

BOOK REVIEW

Writing patients' histories

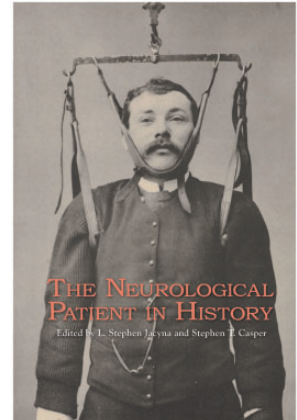
Dorothy Wordsworth's migraines

On Christmas Day 1801 Dorothy Wordsworth wrote in her journal, 'A very bad day... I went to bed after dinner'. Things had not improved on Boxing Day: 'My head ached and I lay long in bed and took my breakfast there'. She recorded further headaches on 4 days in February 1802 and 6 days in March, including one spell of four continuous days. Her brother William, at that time engaged in writing many of the poems that would seal his place in the pantheon of English literature, was also afflicted: on New Year's Eve 1801, Dorothy wrote, 'William had slept very ill—he was tired and had a bad headache'. And again in February, 'William [had] a bad headache; he made up a bed on the floor but could not sleep...' (De Selincourt, 1935).

It is clear from Dorothy Wordsworth's journals and letters that she suffered from recurrent headaches for much of her adult life. The earliest reference that I have come across was in letter written in 1787 at the age of 16; the last in 1829 at the age of 58, shortly before she experienced a serious illness while visiting friends in Halifax. The Grasmere journals, written between 1800 and 1803, are full of Dorothy's headaches and bowel complaints, and there can be little doubt that her problem was migraine. She employed various means to deal with them—usually resting or sleeping, occasionally going for a walk and rarely taking laudanum. In February 1804, after a particularly severe attack, she wrote to her friend Catherine Clarkson, imploring her to ask the famous Bristol physician Thomas Beddoes what she should do:

'I began with sickness, violent head-ache, yellow and pale looks... all times when I am not in uncommon strength (as I was before the last attack) after writing for any length of time or doing anything that exerts my thoughts or feelings, I have a very uneasy sense of want and weakness at my stomach, a mixture of emptiness, gnawing, and a sort of preparation for sickness—eating always removes it for a time... William after reading over my letter is not half satisfied with what I have said of myself—he bids me add that I *always* begin with sickness and that any agitation of mind either of joy or sorrow will bring it on—if any thing puts me past my sleep—for instance—also being in much company and hot rooms... Ever since I can remember going into company always made me have violent head-aches'.

THE NEUROLOGICAL
PATIENT IN HISTORY
By *L. Stephen Jacyna and
Stephen T. Caspar* Eds. 2012.
Rochester: University of
Rochester Press
ISBN: 9781580464123
Price: £50.00



Sadly the reply to this letter does not survive, but it is clear that Beddoes's opinion was sought, for in June she wrote again to Catherine:

'... perhaps you may have seen the letter I wrote to him a few days ago from which you would learn how grievously we had mismanaged about the medicines he was so kind as to prescribe for me... You know how inconvenient it is in such cases to be so far from the Apothecary, and how easily one is persuaded to delay from time to time because there is a little trouble in sending, else when we did not get the Scales, though I was so well, we should have certainly sent the medicines back to be weighed by Mr Edmundson. I have been quite well ever since I wrote to you, as if the very name of Dr Beddoes had acted upon me like a charm...'

Dorothy Wordsworth is somewhat unusual for her era in being literate, but in other respects it is likely that she is very much a typical patient dealing with a chronic neurological condition. She learns to deal with her headaches, recognizing situations that bring them on and devising ways to manage them. She actively uses local resources such as the apothecary, as well as accessible sources of information such as William Buchan's *Domestic medicine*. Eventually she goes to the trouble of consulting one of the foremost authorities in the land, but then she fails to

take his prescribed medicine. This too, is likely to be absolutely typical; pretty much everything we know about adherence to, or compliance with, prescribed medication regimes suggests that rates are low.

Poor compliance may of course be due to a break-down in communication between the doctor and patient: including failure to point out the importance of treatment or the rationale for the choice of therapy prescribed; lack of warning about side effects; or inadequate explanation of dosing regimes. The doctor may not have engaged sufficiently with the patient's world view, or understand whether the patient wants treatment, a diagnosis or simple reassurance. Receiving an 'expert' opinion may be therapeutic in itself; Dorothy Wordsworth certainly seems to think so.

