

The confusion between disease and illness in clinical medicine

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Not everything we count counts. Not everything that counts can be counted.¹

Biomedicine is an established physical science that rests securely upon foundations laid down in 1858 by Rudolf Virchow.² Modern clinical medicine is a hybrid, a mixture of art and science. In addition to addressing problems specific to the investigation and treatment of physical diseases, it necessarily addresses those diseases in living persons. Consequently it is confronted by patients' personal experience of their disease and any consequent actions, as distinct from the disease process itself.^{3,4} Scientific physicians use a precise language to communicate about pathologic bodily change, but there is confusion and disarray in clinicians' language when they attempt to communicate among themselves about their patients' experiences and actions.^{5,6} One common confusion is the mix up between disease (pathologic change in the body) and experience of that disease. Sometimes both of these are confounded with "illness behaviour", the patient's actions borne of experienced disease.

Recently Barondess³ suggested that some of this clinical confusion might be clarified if we use separate terms to denote bodily pathologic change on the one hand and experienced suffering on the other. He has used two words that have been treated interchangeably until now: disease, for pathologic bodily change, and illness, for experienced suffering. Bearing in mind that a word is simply a label, I agree that Barondess's suggested clarification is useful. It avoids the confusion entailed by using the word "disease" in a metaphoric sense to mean suffering not arising from pathologic bodily changes; furthermore, it is in accord with long-standing usage. Before looking at three specif-

ic instances of this confusion, I will look more closely at some consequences of Barondess's proposed distinction.

What is disease?

We all suffer. Because our suffering remained undifferentiated before 1858, words like sickness, malady, disease, ailment and illness were synonymous. Early medical explanations of suffering, such as Hippocrates' system of pathology based on a theory of humours, impeded the development of an effective understanding of disease by allowing as many "sufferings" as patients. Two major transformations in our understanding were required for us to escape from the inevitability of such views. First, someone had to propose that disease processes exist independently (a fact psychiatrists still challenge).⁷⁻¹¹ Second, their existence had to be demonstrated.

In 1676 Thomas Sydenham¹² took diseases to exist "by convention" and suggested that, unseen and unknown, their effects on patients could be documented by charting the course of symptoms and signs observed at the bedside. He founded clinical medicine as we know it, pointing out that "Nature, in the production of disease, is uniform and consistent; so much so that for the same disease in different persons the symptoms are for the most part the same; and the self-same phenomena that you would observe in the sickness of a Socrates you would observe in the sickness of a simpleton." At one stroke Sydenham introduced order and the possibility of progress into medical thought and practice. However, he had nothing useful to say about the ultimate nature of his conventional diseases, largely because of the embryonic state of natural science in the late 1600s.

Almost two centuries later Virchow² answered the obvious question — What gives rise to the natural history of disease? His vision of the inter-

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section of the art of clinical medicine and the science of biology allowed him to demonstrate that some "sufferings" (particularly many of Sydenham's conventional diseases) arose out of the pathologic cellular processes that caused the known lesions of morbid anatomy. He thus founded scientific clinical pathology, biomedicine and, *pari passu*, our current understanding of disease.

Biomedical disease is demonstrable pathophysiology or pathochemistry and is diagnosed by the demonstration of pathologic features through the investigation of relevant symptoms and signs. Its study lies within the public domain of natural science. Clinical diagnosis, virtually the only kind of diagnosis made before the 1800s, is an educated guess at the underlying pathologic disorder based on a patient's self-reports, behaviour and any observed signs and so is necessarily provisional.¹³ A pathological diagnosis, on the other hand, is a statement about a patient's body based on evidence that is independent of the patient's reports or actions and so is final.

What is illness?

Although disease and illness are intimately related, there is an important, frequently ignored, discontinuity between them. Disease is a matter of physics and chemistry whose presence is betrayed by physical signs. Illness is experience whose presence is often communicated by complaint. It cannot be investigated by the methods of biomedicine because its study ultimately depends directly on phenomenologic analysis of experienced suffering through individual self-reports and behaviour.¹⁴ Its presence cannot be objectively established by physical signs.

A corollary of this distinction is that one can be seriously diseased without being ill; for example, with silent hypertension or an occult malignant disorder. Conversely, one can be seriously ill without being diseased; for example, with severe depression in response to a loss. Either state can be fatal.

It also follows that pain, suffering and distress are dimensions of illness, not of disease. This underlies the paradox in which modern scientific physicians find themselves. The more effective they have become in diagnosing and curing disease, the more patients complain that they have become impersonal. Patients are concerned primarily with their illness (i.e., their suffering), while physicians are more concerned with their disease. The emergence of biomedicine's remarkable effectiveness in curing disease has apparently been accompanied by a relative neglect of patients' experience of disease and, even more so, of their nonmedical ills.

