A patients' history of medicine

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Introduction

This paper outlines a project originally entitled 'The true history of medicine'. It was intended to be taken with a pinch of salt, like the name of Peter Carey's Booker Prize-winning novel, *The true history of the Kelly Gang*.[1] 'If you call a book "true history" each word calls the other into question',[2] Carey has said and that was, in part, my purpose. There are good reasons for the adoption of another title, but the original one had its usefulness. It put on the table a claim which is all but indisputable: that medical history has, if not entirely ignored, at least marginalised, the history of patient experience.

To say that the true history of medicine has not yet been written can sound absurd. There is a vast archive of articles, journals and books on just this topic – the history of medicine. But this is, rather, the history of a profession, the history of medical practice, seen from the professional point of view. It represses the epistemological subject, or – to put it less philosophically – ignores, by and large, the experiencing patient. There must be another history of medicine which draws on the writings of patients, a history which can at least claim to represent the impact of medical institutions and procedures on their subjects. In shifting to the title 'A patients' history of medicine',[3,4] I am acknowledging that this would be an account distinct from official history. But it would fill an enormous gap.

Medicine could be considered as a drama, an interchange in which the physician plays a major role, but in which there are other important actors, in other roles: the pharmacist, the nurse, the carer, and the patient and their family. The patient is an actor – not, as the very term implies, the recipient of others' expertise and attentions but actively involved in interchange or dialogue with the other role players. This actor's role is more important than any other, if only because they are always on stage. Their experience would be the great monitor of the inventions, innovations, and organisational changes that medicine has seen over the last two and a half centuries.

If this is the theatre of medicine, it follows that we should draw out and listen to the patient's voice. But the term 'voice' throws all the emphasis on speaking, and I want to emphasise the importance and significance of patients' writing. 'A patients' history of medicine' (with all the qualifications denoted by that tiny prefacing pronoun) can and must be built from the consciously formulated, carefully composed and meditated narratives of patients. Casually recorded comments (in diaries, for example) are distinct from those writings which are enterprises of patienthood. To emphasise their narratives is to propose that the present-day patient, facing the dilemmas of their suffering alone, may inherit an intellectual tradition.

Story and narrative

This should be distinguished from the current model of 'narrative medicine', as proposed by Rita Charon. As she puts it, 'the effective practice of medicine requires narrative competence'; more specifically:

> *[A]long with scientific ability, physicians need the ability to listen to the narratives of the patient, grasp and honor their meanings, and be moved to act on the patient's behalf. This is narrative competence, that is, the competence that human beings use to absorb, interpret, and respond to stories.*[5]

Charon's admirable project is to humanise medicine by training physicians in the capacity to understand and reflect upon the 'stories' that their patients tell them.

There is or ought to be a distinction between 'story' and 'narrative'. Because a story is told in real time, to a listener, it is both interactive and provisional. Narrative refers in the first instance to a written text. And because it refers primarily to a text, it can, and often does, include the ideas of shaping, organisation, and most importantly, reflection upon experience. It does not require a present listener, or

NEW SERIES

This series comprises three keynote papers from the 2006 annual meeting of the UK Association for Medical Humanities (King's College London) organised by Brian Hurwitz and Neil Vickers (see www.amh.ac.uk/amh_conference_2006.htm). The first paper is by the internationally-renowned Jane Austen scholar, John Wiltshire. It offers a new approach to the history of medicine, one that is grounded in patients' experience, using literary and historical sources. A regular column exploring links and synergies between medicine and literature will follow in 2008. What roles can literature play in reflecting and influencing good practice, and what sorts of images of doctoring are to be found in drama, poetry, fiction, biography, electronic fora and film? The editors would be pleased to receive short papers, ranging from 500–1,000 words, on relevant topics. Those interested in contributing should e-mail brian.hurwitz@kcl.ac.uk or neil.vickers@kcl.ac.uk

interlocutor: instead it is addressed to the community of possible readers. The construction of a narrative can be, and often is, an independent, self-conserving, even self-making, experience. And because it exists as a text, a narrative may possess an authority that a story, *qua* story, does not.

In ordinary discourse these two terms are certainly interchangeable. Charon's description of 'narrative competence' translates readily into the desirable ability to 'respond to stories'. Narrative, the intellectual term, is associated with the doctor. Story, the informal, everyday word, is attributed to the patient. Those qualities of narrative I have just described are elided when the focus shifts to the patient, who simply tells a 'story'. 'Narrative medicine', formulated from the viewpoint of the clinician, is in danger of robbing the patient of the authority to represent themselves independently of medicine. It continues rather than investigates the traditions of medical hegemony.

