
Narrating the Body: Disease as Interpersonal Event

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The writing of disease has a particular resonance for literary studies. What we generally think of as 'histories of disease' are written by scholars: medical historians, medical sociologists and historians of science. There is also, however, a body of writing which presents a different sort of history and phenomenology of disease, and can provide a sort of counterpoint to academic accounts of disease. In this paper, I propose that biographical narratives of illness experiences, often called pathographies,¹ have implicit in them an idea of the body which is fundamentally in conflict with the usual subject of biomedical history. The sick body represented in autobiography is *alive*, even if it is on the point of death, and this means that it has to be understood differently from the body of the anatomy lesson, what Drew Leder describes as 'the Cartesian Corpse' of Western biomedicine.² A dead body is imagined as inert and stable, anatomically speaking.³ A living body is

1. The term has been objected to as one which pathologizes the sick person. It seems to me, however, that it has its uses: in particular, the term aligns the work linguistically with other ways of writing the self, with autobiography rather than biohistory. For discussion of this issue, see Arthur W. Frank, 'Reclaiming an Orphan Genre: The First Person Narrative of Illness', *Literature and Medicine*, 13, No 1 (Spring 1994), p. 18, note 3.

2. Drew Leder (ed.), *The Body in Medical Thought and Practice*, University of Chicago Press, Chicago, 1992.

3. It is not, of course. A dead body examined over time would certainly change: it would decompose. The trope of the stable corpse is a teaching strategy, a feature of medical education: see Stefan Hirschauer, 'The Manufacture of Bodies in Surgery', *Social Studies in Science*, 21 (May 1991), pp. 311-12.

configured dynamically, both physically (it grows, ages, heals) and psychologically (it has a psychosomatic capacity, it is enmeshed in a range of reciprocal relationships). How do these different ways of representing the body, the biomedical and the pathographical, affect the understanding of embodiment, and of 'diseases'?

In this paper I argue that the considerable differences between the account of a disease which is written by a sufferer or someone close to her, and one produced by a biologist or a sociologist, need to be elaborated and explored because they are crucial to an understanding of what 'disease' means in the history of medicine. Reading patient narratives of various sorts suggests that embodied disease (that is, disease as manifested in a living individual as opposed to, say, a tissue culture) cannot be understood, even at the biochemical level, outside the context of that individual's 'internal' world⁴ and relationships (or their absence) with significant others, typically parents, children and partners. Indeed, I would say that no disease is lived and experienced in one body. Like other aspects of embodiment, diseases exist in the realm of the interpersonal,⁵ in what Harry Stack Sullivan called 'me-you patterns'.⁶ It is easier to discern the effect of these 'me-you patterns' in patient accounts of illness, which tend to factor relationships *in* to their narratives, than in medical or even sociological writings, which tend to factor them *out*. Some patient accounts actually turn on the disjunctions between these two ways of considering illness: Peggy and Robert Stinson's *The Long Dying of Baby Andrew*,⁷ for example, is organized around the parents' agonized conflict with a medical establishment which insists that the condition of the very premature Andrew Stinson is meaningful in exclusively biomedical and biomechanical

4. This is defined as '... as real a place to live as the outside world ... an internal world of actual objects (not images or representation) engaging in relations with each other and with the subject'. R. Hinshelwood, *A Dictionary of Kleinian Thought*, Free Association Books, London, 1989, p. 331.

5. I am using this term as it is employed by the Interpersonalist school of Psychoanalysis: '... self exists in relations with others. There is no hidden chamber, nor does the subject maintain control over exposure or concealment. Self is woven into reciprocal interactions between the subject and other, particularly in the language that is the common medium of those interactions. This is a view of self as multiple and embedded in relational contexts.' Stephen Mitchell, *Hope and Dread in Psychoanalysis*, Basic Books, New York, 1993, p. 96.

6. H.S. Sullivan, *The Fusion of Psychiatry and the Social Sciences*, W.W. Norton, New York, 1964.

7. Peggy & Robert W. Stinson, *The Long Dying of Baby Andrew*, Little, Brown and Co., Boston, 1983.

terms. The Stinsons argue fruitlessly that Andrew's illness affects and is affected by many lives (his sibling, yet-to-be born siblings, grandparents, parents, friends). *The Long Dying of Baby Andrew* demonstrates the hiatus between the two ways of thinking very economically, by juxtaposing dated passages from the medical records with their own diary entries. What this literal 'heteroglossia' reveals is the hopelessness of dialogue between the two systems. Andrew's doctors do not think of Andrew's body and life as being the sort of thing his parents believe it is. The baby's parents think of Andrew as part of sets of overlapping me-you patterns; his doctors think of him as part of a train of treatment protocols.