Biomedicine does, however, enable us empirically to separate illnesses into two mutually exclusive classes: those arising from disease or injury (medical illness) and those arising from other

personal difficulties in living (nonmedical, or existential, illness*). Separation is effected in practice by pathological diagnosis of any underlying disease.

Despite their radically different origins medical and existential illnesses are close relatives. Unlike disease, both kinds of illness vanish if consciousness vanishes (e.g., because of coma or the administration of a general anesthetic) and both can be modified by modifying consciousness (with analgesics or tranquillizers or through effective psychotherapy). In fact, any agent or event that alters an individual's consciousness via the central nervous system (the necessary, if insufficient, underpinning of experience) can affect experience in general and therefore illness in particular, while leaving disease unaffected.

The problem of illness contains within it another much discussed conundrum: the problem of "health". Health is frequently mistaken for the opposite of disease. The World Health Organization¹⁵ defines health as "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity". This defines, quite precisely, the opposite of all medical and existential illness. It does not define the opposite of disease; in fact, it could not, because disease does not have an opposite, any more than "body" or "lung" has an opposite.

Health and illness are two ends of a spectrum of experiences, just as disease and its absence form two ends of a spectrum of physical states. However, these spectra differ in two very important respects. The health/illness spectrum of experiences is continuous, and its investigation lies outside the domain of biomedicine. The disease/disease-free spectrum of bodily states is discontinuous (in that we either are or are not diseased), and its investigation lies within the domain of biomedicine; the point of discontinuity is established in individual cases through pathological diagnosis. There is no equivalent discontinuity between health and illness, and so there is no equivalent diagnostic procedure. This distinction is of prime importance in the ongoing debate about whether psychiatric conditions are diseases and also in the understanding of "medical" puzzles, such as functional overlay,¹⁶ the placebo effect¹⁷ and the nature of psychogenesis in general,¹⁸ all of which derive from the metaphoric use of the word "disease".

The confusion between disease and illness

Virchow's findings notwithstanding, we still regularly confuse disease with the illness it occasions and existential illness with nonexistent disease. Moreover, symptoms (a subset of the much

*"Illness" is a rather confusing word to use for difficulties in living as widely disparate as hysteria, mourning, "physical" pain, depression, sexual difficulties and so on; however, its use is established in the literature.

larger class of "complaints") and signs are not always kept sufficiently distinct; diseases cannot have symptoms because they cannot complain or feel, and illnesses cannot have signs because experiences cannot swell or bleed. (This is a strictly pragmatic division, of course, not one based on Cartesian dualism; we function as undivided wholes.)

Let us look at three examples to clarify the disease/illness distinction and to see some of its practical consequences for practising physicians. Consider the following statements.

- "Brucellosis is a very deceptive disease" with a "disabling chronic form."¹⁹

- "There are multiple health hazards at . . . surprisingly low levels of obesity. Obesity, therefore, is a disease."²⁰

- "Hysteria is an extraordinary interesting disease, and a strange one."²¹

Some physicians would accept these statements as true. Others would reject them as false, maintaining that some or all of these conditions are not diseases. This disagreement is more than clinical controversy; it represents a fundamental disagreement over what disease should be taken to be.

The statement on chronic brucellosis provides a specific example of the general error of confusing persistent complaints following acute infection with symptoms of chronic disease. This error has been demonstrated experimentally by Imboden and colleagues²² for convalescence from influenza as well as for chronic brucellosis. In both cases the patients whose recovery was prolonged did not differ from the others with respect to physical signs, laboratory findings and complications. They did differ from the others by experiencing more emotional disturbance and having more complaints and a propensity to become depressed in the face of adversity. There was a clear tendency for them to use their earlier disease to explain present life difficulties. Rare exceptions aside, the diagnosis chronic brucellosis "medicalizes" the postdisease experience and behaviour of some otherwise recovered patients; the notion of "delayed recovery" functions similarly in cases of influenza. Chronic brucellosis and influenza are existential illnesses, not diseases. Imboden and colleagues cite similar data for several other kinds of infection.

The confusion between disease and illness is exemplified in the literature on chronic brucellosis. The *Cecil Textbook of Medicine*²³ reports that acute brucellosis "treated with appropriate antimicrobial therapy for a sufficient period is . . . completely curable . . . [so] chronic brucellosis is extremely rare" and is a consequence of inadequate chemotherapy. A specialist text, *Principles and Practice of Infectious Diseases*,²⁴ states that chronic brucellosis is an emotional disturbance "related to the patient's pre-illness personality structure and concurrent life situation" and not to prior chemotherapy. *Harrison's Principles of Internal Medicine*²⁵ asserts

that "the status of chronic brucellosis is extremely difficult to assess", whereas the *Oxford Textbook of Medicine*²⁶ treats chronic brucellosis as an organic disease for which "moderate splenomegaly is the only noteworthy sign. It is present in a minority. . . . Symptoms may persist when serologic evidence of infection has disappeared. [It] . . . must be assessed clinically, and not according to the laboratory findings." If there are no physical signs and no relevant laboratory findings where is the disease? There is none. There is only medicalized experience and behaviour, with complaints being mistaken for symptoms.

