

## Disease and its Meanings

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To recognise disease in ourselves or in others is to reflect, however fleetingly, on its moral significance. Our perceptions of disease have always prompted a search for attribution and responsibility; but more importantly they bring into focus the concerns we have about the way we live our lives, our relations to community, environment and cosmos, and they challenge us to explain the purpose of malfunction and suffering. Why me?—or why them?—and why now?, we continue to ask. Hans Castorp, in Thomas Mann's *The Magic Mountain*, discovered that 'all interest in disease and death is only an expression of interest in life'.<sup>1</sup> We feel the full force of this observation perhaps only when we try to make sense of our own frailty. Hervé Guibert, in the last stages of AIDS, described 'an illness in stages, a very long flight of steps that led assuredly to death, but whose every step represented a unique apprenticeship. It was a disease that gave death time to live and its victims time to die, time to discover time, and in the end to discover life.'<sup>2</sup>

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1. T. Mann, *The Magic Mountain*, trans. H. T. Lowe-Porter, Alfred A. Knopf, New York, 1944, p. 495.

2. H. Guibert, *To the Friend who Did not Save my Life*, trans. Linda Coverdale, Atheneum, New York, 1991, p. 164.

In one sense, then, little has changed in a thousand years, but much else has altered beyond recognition. Disease perception still gives expression to personal, social and spiritual anxieties, but the vocabulary we use has varied with time and place, and differed in physical exactness and moral complexity.<sup>3</sup>

Until the last few hundred years, those who suffered and those who sought to relieve suffering shared many assumptions about the character of health and disease. The basic conceptual framework seems to have been remarkably widespread. Bodies were constantly in a state of ebb and flow with their environment, themselves changing and subject to the changes around them. Always in a state of becoming, they were vulnerable to variations in activity, diet, excretory function, sexual indulgence, season, climate and a host of other behavioural and environmental factors. All change was potentially pathological. The body in health existed in an easy equilibrium with its circumstances; dis-ease was, as the word implies, a systemic imbalance in intake and excretion, a disturbance of function readily perceived by patient and doctor alike; the goal of any therapy, therefore, was to restore equilibrium.<sup>4</sup> Disease was thus inseparable from individual temperament, or idiosyncrasy, and one had to know the whole person, mind and body together, to perceive the sickness. The experience and the words of the sick individual necessarily were paramount. In this common culture of disease perception, naturalistic explanation and moral commentary jostled together. Illness, a bad or unhealthy condition of the whole body, might develop in response to the change in seasons, or it might be the result of abstinence or immoderate behaviour, the consequence of natural disorder or a fall from grace. At the same time as the body was an element of the natural world, and subject to naturalistic explanation, it also found ambiguous expression in a range of moral narratives.

As societies became more complex, elite groups of healers emerged, and many of their theories and practices began to diverge from common intuitions of health and disease. The separation of disease diagnosis from the experience of sickness, and from

3. C. E. Rosenberg, 'Framing Disease: Illness, Society and History', in C. E. Rosenberg & J. Golden (eds), *Framing Disease: Studies in Cultural History*, Rutgers University Press, New Brunswick, 1991, pp. xiii–xxvi.

4. J. H. Warner, *The Therapeutic Perspective: Medical Knowledge, Practice, and Professional Identity in America, 1820–1885*, Harvard University Press, Cambridge, Mass, 1986.

the circumstances of suffering, is perhaps most striking in Europe. For more than two hundred years, doctors working in the Western tradition have sought to localise disease within the body, to identify specific pathological lesions, first in organs, then tissues, then cells, and now molecules. Increasingly, disease was perceived as separable from the body as a whole; it could be recognised as a standard package, largely indifferent to individual idiosyncrasy; and it might run its course without the patient ever experiencing it.<sup>5</sup> Conversely, a person could now feel sick without fitting any validated diagnostic category. During the past century or more, medical scientists have successfully attached specific agency to this reductionist pathology. A germ, toxin or gene can be held to account for most ailments, while the importance of predisposition, bodily constitution, and social or environmental circumstances has diminished.<sup>6</sup> The seed generally is more interesting than the soil. Disease has thus become a thing that invades individual bodies and can move between them, or else it arises unbidden within them, taking them over. Bodies can be treated as little more than potential receptacles for disease, uninteresting until infected. As the pathogenic agents to which these alienated bodies succumb are usually invisible, and since our experience of sickness has become so unreliable, we must hope that medical experts will perceive our diseases. Even so, the sicknesses that we feel may continue to exceed, to overflow, such rationalistic inquiry.<sup>7</sup>

