

Medicine and Society

Bridging the disease–illness divide in modern medicine

K. S. JACOB

INTRODUCTION

Healthcare in India is at the cross-roads. The increased cost of healthcare is often a major reason for indebtedness among the lower socioeconomic strata of society. The urban-centric nature of our current health systems makes it inaccessible to the large mass of people who reside in rural areas. The free market in healthcare, with its business practices (i.e. commissions paid for ordering diagnostic tests and for prescribing specific treatments and products) and poor regulatory controls have changed the healthcare scenario. In addition, lack of information in the public domain about medical procedures and treatments and their complexities do not allow for an informed choice. The health–hospital, pharmaceutical and medical education industries, which profit from disease and illness, have also complicated the scenario. Self-treatment, family care, self-help groups, religious practitioners, traditional healers and indigenous medicine are often the first and only source of healthcare for many. This has led to divergent perceptions of issues related to health, disease and illness between the medical fraternity and those who seek healthcare. I discuss issues related to the problematic conceptualization of disease and illness which underpins many of these issues. I also attempt to suggest possible solutions to bridge this divide.

THE DISEASE–ILLNESS DISTINCTION

Disease is defined as: (i) a pathological condition of a part, organ or system of an organism resulting from various causes such as infection, genetic defect or environmental stress, and characterized by an identifiable group of signs or symptoms; (ii) a condition or tendency, as of society, regarded as abnormal and harmful; (iii) lack of ease; trouble (obsolete).¹ Illness and sickness have been suggested as synonyms.

On the other hand, illness has been defined as: (i) poor health resulting from disease of body or mind; sickness; (ii) a disease. The interchangeable use of these terms highlights the lack of clarity and also documents a circularity in the argument.²

Medical definitions of disease highlight the pathological process and deviation from biological norms.^{3,4} Illness, on the other hand, is the patient's experience of ill health (Table I). Doctors diagnose and treat diseases while patients suffer from illnesses. Diseases are pathological entities conceptualized by physicians who offer scientific, causal explanations and prescribe treatments with the aim to cure. Illness, on the other hand, is a subjective experience based on personal sociocultural orientation and explanations. It focuses on dysfunction within self/family. The expectation is of symptomatic treatment to relieve suffering. Illness is shaped by perceptions, labelling, explanation, expectation and help-seeking, which are influenced by local culture.

Department of Psychiatry, Christian Medical College, Vellore 632002, Tamil Nadu, India; ksjacob@cmcvellore.ac.in

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While there is an overlap between disease and illness, the divide persists because of the absence of a one-to-one relationship between disease and illness.⁵ Similar degrees of pathology generate different amounts of pain and distress. The course of a disease can be different from that of an illness. In addition, illness can also occur in the absence of disease. This results in differences in perception of a patient's disease/illness between doctors and their patients. For example, many patients present with physical symptoms to medical and primary care settings for which no known medical cause can be identified. Patients have symptoms which represent an illness for which physicians can offer no disease explanations. The prevalence of such presentations clearly supports the differences in perception between physicians (disease) and patients (illness).

MODERN MEDICINE IN PERSPECTIVE

Vaccinations, drugs and surgical techniques have resulted in the prevention of many diseases and changes in treatment of various ailments. The rapidity of cure for life-threatening conditions has made the reliance on curative treatments an attractive option. However, modern medicine and the way it is taught and practised has limitations.^{4,5} The spotlight on disease results in a single-minded pursuit of cure ignoring the reality of illness, the associated suffering and its meaning. Physicians often disregard patients' interpretations and explanations. The failure to realize the importance of and need for healing is often the cause for patient dissatisfaction. In addition, the sole reliance on technological fixes usually results in a disregard for the human context.

Diseases, or physician conceptualizations, are often removed from the reality of patients' illnesses. Physicians are taught to focus on underlying structural and functional defects and often tend to ignore the impact of the patient's illness on his/her life, family and work. In addition, modern medicine has yet to find cures for many ailments (e.g. hypertension, diabetes mellitus, atherosclerosis, etc.) and the current treatments mainly focus on control. This is further complicated by the fact that many disease

Table I. Differences between disease as viewed by physicians and illness as experienced by patients⁵

Characteristic	Disease	Illness
Definition	Professional conceptualization	Patient and family concepts
Orientation	Objective criteria	Subjective experience
Phenomena	Clinical pattern	Dysfunction
Explanation	Scientific	Folk
Treatment	Specific	General
Goal	Cure	Relief of distress
Common help seeking	Hospital	Traditional healers
Conceptualization	<i>Etic</i>	<i>Emic</i>

labels suggest ignorance (e.g. pyrexia of unknown origin, myalgia and somatoform disorder) or limited understanding (e.g. hypertension, diabetes mellitus and schizophrenia).