I have touched upon the history of one early 19th century patient with a neurological condition to make the general point that patients are, for good or ill, active agents in the processes that determine their health. At one level this is a banal or trite thing to say—of course people are not passive receptacles into which fluids labelled 'health' or 'disease' are poured—but it is an essential point in the discussion that follows. One must naturally be cautious in extrapolating from the particular to the general, but there can be little doubt that sick people throughout the ages have been active agents in determining what they do about illness and disease. Our first question is, therefore, does the history of medicine as it currently exists, reflect this fact?

The historiography of the patient

In their introduction to the essays contained in *The neurological patient in history*, Stephen Jacyna and Stephen Caspar provide a succinct and useful introduction to the historiography of the patient. They take as their starting point a seminal essay by the late lamented Roy Porter, published in 1985, entitled, 'The patient's view: Doing medical history from below' (Porter, 1985b). In this article Porter exhorts practitioners of the emerging social history of medicine to take patients seriously. Previous histories of medicine are, by this account, almost exclusively written from the point of view of doctors, and to a much lesser extent of public health administrators and nurses. They fail to do justice to patient agency and the rich historical context in which doctors and patients ply their trade.

Porter was already mining the rich vein of the 18th century medical world to illustrate this point in a series of coruscating articles and monographs that introduced the concept of the medical marketplace and reinforced the power of the patient in making choices between competing medical practitioners, all of whom needed to make a living in an increasingly consumerist 18th century society. Jacyna and Caspar claim that the brilliance of Porter's portrayal of this era is in some way an 'implicit celebration' of a consumerist approach to medicine that ties in with the political upheavals occurring around the time the article was written, ultimately resulting in the provider–purchaser split in the NHS introduced during the third Thatcher administration. I am not sure that Porter would have recognized this interpretation of his work. It lies rather within a programme of historical enquiry

(that includes the work he did with Dorothy Porter on patients and practitioners in early Modern England) that makes the valid historical point that patients have always been active agents in choices and decisions about their health, even if their ability to choose between different doctors is constrained by their social and economic circumstances (Porter, 1985a; Porter and Porter, 1989). An excellent example of this in a slightly later period is George Eliot's depiction in *Middlemarch* of how the middle classes, with whom her novel is mostly concerned, generally relied upon the surgeon-apothecaries, Toller and Wrench, and did not normally have recourse to physicians, except 'when danger was extreme, and when the smallest hope was worth a guinea' (Eliot, 1874). Jacyna and Caspar also criticize Porter for being 'fixated upon patients of wealth and reputation'; whilst on one level this is a valid criticism, there can be no doubt that in an era before mass literacy, the most complete accounts of sickness and health necessarily come from the literate upper or professional classes, and that it is extremely difficult to find extensive historical resources that allow one to reconstruct the experience of sickness in other classes of society prior to the 19th century. This is not to say, however, that there are not excellent examples of attempts to do so, such as Mary Fissell's work on the hospitalized poor in 18th century Bristol (Fissell, 1991).

To my mind a more germane criticism of Porter is that the very subtitle of his article, 'Doing medical history from below', implies a power relationship of the doctor and patient which is not necessarily reflective of the actual medical encounter, particularly for the period prior to the mid-19th century with which Porter was most concerned. Whilst the medical profession might, and did, strive for ever-increasing degrees of control over its social relations with patients, their patients' adherence to treatment, and the direction of medicine within society as a whole, it is doubtful that the profession has ever achieved its goals in this process, even at the heights of the deferential society of the 1940s and 50s as epitomized and caricatured in Richard Gordon's novels or the *Carry On* films. Whilst Porter's exhortation has been taken to heart in the development of the history of medicine through its 'social' and 'cultural' turns of the 1980s and 90s, the very fact that a meeting such as that on which this volume is based was deemed necessary 25 years after the publication of Porter's essay, stresses the persistent lacune in the fabric of the historical literature where the narratives of patients are concerned, and reminds us just how difficult it is to recapture historical voices and accounts of sickness, illness, disease and death.

Jacyna and Caspar are uncomfortably aware that despite their best intentions, their volume may not succeed in this task: most unusually, the volume contains two essays which are analyses of the question as a whole and of the contributions that the other eight essays make to it. As they point out, Roger Cooter's piece on 'Neuropatients in historyland' suggests that the patient 'remains as elusive as ever': 'the hole in the middle of the donut [sic]', whereas Max Stadler argues instead that by triangulating different constructions of the neurological patient (those of doctors, the legal profession, carers, patient groups and patients themselves), the volume starts to flesh out the neurological patient 'as a category of historical contemplation'.