The personal narrative of illness experience has been termed 'pathography', which shifts the focus from a patient-owned genre, and puts it 'under the authority of the medical gaze'.[6] But I shall use this unhappy word because it is so useful in gathering together a heterogeneous collection of material, treating an enormous range of medical conditions and experiences, and include within it narratives of illness experience not published by the patient themself. It is important to understand that 'autopathography' is not the only, or even the most telling, form of extra-clinical medical narrative.

Pathography

There is another branch of medicine in which narrative now plays an important role: bioethics. Its arrival is commonly dated to the introduction of the kidney dialysis machine in the 1960s, and the subsequent problems of triage. Concurrently, pathographies began to be published in greater numbers. Pathography may then, like bioethics, owe its flowering to biomedicine. Such issues as whether it is right to maintain life by artificial means, whether one should tell 'the truth' to a dying patient, under what conditions it is right to terminate treatment appear in many patient narratives of the 1960s and 1970s, and the same issues are debated within bioethics. But there the resemblance ends. Bioethics, though supposedly 'patient centred', is also naturally physician-addressed. The patient's 'story', often abstracted and simplified, with attendant circumstances removed to preserve privacy, is an item in a larger discourse. It is the clinician or philosopher who is made the repository of ethical consciousness in the narratives of bioethics: the patient's 'voice' is manipulated, necessarily, within the ethicist's design.[7]

Pathography has therefore only been around for about 50 years. Or so we assume. Anne Hunsaker Hawkins's *Reconstructing illness: studies in pathography* focuses almost exclusively on contemporary or near-contemporary works, declaring that 'Pathography is remarkable in that it seems to have emerged *ex nihilo*,' and that 'book-length personal accounts of illness are uncommon before 1950 and rarely found before 1900.'[8] This would be one problem for the project I am outlining. Another is that modern medicine grew from the possibilities opened up by the foundation of the public hospitals in the early 18th century. Such hospital patients had neither time nor capacity to record their medical experiences. As far as the historical record is concerned, they are dumb.

The prospect of constructing a history of patient experience begins to seem impossible. Perhaps Roy Porter's 'Medical history from below' has taken this concept as far as it could go.[9] But this, in effect, is the social history of medicine: in Porter's phrase, 'how ordinary people in the past have actually regarded health and sickness'. It certainly can deliver, by means of statistics, record books, letters, diary entries and other circumstantial evidence, a sense of what patienthood in earlier centuries might feel like. But the premises of the social history of medicine mean that the patient must always be ultimately the generic, 'ordinary', representative patient.

A cornerstone of this history, though, would be the uniqueness of each patient's experience. 'Same virus, different disease': this comment on AIDS as experienced in different locales might be extended to all other conditions diagnosed and categorised by medicine.[10] Different disease: different body, different treatment, different circumstances, life history and imagination. A patient's history of medicine would draw then on necessarily idiosyncratic and peculiar accounts; it might even tend towards a cacophony of different enterprises. But if each narrative 'voice' were situated within the medical culture of its time, then this history would not become shapeless. Instead it would, along with an enhanced understanding of patient individuality, contribute to a more accurate assessment of medical change or progress.

So this project must disavow representativeness in any simple or statistical sense. There is a further difficulty. Even in the past 50 years patients who document their experience are the exception. The authors of pathography are, by definition, self-selecting. They are often writers, or celebrities, before they become patients; that, commonly enough, is how they get published. And some of these pathographies are, apparently, 'ghosted'. One might certainly object that the pathography is a middle-class genre, hardly likely to yield knowledge about the majority of patients throughout history. But these difficulties can be worked around, and may even yield insight, as I shall demonstrate.

Is pathography, also, as Hawkins claims, a recent genre? If not, where are the materials for a history of patient experience before the pathography of the 1960s? This is not an easy question to answer, partly because it is only just beginning to be asked. W.E. Henley's poetic sequence 'In hospital', first published in 1875, may give us some idea.[11] The first poem is called 'Enter patient':

I limp behind, my confidence all gone,
The grey-haired solder-porter waves me on,
And on I crawl, and still my spirits fail:
A tragic meanness seems so to environ
These corridors and stairs of stone and iron,
Cold, naked, clean – half workhouse and half-jail.