The difference in focus and emphasis often results in divergent perspectives about disease and illness between doctors and their patients. While doctors highlight naturalistic explanations for a disease (e.g. abnormality, degeneration, dysfunction, infection, malignant change, etc.), patients focus on personalistic beliefs about causation (e.g. beliefs in *karma*, sin, punishment, evil spirits, black magic, supernatural explanations, etc.). Many patients in India seem to simultaneously hold naturalistic explanations about disease as well as personalistic perspectives on illness despite their apparent contradictions.^{6–8} Patients and their relatives also concurrently seek diverse medical and non-medical interventions. In fact, hospitals which practise modern medicine compete with facilities which offer faith healing, traditional and indigenous systems of medicine. People with illness who fail to respond to traditional methods of healing visit allopathic centres with reasonable success and *vice versa*.⁹

Diverse systems of medicine and healing flourish in India. However, there has been a phenomenal increase in the cost of modern medicine in recent years. While technological advances have had a major impact on the health of individuals, many other issues also seem to define health and disease. Financial gain for doctors and hospitals, niche markets for the pharmaceutical industry, insurance reimbursements and opportunities for academics also influence disease categorization. While there has been much progress, many so-called advances are illusions. Many new disease categories are introduced without adequate scientific evidence.¹⁰ Re-categorization of existing entities without adequate basis is common.¹⁰ Expensive new drugs with no real improved efficacy give an impression of superior solutions.¹¹ Although medical advances have resulted in improvement in the health of individuals, many indices of the health of populations suggest major unsolved problems.

THE SUCCESS OF TRADITIONAL AND FOLK MEDICINE

While the achievements of traditional and folk systems of medicine are debatable, many traditional systems continue to enjoy the confidence of the people. Their success can be attributed to their focus on the illness experience and eliciting a patient perspective. These systems of medicine seem to be in tune with local and cultural explanations, and expectations of common illnesses. They aim at healing rather than cure. They seem to successfully elicit, offer and negotiate explanations and expectations with their patients.⁵ Traditional healers also redefine illness as disease. However, they share symbols and metaphors consistent with lay beliefs and their healing rituals are more in tune with the psychosocial context of illness.⁴

THE NEED FOR A NEW CONCEPTUALIZATION

We need to understand that the illness experience dominates patient reality. Consequently, physicians need to appreciate that the sole focus on disease and cure undermines the experience of illness and the need for healing.

While traditional medicine is effective in treating illness, it may less frequently influence the course of disease. On the other hand, modern medicine and physicians can potentially treat both illness and disease. However, this requires a shift in the mindset of healthcare professionals to realize the importance of illness. We need to elicit patient perspectives about the illness, its impact on their life and their expectations. We should present biomedical

perspectives as an alternate reality without claiming exclusivity. We must negotiate a treatment plan keeping in mind local and cultural issues.

Healthcare is often less than satisfactory and treatment less effective when only disease is treated rather than when both disease and illness are managed together. Poor compliance, poor clinical care and medico-legal problems are often due to discrepancies between the views of the patient and doctor of the clinical reality. Doctors need to uncover the patient's explanations on causes, course, expectations and outcomes to be successful in management.¹²

Although disease and illness may be divergent perspectives, they also share many similarities.⁵ Diseases and illness are concepts/models explaining the sickness episode. Each helps construct clinical reality for patients and doctors. They are equally culture-specific and value-laden. Thus, physicians need a new conceptualization of the issues. We need to acknowledge the dynamic interplay between biological, psychological and sociocultural inputs. We need to accept the limitations of current medical approaches, which seem to focus on symptom checklists and diagnostic criteria. We need to acknowledge the holistic picture and context. We need to use medication and technology-based solutions within the context of human perceptions, local contexts and cultures.

The growth of medicine over the past century has seen the decline of family medicine and general practice, and the meteoric rise of specialist approaches. Many problems presenting to primary care are now viewed from a specialist perspective. The progressive medicalization of distress has lowered thresholds for the tolerance of mild symptoms and for seeking medical attention for such complaints.¹³ Patients visit general practitioners and physicians when they are disturbed or distressed, when they are in pain or are worried about the implication of their symptoms.¹⁴ However, the provision of support currently mandates the need for medical models, labels and treatments to justify medical input.¹⁵ Nevertheless, context and local knowledge are critical to understanding illness in medical practice.