Constructing the neurological patient

The substance of *The neurological patient in history* is contained in eight essays, grouped in four pairs dealing with the question from the point of view of the medical profession, the public and private spheres [specifically the 19th century British legal profession, and the wife of an early 20th century patient with disseminated (multiple) sclerosis], patient groups and patients themselves. The first two articles, by Stephen Caspar on the evolution of the standard neurological examination and Ellen Dwyer on experimental epilepsy studies in inter-war Illinois, are interesting but familiar additions to the literature on the development of neurology as a discipline. Caspar makes convincing points about how structures were created that allowed previously tacit clinical knowledge to be conveyed in a reliable and reproducible manner. To treat this topic in the detail that it deserves is of necessity a huge task and Caspar's article feels shallow and rushed in places; but it nonetheless tantalizes with some glimpses of the historical process, the most fascinating of which is the concluding discussion of the institutionalization of neurological examination after World War II under the auspices of the splendidly named National Hospital Service Medical Supplies Working Party, which co-opted specialists and asked them to provide a list of equipment required for the performance of their speciality. Denis Williams and Macdonald Critchley duly complied; including familiar equipment such as tuning forks, patella hammers, bottles filled with substances for testing taste and smell, and von Frey hairs, as well more arcane items including special mattresses, toys for child patients and equipment necessary for insulin therapy and electroconvulsive therapy.

Marjorie Perlman Lorch's article on the medico-legal aspects of aphasia in 19th century Britain need not detain us, but the following essay by Katrina Gatley on the Cambridge artist and wood engraver Gwen Raverat, whose husband Jacques was diagnosed with disseminated (multiple) sclerosis in 1915, is a gem. Gatley mines the Raverat family correspondence to present the story of a spouse coping with her sick husband before and after a medical diagnosis is given (in this case by Risien Russell in 1915). Gatley shows how Gwen Raverat interpreted her husband's behaviour (both physical and emotional) in the context of his neurological disease, and how she used the fact of his illness and of the (at that time) inevitable decline associated with it, to negotiate with him, their family, and the world at large in deciding upon their mode of life as the disease progressed. Despite assimilating the medical understanding of disseminated sclerosis (and using that understanding to her benefit), Gwen found little comfort in this knowledge; as she later wrote, it was 'the worse thing in the world to watch suffering in helpless understanding'. In her conclusion, Gatley raises interesting questions about the issue of gender in 'influencing, deciding and delivering the home care and medical care needs of ill spouses' that would surely repay further research.

The articles on the role of patient groups—by Jesse Ballenger on Alzheimer's disease and Howard Kushner on Tourette's syndrome—are important contributions to a very sparse literature on these bodies. Any neurologist active over the last half century will recognize the increasing influence that patient groups exert over many areas of the discipline, driving research, political advocacy and local and national care initiatives. There is a tension in this

process, particularly evident in Ballenger's account, when 'exemplary' (often famous) sufferers are presented to the public. Ballenger discusses the cases of Rita Hayworth (whose cognitive problems were widely assumed to be alcohol-related), Janet Adkins (who in 1990 ended her own life at an early stage of the disease with the aid of Dr Jack Kevorkian) and Ronald Reagan. There is no doubt that a famous and motivated patient or carer can bring publicity, funding and political clout (Nancy Reagan for Alzheimer's disease, Michael J Fox for Parkinson's disease and Christopher Reeve for spinal cord injury, for example—all high profile Americans, interestingly), but are these 'exemplary' patients really typical? Can the testaments of the rich and famous truly speak to the experience of chronic neurological disease of less privileged members of society? Does their desire to 'beat' their disease (absolutely required to push for research funding) render such patients less suitable as role models for those who wish to understand how to accommodate their lives to chronic neurological disorders? And finally, as Kushner alludes to in his discussion of the role of Tourette's syndrome support groups, what happens when patient groups themselves marginalize patients with particular manifestations of a disease, or contribute to therapeutic inertia by resisting the withdrawal of drugs whose efficacy has been questioned? All of these questions deserve further consideration.

