaints.

Disease can occur in the absence of illness. In severe acute conditions, such as massive trauma or overwhelming infection, there may be no time to shape the disease into the illness experience (Kleinman, 1980). In some cases, for example asymptomatic hypertension or early cervical carcinoma, patients may be told they have a disease even though they do not feel ill. As a result, they may not see the necessity for medical treatment. Patients who have an asymptomatic disease, but no illness, may therefore be unwilling to consult their general practitioners for regular check-ups, repeat prescriptions, cervical smears and so on. This may help explain the phenomenon of non-compliance with a doctor's instructions (Stimson, 1974).

Illness can also occur in the absence of disease (Einsenberg, 1977; Cassell, 1978). Hypochondriasis is an example, though this group includes a wide variety of subjective feelings of not feeling well which are often of psychological origin and for which no physical cause can be found. A general practitioner who emphasizes only the treatment of disease, without considering the illness dimension, may be dismissive of a patient in whom no physical disease is found. This may cause dissatisfaction on the patient’s part, and may lead to non-compliance, self-medication or consultation with unqualified practitioners who are more willing to deal with illness. Most general practitioners, though, will treat illness as well as disease.

It should also be noted that some medical treatments, for example drugs or operations, may cause illness and, in some cases, diseases.

Disease and illness in the surgery

In Britain, the main interface between medical and lay models of ill-health is the consultation in general practice. While most symptoms are dealt with by patients themselves, the general practitioner is the first point of contact for about 90 per cent of those who do seek professional medical treatment (Levitt, 1976). At the consultation, the doctor and patient must agree about the interpretation of the patient’s symptoms and the treatment to be given. The doctor’s view of the disease process must be reconciled with the patient’s subjective view of his own illness and contradictions between the two models must be resolved by the process of negotiation (Stimson and Webb, 1975). Both the diagnosis and the prescribed treatment must make sense in terms of the patient’s lay models of illness or they will not be accepted. For this reason, general practitioners usually use concepts and vocabulary borrowed from both lay and medical models (Eisenberg, 1977; Helman, 1978) in order to establish “a consensus for purposes of action” (Fabrega, 1975). Without this consensus, poor doctor–patient relationships, non-compliance and medico-legal problems can easily result.

Conclusions

The disease/illness model developed by medical anthropologists provides a useful perspective on the diagnosis and treatment of ill-health in general practice and on such phenomena as non-compliance, self-medication and dissatisfaction with medical care. For medical care to be most effective—and acceptable to patients—general practitioners should treat both illness and disease in their patients at the same time. They should also be aware how the perspectives of the lay and medical models of ill-health differ and should recognize the clinical implications of these differences.

References


Dear Dr. Helman,

I wish to acknowledge the help of Mrs. E. Packter, Librarian, Postgraduate Medical Centre, Edgware General Hospital.

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Salbutamol

A study was carried out to ascertain the most effective method of giving salbutamol. Seventeen children with severe asthma received active salbutamol (4 mg via a nebulizer, 400 µg as an inhalational powder, or a 4 mg tablet) together with complementary placebos on a double-blind, triple-dummy randomly allocated basis. The bronchodilation effect was assessed by measuring the peak expiratory flow rate.

The bronchodilation effect was greatest when patients received nebulized salbutamol (p<0.05) but lasted longest when they received the tablet (p<0.001); the onset of the effect was rapid with all forms of administration.

These results indicate that nebulized salbutamol gives the best relief in severe asthma; in less severe cases, however, a regimen combining the inhalational powder and tablets is sufficient and more convenient.


Best regards,

[Signature]