As modern biomedicine advanced in technical competence, moral commentary did not disappear, but often it dwindled into a simple and rather mechanistic attribution of blame, a form of moralising.<sup>8</sup> The onset of epidemic disease had always incited prejudice, permitting the stereotyping of foreigners, the poor, and other races, as inherently disease-dealing and polluting.<sup>9</sup> On contracting

5. O. Temkin, 'The Scientific Approach to Disease: Specific Entity and Individual Sickness', in A. C. Crombie (ed.), *Scientific Change: Historical Studies in the Intellectual, Social and Technical Conditions for Scientific Discovery and Technical Invention from Antiquity to the Present*, Basic Books, New York, 1963, pp. 629-47.

6. W. F. Bynum, *Science and the Practice of Medicine in the Nineteenth Century*, Cambridge University Press, Cambridge, 1994.

7. A. Kleinman, *The Illness Narratives: Suffering, Healing, and the Human Condition*, Basic Books, New York, 1988.

8. A. M. Brandt & P. Rozen (eds), *Morality and Health*, Routledge, New York, 1997.

9. A. M. Brandt, *No Magic Bullet: A Social History of Venereal Disease in the United States since 1980*, Oxford University Press, New York, 1985.

an epidemic disease, the victim often was rewarded with stigma and segregation. Germ theories simply added pathological depth to older social and political resentments: minorities might look clean but who knew what transmissible threat lurked within? Now, of course, we can trace individual responsibility for all disease, even the most sporadic and trivial, much more precisely. What did the individual do wrong? Smoke? Eat too much fat? Drink too much alcohol? Have sex without a condom? Perhaps a more complex moral narrative lies behind such a banal, if technically correct, calculus of risk, but few practitioners seem competent to reflect on it. In the past, we have known diseases of divine providence,<sup>10</sup> diseases of poverty,<sup>11</sup> and diseases of civilisation,<sup>12</sup> but most diseases now are just diseases of innocent or guilty individuals—though the notion of diseases of ecological destruction might yet provide a new organising principle relating disease to the cosmos.<sup>13</sup>

During the past two hundred years or so, the historically rather peculiar explanatory model of disease that developed in Europe has become a global influence on disease perception. Just as we are immersed in a global disease pool, so are we all exposed to some degree to the insights of biomedicine. Its reductionist, technical character makes it virtually context-free and has allowed an efficacious mass-production of disease diagnosis across the globe. And yet, while standardised biomedical models may now dominate disease perceptions they do not go uncontested, even in Europeanised societies. The range of health belief is probably as broad as it ever was, and many of the sick still find in alternative explanatory models a more satisfying understanding of their illness.

Why should this be so? It seems almost as though, within biomedicine, our perception of disease has become so constrained by our technical competence in diagnosing and treating malfunction, that even as we invent an ever richer mechanistic vocabulary, we are left with an ever more impoverished moral language. The romance of technology is so entrancing, and indeed so physically ef-

10. T. Ranger, & P. Slack (eds), *Epidemics and Ideas: Essays on the Historical Perception of Pestilence*, Cambridge University Press, Cambridge, 1992.

11. R. Dubos & J. Dubos, *The White Plague: Tuberculosis, Man and Society*, Little, Brown, Boston, 1952.

12. C. E. Rosenberg, Pathologies of Progress: The Idea of Civilization as Risk, *Bulletin of the History of Medicine*, vol. 72, 1998, pp. 714–30.

13. L. Garrett, *The Coming Plague: Newly Emerging Diseases in a World out of Balance*, Farrar, Strauss & Giroux, New York, 1994.

fective, that, as practitioners, we may be blind to the potential for a moral structuring of disease, or we may simply believe that non-technical explanation is none of our business. But many of those who suffer from disease want, like Hervé Guibert, to learn more about their lives even if, as technically trained doctors, we cannot, and perhaps should not, satisfy their demands. Charles Lamb once observed that 'sickness enlarges the dimensions of a man's self to himself'.<sup>14</sup> Now, at the end of the millennium, we will tell our patients that it's just a virus. 'Why me? Why now?' ask our patients, and we stay not to give an answer.

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14. C. Lamb, 'The Convalescent', in C. Lamb, *The Last Essays of Elia*, Little, Brown & Co., Boston, 1892, p. 63.