Henley (1849–1903) spent a year in the Old Edinburgh Infirmary under the care of Lister. Granted, he was not an average patient. He records, in effect, a loss of caste, and the

demeaning environment is felt as a matter of personal shame. Nor was George Orwell, whose account of a stay in a French public hospital ward in 1929, 'How the poor die' was published in 1946 (Orwell makes the point that conditions in the Paris hospital resembled those in English hospitals of an earlier period). These descriptions are the more forceful, in fact, because they are seen through the eyes of a stranger. Both Henley and Orwell, upper-class men, are shocked at what they find, and see and feel sharply. One thing that emerges from almost all pathographies, contemporary as well as past, is that the patient is stripped of their social status. Thus the issue of class is a diversion.

Fantasy and reality

There is still, however, a further objection to the outlined project. Do patients who document medical experiences not shape and organise them according to far more demands than the truthful recording of facts? Or, to put it another way, are patient narratives not more expressive of the culture in which they are written (and published) than about historical reality (whatever that is)? It is certainly correct to assume that patients will reflect the narrative conventions of their time, and if, in addition, they are shaped and organised, this may involve conscious or unconscious distortion. But this is no different from any other history built from first-hand materials. Oliver Sacks once commented that 'Patienthood is a nightmare'.[12] Not just that being a patient can be a dreadful experience, but that the patient may live in a fantasy world. The patient is reduced by pain, stress, fear, the effects of drugs and the unfamiliarity of the world in which they find themselves, to a childlike state, in which atavistic terrors and hallucinations may take over, or obscure, the realities of treatment. But this need not be a drastic objection to the project. It does mean, though, that we must expand the category of 'experience' to include the patient's fantasy.

Fundamentally, as psychoanalysis has taught us, reality and fantasy co-exist, and it is always a struggle to reconcile the two. But one way in which we can recognise the presence of fantasy in the patient narrative is that, so often, doctors and nurses are divided into that simple black and white which is the small child's means of organising the world. Even in sophisticated narratives, like Simone de Beauvoir's *A very easy death* (1963), a bad doctor and a good doctor, an angelic nurse and a cruel nurse populate the imagination of the narrator.[13] In the most famous early pathography, Frances Burney's 'A mastectomy' (1811), the surgeon Dominique-Jean Larrey is the embodiment of sensibility – tender, sympathetic, considerate, kind – while Dubois, his colleague, who acts as 'commander in chief' and gives his commands '*en militaire*', is the ruthless authoritarian who causes the patient her terrible pain.[14] Yet it is Larrey who actually performs the surgery.

Burney's narrative is probably the best example to illustrate how the patient's experience – their feelings and fantasies – can be represented concurrently with historical and 'real' conditions. Most readers, for example, caught by the appalling details of surgery before anaesthesia, are tempted to read the assembled doctors as enemies of the patient. The sudden arrival of 'seven men in black', a moment which Burney revives with the cry 'Why so many? [And] without leave?'[14] suggests invasion, and her account of the surgeons' preparations, seen through a muslin handkerchief placed over her face (Dubois describing a circle and cross in the air) has ritualistic elements that have led many readers to describe the experience as a form of rape.[15] (In one of Burney's later additions to the document, Dubois becomes 'the Magician.'[15]) The narrative simultaneously registers the surgeons' side of the experience: the delays that are attributable to their reluctance to proceed, Dubois's conviction that the operation cannot succeed, the arrival of apprentices to learn from the operation (thus the unexpected appearance of seven men) – the need above all, in this dangerous operation on a fifty-nine year-old celebrity, to share responsibility. The moment that Burney experiences as most terrible is when Dubois insists on the scraping of every 'peccant atom' from the wound – but he is, as medical readers will realise, only doing his job. There is much evidence that this operation is certainly not 'for them ... a clinical, routine, impersonal event'.[15]

Genre

What needs stressing though is that the patient's experience, which must include the patient's hopes, fears and fantasies, is as much part of medical history as the official or objectivist history of medical men, discoveries and organisations.

Burney's account of her mastectomy was not the only pathographic narrative she composed. Much less well known is her 'Narrative of the last illness and death of General D'Arblay' (1820), an account of her husband's last year with (probably) rectal cancer when they were resident in Bath.[16] It depicts fully and dramatically, and over a period of months, the emotional histories both of the patient and the wife who is his constant companion and nurse. Madame D'Arblay does battle – as do so many of her successors in similar situations – with both religious and medical professionals. If Burney's 'Mastectomy' is the first fully fledged pathography, her 'Narrative' in fact is the first extended narrative by the figure we now know as the carer.