The disease–illness dichotomy is very similar to Rubin's vase/profile illusion (Fig. 1). It can be perceived either as two black faces looking at each other, in front of a white background, or as a white vase on a black background, depending on whether one focuses on the figure or on the background.

The divergent frameworks used to view the clinical reality of the disease or the illness artificially forces the divide. There is a need to view the disease–illness issues through alternating medical and patient lenses in order to see the full picture. Both the disease and illness perspectives are partial truths and need to be managed simultaneously for cure and/or healing—the implementation of holistic care. While the powerful frameworks of the figure/ground illusions do not allow us to simultaneously view both perspectives, they demand that we consider the divergent frameworks and issues in the course of management. Rapid alternations between the disease/illness points of view allow good clinicians to see the whole, which is always greater than the sum of its parts. The Newton's wheel (a disk with colours of the optical spectrum, when rotated, appears white) is an appropriate example of rapid changes in perspective allowing for a new synthesis.

These issues raise many concerns. There is a need to accept multiple approaches to restoring health; to understand patient's perspectives and to explore different dimensions of patient experience. Physicians have to attempt to integrate the apparent contradictions between the divergent perspectives. They need to

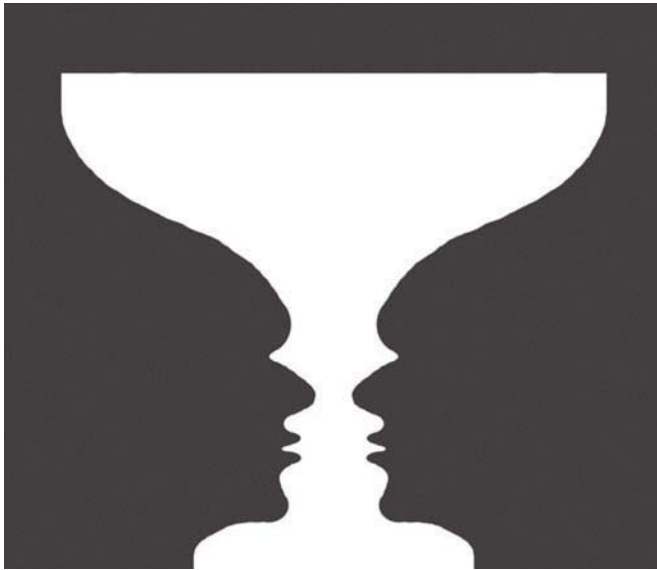


FIG 1. The Rubin vase/profile illusion. The observer's 'perceptual set' and individual interests can bias the situation. It can make one interpretation stronger than the other. Such illusion involves higher cortical processing based on stored information that contains knowledge about vases and profiles (or about diseases and illness). The vase/profile illusion shows that perception is not solely determined by an image formed on the retina (or the impact of clinical reality on the brain). The spontaneous reversal illustrates the dynamic nature of subtle perceptual processes. These processes underscore how the brain organizes its clinical reality for patients and doctors.

negotiate shared goals/treatment plans. They also need to encourage the use of diverse strategies to restore and improve psychological health and functioning.

THE CLINICAL APPROACH

The determinants of clinical presentation depend on the setting, the system of medicine and the practitioner resulting in the translation of suffering into appropriate complaints. Consequently, there is a need to explore patient explanations, meaning and expectation. Kleinman¹² proposed the use of the following 8 questions for eliciting patient perspectives: (i) What do you call your problem? What name does it have?; (ii) What do you think caused your problem?; (iii) Why do you think it started when it did?; (iv) What does sickness do to you? How does it work?; (v) How severe is it? Will it have a long or short course?; (vi) What do you fear most about your sickness?; (vii) What are the chief problems your sickness has caused for you?; and (viii) What kind of treatment do you think you should receive?

What are the most important results you hope to receive from the treatment? These questions allow doctors to understand the patient's and local perspectives.

The clinical strategy should include (i) eliciting the patient's (and family's) perspective, (ii) presenting the biomedical model, (iii) comparing the patient's perspectives with the medical model and (iv) the negotiation of shared models and goals and making a mutually agreeable plan.

CONCLUSIONS

The disease–illness dichotomy and the consequent cure–healing divide are common issues in clinical practice. The disease–cure and the illness–healing models are part perceptions of the whole and often result in a gap in communication between doctors and patients. The dysfunctional consequences of the Cartesian dichotomy (i.e. mind–body dualism; disease–illness dichotomy) have been made worse by modern medical technology widening the gap between what patients seek and doctors provide.⁴ Failure to address issues related to these aspects of clinical care are a cause of patient dissatisfaction. Good doctors know the difference between disease, illness, healing and cure. They also know how to manage them.

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