The final pair of essays—Stephen Jacyna's account of the 'psychasthenic poet' Robert Nichols, and Paul Foley's discussion of patients with encephalitis lethargica—also raise many questions. Foley's essay again asks whether it is possible to access the experience of patients in whom there is a profound disruption of consciousness, awareness or insight. Discussing the case of the journalist Duff Gilfond, he also points out another difficulty facing the would-be historian of the patient: does the patient even have the purported condition? In the case of Gilfond, Foley doubts that she did. The problems raised by Jacyna's essay are somewhat different: understanding Nichols's condition is difficult. What did it mean to be suffering from neurasthenia or psychasthenia in this period (these categories are no longer valid in modern neurology and psychiatry). Nichols suffered a nervous breakdown under bombardment in 1915; Jacyna is vague about his symptoms, and provides little detail of the neurological interpretation thereof (presumably because he only has one half of the correspondence to draw upon). He reproduces and comments upon some of Nichols's letters to, and about, the neurologists Henry Head and George Riddoch, and provides an interesting account of how Nichols drew upon the work of the French psychologist Pierre Janet to try and understand his symptoms and manage them. Nevertheless, the essay is curiously unsatisfying: I find myself wondering how relevant the rather self-obsessed musings of an obscure early 20th century poet are to the broader understanding of neurological patients, but perhaps I am biased. Neurologists (even historically-minded neurologists) often find such patients (these days one would call his symptoms 'functional') difficult to manage. Perhaps instead I should regard patients such as Nichols as really rather typical, and admire and learn from George Riddoch who was, as Nichols wrote,

'awfully good at his job. I know he gave me suggestion but I don't know when it was. I rather think it was when he made me touch my nose first

with one finger & then another. And he lulled me beautifully with parallels from Schubert etc. But the froth of flattery on the beer of psychological fact was spread so deftly that the beer went down oh deliciously. I came out feeling braced'.

What is a patient?

Reading and re-reading this volume, it is difficult to escape a niggling question: what is the point of all this? Why should one be interested in the neurological patient in history, or in the history of neurology? What, in short, is the point of the history of medicine?

It is quite clear, having recently returned to teaching the history of medicine after almost 15 years out of active practice in the field, that the subject has in the interim gone through something of a crisis of confidence that turns on this very question. When I first encountered the discipline in the late 1980s, the intellectual vigour was to be found very much in the social history movement of which Roy Porter was a leading light. Around the turn of the century there was a 'cultural turn' in the subject that looked to embed the history of medicine in the broad mainstream of cultural history. In the UK this seems to have been as much an administrative as an intellectual process, as the Wellcome Trust changed its policy of supporting independent History of Medicine units, embedded within medical schools or History and Philosophy of Science departments, to that of supporting individual researchers in general history departments. In this view of things, the history of medicine was simply to be a branch of social or cultural history—a fertile, interesting, and exciting branch to be sure—but nonetheless subservient to the broader interests of the wider historical community. In other parts of the world, however, the notion that the history of medicine might somehow be of use to doctors in training and in practice continues to be more widely held. Several of the articles in an important collection entitled *Locating medical history* (a *fin de siècle* status report on the discipline edited by Frank Huisman and John Harley Warner) expound the view that the main purpose of the history of medicine is to provide a moral compass for the medical profession (Huisman and Warner, 2006).

Whether one regards the history of medicine as simply a branch of general history, or as something that provides moral lessons for medicine, the importance of understanding the past accounts of patients cannot be overstated. *The neurological patient in history* offers a contribution to that record, and contains material of heuristic and substantive importance. I conclude with one final thought: before a definitive history of the patient can be written, a crucial historiographical question should be addressed that is neither covered by this volume nor indeed by the existing literature on the history of patients. It is this: at what point does a sick person become a patient? Is a patient solely what the medical profession and its much vaunted Foucaultian 'gaze' makes of a sick person? If the fundamental point of the clinical encounter is to turn a sick person into a patient, what effect does this transformation have on the sick person and those around them?

Mark Weatherall

References

- De Selincourt E, editor. The letters of William and Dorothy Wordsworth. Vol. 3. Oxford: Clarendon Press; 1935. p. 39.
- Eliot G, editor. Middlemarch a study of provincial life. London: William Blackwood & Sons; 1874.
- Fissell ME, editor. Patients, power, and the poor in eighteenth-century Bristol. Cambridge: Cambridge University Press; 1991.
- Huisman F, Warner JH, editors. Locating medical history: the stories and their meanings. Baltimore: Johns Hopkins University; 2006.
- Porter R, editor. Patients and practitioner: lay perceptions of medicine in pre-industrial society. Cambridge: Cambridge University Press; 1985a.
- Porter R. 'The patient's view: doing medical history from below.' *Theory Soc* 1985b; 14: 175–98.
- Porter R, Porter D, editors. Patient's progress: doctors and doctoring in eighteenth-century England. Stanford: Stanford University Press; 1989.