There is nothing special about the organisms that cause acute brucellosis or influenza. Imboden and colleagues²² have simply provided us with evidence demonstrating a more general fact: that reaction to any disease or injury, even after physical recovery, is a personal matter involving courage and perseverance or a lack thereof, and that if we ignore this we may diagnose chronic disease instead of nonmedical illness.

A further example of this particular confusion between persisting complaints in the face of life's difficulties and the presence of chronic disease is provided by McHugh.²⁷ He describes the impact on a patient's behaviour of a physician's mislabelling complaints as symptoms and illness as disease. McHugh clearly sees the risk of the physician's fostering an inappropriate passivity in the patient, in the face of his or her life's demands, through such a "diagnosis".

The second statement, on obesity as a disease, is an example of the medicalization of a physical consequence of wilful behaviour. Obese or overweight people (the division is arbitrary) have increased rates of illness and death proportional to the amount of excess weight, which is reversed by weight loss.²⁸ Surgical treatment (i.e., gastroplasty or intestinal bypass), medical treatment (e.g., with phentermine or diethylpropion hydrochloride) and various forms of psychotherapy flourish. But, according to Galloway and associates,²⁹ "whatever method you use, whether it is dental splinting or drug therapy or starvation or any other, you will get weight rebound occurring when you stop", because therapy does not help to re-educate faulty eating habits. This mix of failed biomedical treatments and ineffective psychotherapy is common when behaviour (in this case, underexercising or overeating or both) arising from experience (in part, recorded in memory as appetite) yields a consequence (increased body fat) that becomes confused with disease. In rare cases obesity is a sign of disease. In all other cases there is no evidence that excess triglyceride is deposited in adipose cells by a pathologic process unrelated to conscious or unconscious wilful overeating. This would remain true even if constitution or genetic predisposition made it more difficult for some people to lose or gain weight.

Furthermore, if increases in the rates of illness and death are the characteristics of obesity that

make it a disease, then the increases themselves would inevitably be central diagnostic criteria. However, measured increases in these rates start at 20% below average weight.³⁰ So, many people whose weight is average or below average would be described as having a disease rather than as having eaten too much or exercised too little, or both. In all these cases, as well as most involving above-average weight, the "diagnosis" shifts the responsibility for correcting the overeating or underexercising from "patients" to "therapists" (to the delight of both, perhaps).

The third statement, on hysteria, is simpler to assess. By definition, the symptoms of hysteria must not have a physical cause, so hysteria is an existential illness. Confusion about this disorder arose most recently at the end of the last century, from Freud's implicit proposal (a proposal, I suggest, is actually a second, covert disease convention) that we take hysteria to be a "functional disease".³¹ He borrowed the word functional from physiology, where it had had a clear operational definition with specific reference to bodily function, and stretched it to include social and personal functions. By so doing, he was able to call social or personal dysfunctions or complaints, like those seen in hysteria, "symptoms" of "functional diseases". These putative diseases comprise a class that includes many traditional "sufferings" that have not been shown to arise from underlying organic disease. Clearly, although the word "functional" had a single scientific meaning in medicine in the late 19th century, it now has two quite unrelated meanings. The fact that we confuse them is a further example of our failure to distinguish disease (which concerns only physiologic dysfunction) from illness (which concerns the social and personal dysfunctions Freud added). The few following examples from the medical literature on hysteria reveal the confused and confusing consequences of Freud's convention.

- *Oxford Textbook of Medicine*:³² Hysteria is a disease with "no organic pathology" yet with "physical signs and symptoms [that] result from unconscious mental processes" — an impossible medical will-o'-the-wisp! How signs (i.e., physical bodily changes caused by disease) can arise from unconscious mental processes is not discussed. (You will recall that an absence of physical abnormalities is a *sine qua non* for the diagnosis.)

- *Osler's Principles and Practice of Medicine*:³³ Hysteria is an "irrational answer to a conflict . . . [that is] cured by persuasion". There is no comment on what sort of spiritual backsliding might underlie this.