Pathographies explore the protagonists' experiences of mediating the parallel universes of 'experiential illness' and 'biomedical disease'. As we all find out, sick people often experience a drive towards reconstituting an illness experience as a shaped narrative. Many want to talk about it, and quite a few want to write about it. This is perhaps because of the startlingly mute, unrepresented nature of 'raw' body experience *per se*: working towards the production of a narrative reshapes the sick person's selfhood by allowing them to insert their (experiential) selves back into their own (biomedical) story, to insist that the self is embodied, the body is self. A pathography may thus produce a text which is, to make use of Arthur Kleinman's distinction between patient-experienced 'illness' and physician-diagnosed 'disease', more interested in providing an account of an illness than of a disease.⁸ That is, the sufferer is likely to write more about how they experienced their condition ('I hated the smell of my wound') than about the objective facts or progress of their condition ('Uneventful healing', or perhaps, as Andrew Stinson's doctors say of his many collapses, 'crumpled'⁹). Patients' feelings about their situation may not be confined to the conventional conceptual or clinical arenas. They move away from the *incident-diagnosis-convalescence-cure/deterioration-death* narrative beloved of biomedical plotting. They seem to move inevitably towards blurred interpersonal boundaries, multi-determined aetiologies, conflictual solutions. It seems unlikely that this is because pathographers simply do not comprehend the linear nature of dis-

8. Arthur Kleinman, *Social Origins of Distress and Disease: Depression, Neurasthenia and Pain in Modern China*, Yale University Press, New Haven, 1986.

9. A shorthand term used in Andrew's medical records (presumably an abbreviation of 'crumpled') which indicates a collapse requiring resuscitation.

ease and its resolution one way or the other, towards cure or death.

James T. Patterson's comprehensive account of the history of the writing of disease ends by addressing this crucial point. He notes that, as the geneticist Richard Lewontin indicates, popular culture and many branches of the medical establishment, show a 'rage for monocausal ('gene of the week') explanations for processes that in fact involve dynamic processes', a desire to find the magic bullet that will 'cure' modern diseases: obesity, cancer, heart disease. The concept of the monocausal disease is related to the trope of the Cartesian corpse. It imagines disease as a biochemical or microbiological event which assails the non-participant body. In the contemporary West, biomedicine 'lays claim to a primary system for reading the body and its parameters', and tends to draw even the biological boundaries very narrowly, representing the body as somehow understandable outside a chain of micro-biological exchange.¹⁰ Frank Ryan, in his luridly titled *Virus X: Tracking the New Killer Plagues Out of the Present and Into the Future* notes that while medical virologists think of viruses as malevolent parasites which put the innocent body under external siege, 'contributing nothing positive to life on earth', virologists who are not working as physicians may think of viruses as, for example, 'vehicles for genetic exchange between the disparate species which make up life on earth':¹¹ for them, even our bowels may be thought of as the natural habitat of the enteric microbes which make up 'two-thirds of the bulk of human faeces'. Granted that nobody is likely to be keen to sacrifice their own existence to the well-being of a virus or bacterium, how do we preserve a sense of the dizzying inter-relatedness of biological phenomena, while still wishing to find what it seems hard to think of in these circumstances as a cure? A disease which is thought to have multiple and compounding determinants occupies a number of categories at the same time: intrinsic biological experience, biologi-

10. A simple example of this is the (now somewhat less common) practice of washing the mother's perineum with antiseptic just before the baby's head is born. The rationale for this is that the infant should be protected from its mother's bacteria, but of course, she is relatively resistant to her own bacteria, and the baby will share this resistance if it is breast-fed. Instead of protecting the baby by allowing its gut to be colonized with bugs against which it can be protected, the attempt to sterilize the maternal perineum simply allows the baby to be colonized by bugs against which its mother's milk cannot protect it, for example, bugs found in the hospital rather than in its mother's home. The microbiological relationship between the mother, her baby and their home is discounted in this scenario; instead, the baby is read as an unaffiliated agent with a neutral micro-biological status.

cal exchange, social-cultural position, and precipitate of the fantasies of a particular psyche-soma. What might 'cure' mean in a dynamic universe?

