



The keys to the kingdom

Making sense of illness: science, society, and disease

Robert A. Aronowitz

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It is clear to me from reading Robert A. Aronowitz's *Making Sense of Illness* that diagnosis is a creative endeavour. We physicians are like members of an academy of the arts. We agree on certain conventions as we transform human complaints, physiologic disturbances and idiosyncracies into diagnostic constructs. This patient has diabetes; this one, schizophrenia; and this third patient — well, we have not decided what he has yet. Of course, we do not seek a label that fits just for fun. If we didn't assign a name to our patients' problems, how would we or anyone else know how to proceed with treatment? However, a diagnostic label has profound personal implications for the patient to whom it is attached.

Aronowitz explores how acceptable diagnostic practice is negotiated between medicine and society. He begins with the familiar distinction between illness and disease proposed by Kleinman,¹ which Aronowitz frames as the difference between a holistic and an ontological perspective. The holistic approach focuses on the patient's unique experience of being ill, an experience that is not equivalent even to that of other patients who, in ontological terms, have the same disease. It is the negotiation involved in the exercise of recognizing and naming these ontological disease entities that is Aronowitz's primary focus.

In his first and most compelling "case study," Aronowitz examines the social history of two syndromes characterized by chronic fatigue. The first, "myalgic encephalitis," apparently emerged in the 1930s as a variant of polio seen in health care workers who had dealt with polio cases. A viral mechanism was postulated, and this appears to have sustained belief in the syndrome as a "real" entity even

though the virus was never identified. The second, "chronic fatigue syndrome," was first described in the 1980s and has also been attributed to a putative viral mechanism. The disease so identified "spread" and became a popular diagnosis, particularly among middle-class North Americans. And it became important to those so labelled — so important that they have resisted vigorously any attempt to take away the diagnosis by undermining its scientific credibility. Why? Probably because a diagnosis of chronic fatigue syndrome locates the seat of the problem outside of the individual: If one has a disease, one cannot be blamed for always being tired.

Aronowitz develops five other case studies, but the shift in responsibility that comes with externalization and labelling seems to be the central issue in all of them. He traces the history of the psychosomatic hypothesis in ulcerative colitis and how it lost ground by placing too much responsibility for the disease and its exacerbations on the patient. He outlines the emergence of Lyme disease and the controversial role played by its victims in its recognition. He discusses angina pectoris and how vivid explanations for it in terms of the patient's temperament evaporated when the focus changed to anatomic narrowing of the coronary arteries. The fall in popularity of the "type A personality" as an explanation for coronary artery disease represents another failure of the temperament hypothesis of disease. The risk factor hypothesis is, so far, a more successful attempt to place responsibility for *future* disease on the individual, perhaps because this very futurity and the probabilistic framing of "risk" lightens the load on the individual, who may think in such terms as "On average, exercise ap-

pears to prevent heart attacks, but who knows in my case?"

We in medicine have the keys to the diagnostic kingdom. We have the knowledge/power to externalize and label someone's problem as diabetes or hypertension or chronic fatigue. We do not, as we usually think, simply describe what is, but create a new world for the people we diagnose. This is such a potent process that society wants and should have a say in it.

Shouldn't individual patients have a say? In family therapy, Michael White has been a successful proponent of externalizing problems.² But in that situation the individual or family plays a role in problem identification and labelling. Is there room for this in medical practice? Could I allow a patient a say in whether he wants to label his problem chronic fatigue syndrome or depression or the old-fashioned neurasthenia or something else? Could the patient choose from a menu that label that affords the most flexibility or empowerment? Have I gone crazy? Perhaps.

But there is more. If diagnosis is a creative process, should it become *more* so? Should we experiment with it? And shouldn't we study the effects? We could ask questions such as "What is the outcome of assigning the label 'chronic fatigue syndrome' versus 'depression' versus a label of the patient's own choosing?" A trial of diagnostic labels seems unthinkable — yet if, as I suspect, diagnostic labelling is the most powerful thing that we do, how can we justify not examining its effects?

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References

1. Kleinman A. *The illness narratives: suffering, healing and the human condition*. New York: Basic Books; 1988.
2. White M, Epston D. *Narrative means to therapeutic ends*. New York: W. Norton; 1990.