- Freud: Hysteria is an organic disease that is simultaneously functional; that is, there both are and are not underlying organic abnormalities.³⁴ Further, Freud stated that "a passive sexual experience before puberty . . . is the specific aetiology of hysteria",³⁵ although later he decided that a memory of a fantasy of such an experience often caused it.^{36,37} He went on to assert that "the symptoms of

the disease are nothing else than the patient's sexual activity"³⁸ and that many cases can be "cured by marriage and normal sexual intercourse"³⁹ (a fact that had been well recognized for centuries). Finally, he said hysteria "has the power of producing illusory pictures of a whole number of serious diseases".⁴⁰

- *Cecil Textbook of Medicine*:⁴¹ Hysteria is not a disease: it is a "disturbance in behaviour in which symptoms and signs of physical ill health are imitated more or less unconsciously."

These several views are obviously incompatible. The literature on hysteria is even more chaotic than these few quotations might suggest, with reports of outbreaks of contagious hysteria still being published.⁴² It is clear that Freud's proposed convention — that existential illnesses like this one be taken to be a special form of "functional" disease — has been as conspicuous a failure as Sydenham's original convention¹² has been a success.

This confusion has unfortunately taken root among some current writers who indicate that they are concerned with the distinction between disease and illness. Consider the following remarks made by Dr. Leon Eisenberg,⁷ a department chairman and professor of psychiatry at Harvard University.

If conversion hysteria serves as a convenient example of "illness without disease", it also provides an apparent contradiction to the thesis that, for contemporary medicine, disease is organ pathology. Hysteria is to be found in the official medical classification of "disease". In part, its tenure is a heritage of the past, when it was the province of neurology; in part, it may be supposed by some to yield its secrets one day to more sophisticated biomedical research into its pathogenesis.

Here hysteria is taken to be an illness without underlying organic abnormalities and as such is offered as a contradiction to the biomedical thesis that diseases must be based on organic abnormalities. Then we are told that hysteria itself may turn out to be a disease with an organic cause discoverable by biomedicine. This kind of equivocation blurs the disease/illness distinction while claiming to clarify it.

The American Psychiatric Association's diagnostic manual⁴³ reveals how many other psychiatric diseases are actually existential illnesses. This explains why counselling is useful in these cases but useless for fractures or pneumonia. Should a Socrates break his leg, his bone will knit in the same way as a simpleton's, but the existential distress of each individual may differ profoundly. While biomedical treatment of disease can be independent of personality, psychiatric treatment of so-called functional disease clearly cannot and, in practice, is not.

Defining the scope of medicine

It is clear that the three examples we have

looked at — chronic brucellosis, obesity and hysteria — cannot reasonably be taken to be diseases in the same sense that are pneumonia and influenza. They lie on the continuum between health and illness; there is no pathological diagnostic procedure with which to unequivocally rule them in or out, and they are clearly a function of personality and behaviour. Yet it is equally clear that all three are taken to be diseases in just that same sense by many physicians, who treat them with scientific medicine without success. I have referred also to evidence supporting the proposition that many other “diseases” fall into the same category.

The human body is subject to scientific law, while personal behaviour (a function of experience) is subject to ethical constraint (as well as to the laws of the state). If disease and illness remain conceptually and practically fused, then a patient's experience and behaviour will be medicalized. This vestige of prescientific medicine will mystify a patient's experience and lead to the uninvited, and therefore unethical, control of a patient's behaviour by a physician and, to a lesser extent, of a physician's behaviour by a patient. These problems are most obvious in the often odious, mutually coercive doctor-patient relationships that characterize modern institutional psychiatry, but I hope I have indicated clearly that they are not confined to that discipline. The subtle dance between a patient who is recovering from a work-related injury, the institute's doctors and psychologists who are attempting to establish a diagnosis, and the Worker's Compensation Board provides an alternative example (so-called compensation neurosis⁴³). A doctor who diagnoses mental disease in an accused felon, with the latter's possible conviction or sentencing in view, provides yet another example. Also, it is estimated that perhaps 50% of patients who consult family practitioners do so for emotional or personal reasons, not because they have a disease: they want to receive help with their illness but are frequently “treated” medically for (nonexistent) disease.

Without my listing further examples of biomedicine's appearing to be stretched beyond its confines to no good end, consider the following remark made by Donald Seldin,⁴ president of the Association of American Physicians.


Medicine is a narrow discipline. It does not promote the realization of happiness, inner tranquility, moral nobility, good citizenship. But it can bring to bear an increasingly powerful conceptual system for the mitigation of human suffering rooted in biomedical disturbances.

The confusion that has followed from not distinguishing between disease and illness and from not confining medicine to disease, as Seldin⁴ suggests, is very clear. For that reason alone, I suggest that it would serve both physicians and patients to maintain conceptual clarity when personal suffering is being investigated. Suffering arising from bodily disease can then be properly

dealt with by physicians trained in the methods of biomedicine. Other suffering can be properly treated by anyone, physician or not, who is sufficiently skilled.

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Meetings

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February

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