Multifactorial diseases, with their ecological, social, biochemical and psychological aspects, certainly resist cure. Should a mouse plague or the employment situation be addressed first? Is fast food or street violence primary? There is evidence that giving advice about the so-called lifestyle factor in health not only does not help to improve the health of populations very much, it can make things worse. We may, for instance, drive a wedge between embodiment and a sense of selfhood when we educate people to distrust the food instincts, and lead to eating disorders of various sorts. The concept of 'disease' is changed when the psyche is factored into the body, no matter how cannily brain chemistry might be reconfigured in order to try to keep it a biochemical game.¹² Factoring in social-political issues changes the story again. Diseases look different if they are considered epidemiologically, as Patterson's paper shows. Cancers look less like a random individual scourge: they change in migrant populations until they resemble the patterns of the adopted country. There are determined attempts to construct obesity, for example, as a mysterious disorder of leptin levels, but it seems to be the case that 'minority populations, specifically minority women, are disproportionately affected', and that 'low socio-economic status is a risk factor for childhood obesity'.¹³ It is enlightening to think of the body and disease as socially and intra-psychically modulated and elaborated, and compoundingly enlightening to think of it as interpersonally created and experienced. This may seem like the ultimate postmodern move, but it has always had some currency in pathographies. D.W. Winnicott, paediatrician and psychoanalyst, famously said that there is no such thing as a baby, meaning that babies without other people in close association speedily become ex-ba-

11. Frank Ryan, *Virus X: Tracking the New Killer Plagues Out of the Present and Into the Future*, Little, Brown and Co., New York, 1997, p. 51.

12. 'Psychoneuroimmunology' (which used to be known as the placebo effect) was the subject of a segment on the 'Health Report' (an Australian Radio National program) on 8 September 1997.

13. 'An inverse relation has been shown between social class and prevalence of obesity in children three to eighteen years of age: rates range from 25% in low-income families to 5% in high-income families' (Health Implications of Obesity, *NIH Consensus Statement*, 1985 (Feb), 11-13; 5(9):1-7.) That is, poor children are five times more likely to be fat than rich ones. This conclusion is drawn from US data, but there is no reason to think that either data or conclusion might be different for Australia.

bies.¹⁴ Is there any such thing as 'a body'? Can living bodies function in isolation? Though the point is not made in exactly this way by the new theorists and historians of medicine, the reconstructions of the 'complex negotiations' of medical care in history that Patterson notes, do exemplify it. A considerable amount of obstetric, as well as psychological and social complication has to be ignored if childbirth is constructed as the expulsive operation of an isolated female pelvis: much obstetric pain, post-partum depression, and the whole idea of a father, for instance. Conservative controlled trials in some maternity hospitals find that labour progresses better (is shorter, less complicated and produces neonates with higher Apgar scores) if the woman is accompanied for the whole of her labour.¹⁵ Readings of bodies and diseases which, for example, read the figure of the midwife or the husband (or the baby, for that matter) back into the story of a labour are in opposition to the conventional construction of disease as invariably experienced in one body rather than another. Pathographies insist that 'disease' is experienced between people.

Two pathographies of this sort are *Patrimony: A True Story*, by Philip Roth,¹⁶ and *A Very Easy Death*, by Simone de Beauvoir.¹⁷ Each of these writers describes the painful dying of the widowed same-sex parent, the one with whom the author has had a conflictual relationship, and its effect on all concerned. A question which structures these texts is: who is the patient in these experiences? Both parents and children seem to experience this confusion. While Roth describes the terrible effects of a brain tumour on his father's vision and balance, he himself has emergency quintuple by-pass surgery, a major illness experience which the text barely registers, in striking contrast to its passionate exploration of Herman Roth's condition. When Herman, who is by this time partly paralysed and to his son looks 'crushed', finds out about Philip's surgery, he starts to cry with fury. 'I should have been there', he says, as if he is freer to experience Philip's illness than his own.¹⁸ When Simone de Beauvoir describes the burial of their mother, her sister Poupette cries 'If it weren't going to happen to me too it

14. D.W. Winnicott, *The Family and Individual Development*, Tavistock, London, 1964, p. 88.

15. M. Enkin, M. Keirse & Iain Chalmers, *A Guide to Effective Care in Pregnancy and Childbirth*, Oxford University Press, Oxford, 1991, p. 177.