It is important to recognise that there are two branches of the genre: the autobiographical pathography (the 'autopathography') and the memoir of the carer or relative. To borrow a term from ethnography, the carer is a 'participant observer,' a person who both partakes (to a degree) in the experience of suffering, and stands outside it – a bridge between the positions of doctor and patient. Any credible history of medicine from the position of the patient must also include pathographical memoirs in its sources. The phrase 'the experience of the patient' which I have been using must be understood to include the experience of the carer–narrator.

It is possible, of course, to give patients' narratives a high degree of intellectual respect, without referring to the external history that frames them. Much of the work that has been done so far on the modern pathography has concentrated on ordering them into sub-genres or species, to see them as odyssey narratives or battle narratives or confessional narratives, for example.

These are archetypes, myths, or ahistorical forms which stories of many different diseases, conditions, and circumstances will exemplify. But this approach to the patient narrative strips it away from the particular social and medical setting in which the experience is embedded. In a word, it depoliticises the patient narrative. By splitting our study of patients' narratives from medicine, we avoid any critique of medicine. But it is precisely in order to further our understanding of medicine that I propose we construct a history of the patient.

We need to recognise both that the present flowering of the pathography is a response to new medical and social conditions, and that the genre has a history. 'A patients' history of medicine' will take an unorthodox form. It will need to be true to the differential experiences of patients – even, or especially, sufferers from 'the same' disease. And it will be a history that somehow contrives to respect different authors' different intentions in writing. Because it will treat patients' narratives as wholes, as purposeful and fully-conscious enterprises and not merely as sources to be drawn upon for an account of social conditions, it will enhance the intellectual status of the patient. To understand that patienthood has a complex and articulate inheritance, to give the patient an intellectual history, would be to make the partnership of clinician and patient a little more mutually sustaining.

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Biography

John Wiltshire is Professor in English at La Trobe University, Melbourne. He writes on literature and medicine, forms of narrative in medical contexts and on medicine, nursing and narrative. He is an international contributing editor on the journal *Literature and Medicine*. With Paul A Komesaroff, he has published *Drugs in the health marketplace* (1995) and, in collaboration with Judith M Parker, articles and chapters on nursing practice in various journals and collections. With Paul A Komesaroff and Philipa Rothfield, he has edited *Sexuality and medicine: bodies, practices, knowledges* (2004) and in preparation is *Medical progress and patient experiences*. His works on Jane Austen, *Jane Austen and the body: 'The Picture of Health'* (1992), *Recreating Jane Austen* (2001) and *Jane Austen: introductions and interventions* (2003), have made him one of the world's leading Austen scholars.

References

1 Carey P. *True history of the Kelly Gang*. Brisbane: University of Queensland Press, 2000.
2 Ingram P. Representing the Irish body: reading Ned's armour. *Antipodes* 2006;20:12–19.
3 Zinn H. *A people's history of the United States, 1492–the present*. New York: Harper Row, 1980
4 Zinn H, Arnove A (eds). *Voices of a people's history of the United States*. New York: Seven Stories Press, 2004.
5 Charon, R. Narrative medicine: a model for empathy, reflection, profession and trust. *JAMA* 2001;286:1897–902.
6 Frank A. *The wounded storyteller: body, illness and ethics*. Chicago, IL and London: University of Chicago Press, 1995.
7 Wiltshire J. The patient writes back: bioethics and the illness narrative. In: Adamson J, Parker D, Freadman R (eds), *Renegotiating ethics in literature, philosophy and theory*. Cambridge: Cambridge University Press, 1998.
8 Hawkins AH. *Reconstructing illness: studies in pathography*. West Lafayette, Indiana: Purdue University Press, 1993:3.
9 Porter R. The patient's view: doing medical history from below. *Theory Soc* 1985;14:175–98.
10 Keniston K. Introduction to the issue. In: Graubard SR (ed), *Living with AIDS*. Cambridge, MA and London: MIT Press, 1990.
11 Henley W. *The Works of WE Henley*. London: D Nutt, 1908.
12 Sacks O. *A leg to stand on*. London: Picador, 1991.
13 de Beauvoir, S. *A very easy death* (trans O'Brian P). London: Penguin, 1964.
14 Hemlow J (ed). *The journals and letters of Fanny Burney*. Oxford: Clarendon Press, 1972.
15 Epstein J. *The iron pen*. Bristol: Bristol Classical Press, 1989.
16 Wiltshire J. Love unto death: Fanny Burney's 'Narrative of the last illness and death of General D'Arblay'. *Lit Med* 1993;12:215–34.