16. Philip Roth, *Patrimony: A True Story*, Jonathan Cape, London, 1991.

17. Simone de Beauvoir, *A Very Easy Death*, Penguin, Harmondsworth, 1992.

18. Roth, *op.cit.*, p. 230.

would be too unfair'. Their mother's dying forces their early identification with her back into consciousness. They have uncanny fantasies that their own embodied state is a part of hers. Remembering her dying mother trying to sip orange juice through a straw, Beauvoir feels her own mouth has become her mother's. Poupette astonishes a nurse by collapsing when she sees her mother's wound. Similarly, Roth weeps as he holds the MRI scans of his father's brain in his hands, and later feels as if his own newly perfused heart might be his mother's suckling babe, feeding on a now-plentiful blood supply, or his father's dependent child, supported by paternal strength. Moreover, Roth and Beauvoir are haunted by their parents' account of the deaths of *their* elderly relatives: Françoise de Beauvoir's story about her Uncle Maurice who died screaming for his service revolver; Herman Roth's memories of his mother Bertha whom, dying, he comes to resemble. When Philip has his coronary bypass, he reflects 'I had come to feel myself *transposed*, interchangeable with — even a sacrificial proxy for — my failing father, choking on his mortality at the dinner table'.¹⁹ These accounts of the painful witnessing of a parent's death, with their echoes of the parent's own such duties, and back over centuries, create a sense of disease and dying as interpersonal, intergenerational, events. One does not experience mortality in one's own body, but in the family body.²⁰

Medical chiller-thrillers get a good deal of effect by exploiting the unspeakable intimacy of virological and bacteriological infection.²¹ These ideas are more familiar than the equally explosive transmissibility of feeling-states to which the pathographies testify. The feelings and bodily states which are part of the death of their parents suffuse the pathographers' own bodies: sorting out who 'has' the pain proves to be next to impossible. I will finish with a brief discussion of an example of the complications that ensue when medicos attempt to sepa-

19. *Ibid.*, p. 226.

20. Elaine Scarry makes this point in *The Body in Pain: The Making and Unmaking of the World*, Oxford University Press, New York, 1985, when she notes that Lear only dies after he has fully experienced the paradox of enduring death as a conscious, living being: through enduring Cordelia's death, as fully a death of self as his own imminent death will be. The same might be said of Romeo and Juliet.

21. See, for example, Robert Preston, *The Hot Zone*, Anchor Books, New York, 1995. This work is about the Ebola virus, and is organised around explicit accounts of the intimacy and violence of infection: a dying man begins an epidemic by vomiting Ebola-laden blood into his doctor's eyes and mouth; infected laboratory animals bite, spit and fling Ebola-packed faeces at their captors.

rate patient and non-patient in this way, the splendidly entitled 'A Case Of Amyotrophic Lateral Sclerosis' (ALS).²² The ostensible purpose of this article is to show the advantages of empathic medical treatment, but what I read in it is the account of a nice doctor who is doing her best in a painful situation, but is defeated by the preliminary question 'who is sick?' She does not, in fact, even seem to know that it is a question that should be asked. She diagnoses her identified patient, the elderly Mr Baker, as having the terminal wasting disease, ALS; his wife wants to retard the progress of the disease, a literally hopeless task. The wife, however, is also elderly, and is not well either, suffering from 'angina, diabetes, and arthritis'. Partly as a result of her angry struggles to care for her increasingly disabled husband, and to force him to get better (struggles which distress the enfeebled Mr Baker), Mrs Baker predeceases Mr Baker, dying of a heart attack some six weeks before he dies of the effects of ALS (a terrible result for both of them). But in this narrative, Mrs Baker's illnesses remain, as it were, outside the category of 'disease'. That is, for the physician and apparently for Mrs Baker too, they remain a *kvetchy* collection of irritating symptoms which are not 'read' as part of a meaningful medical narrative. Mr Baker's disease is one which his doctor feels competent to split off from the body of his wife. It can be argued, however, that this flies in the face of the obvious: Mr Baker's ALS kills his wife, and her angina complicates his condition. What would have happened if the Bakers had been treated as a dying couple rather than as one sick person and one difficult relative?

Much of the history of disease, then, as Professor Patterson shows, can be read as biomedicine's attempts to reduce the concept of embodied illness to questions of biochemistry, pharmacology and surgery. Disease is these things, but it is not only these things. Bringing back complicating modalities such as 'lifestyle' and environment, encourages the consideration of what it means to bring back relationships, with family, society, and with other life forms (including micro-biological ones). Considering disease or even injury as something that runs a course in one body makes it, in some respects, untreatable. Even bullets are interpersonal events.

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22. David Barnard, 'A Case of Amyotrophic Lateral Sclerosis', *Literature and Medicine*, 5 (1986), pp. 27-42.