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### The Patient's View

**Citation for published version:**

Mazanderani, F 2014, 'The Patient's View: Perspectives from Neurology and the 'New' Genetics' Science as Culture, vol. 23, no. 1, pp. 135-144. DOI: 10.1080/09505431.2013.871246

**Digital Object Identifier (DOI):**

[10.1080/09505431.2013.871246](https://doi.org/10.1080/09505431.2013.871246)

**Link:**

[Link to publication record in Edinburgh Research Explorer](#)

**Document Version:**

Peer reviewed version

**Published In:**

Science as Culture

**Publisher Rights Statement:**

© Mazanderani, F. (2014). The Patient's View: Perspectives from Neurology and the 'New' Genetics, Science as Culture, 23:1, 135-144.

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## REVIEW

### **The patient's view: perspectives from neurology and the 'new' genetics**

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*The Neurological Patient in History*, L. Stephen Jacyna and Stephen T. Casper (eds), Rochester, NY: University of Rochester Press, 2012, 264 pages, £50.00.

*Neurogenetic Diagnoses: The Power of Hope, and the Limits of Today's Medicine*, by Carole H. Browner and H. Mabel Preloran, Abingdon: Routledge, 2010, 137 pages, £26.00.

### **Introduction**

In 1985 the historian Roy Porter called for a 'medical history from below', arguing that it was time to move away from a history of medicine focussed on the medical establishment towards one that paid attention to 'the patient's view' (Porter, 1985). Porter was not alone in this; since the 1970s historians and sociologists have been calling for their respective disciplines to pay more attention to what is variously referred to as the patient's 'view', 'experience', or 'perspective'. In no way limited to the social sciences, this repositioning and prioritising of 'the patient' has been shaped by a number of interrelated, yet strangely contradictory, social and political forces. Informed by Marxist and New Left inspired critiques of 'medicalization' (e.g. Zola, 1972; Illich, 1976), patient activists and allied researchers have sought to articulate the lived experience of illness as a means of 'emancipating' patients from medical hegemony. At the same time, a need to 'empower' patients has been championed by growing health consumerism (Lupton, 1997), and related shifts in medicine that place the patient, at least rhetorically, at the centre of clinical practice and health policy.

Despite its highly eclectic genealogy, differences in ideology and overarching aims, research that emphasises the patient's view is united by the common goal of turning patients, to adopt Jeannette Pols' terminology, from 'objects-that-are-known by medicine' to 'subjects-who-know' (Pols, 2005: p.204). Widespread and influential as this subjectification of the patient has been, it comes with its own set of conceptual challenges and contradictions. These range from methodological questions about how to gain access to 'authentic' patient experiences,

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be they historical or contemporary, through to on-going debates about the epistemological and ethical significance of the patient's perspective as a source of knowledge.

The two books covered in this review focus, albeit in different ways, on the 'neurological patient'. Given the dramatic growth in the neurosciences since the 1990s – dubbed the 'decade of the brain' (Rose, 1995) – and the pervasive tendency to turn to the 'neural' as a means for explaining human personality and behaviour (Vidal, 2009), a focus on the 'neurological patient' is clearly timely. Furthermore, as Stephen Jacyna and Stephen Casper point out in their excellent introduction to *The Neurological Patient in History*, what makes this such an interesting topic is the way that neurological disease 'has a peculiar capacity to strike at the core of what in Western culture is taken to constitute personal identity, social status and competence – indeed even what it is to be human' (Jacyna and Casper, 2012, p.1). The subject of the neurological patient is, therefore, not just a topic of interest in its own right. Insofar as neurological conditions tend to affect people's cognitive abilities, speech, and affective responses, it also problematizes the assumption that 'the patient' is always an articulate, rational citizen/consumer whose views can be straightforwardly recorded and taken into account. This does not, of course, mean that people with neurological conditions are unable to share their experiences or that they are not, often, highly articulate and engaged patients. Rather, research on neurological patients as 'subjects-that-know' open up avenues for critically engaging with questions around the *kind* of 'knowing subject' that patients are presumed to be and the types of knowledge they are expected to have.

*The Neurological Patient in History* is concerned with the history of nervous disease in Western medicine, with 'what it *was* to be a neurological patient' (Jacyna and Casper, 2012, p.1). Its ten chapters have been broken up into five 'parts' of two chapters, with each part focusing on different contexts in which neurological patients have been constructed: those of medicine, the legal vs. the domestic sphere, patient groups, individual patients, and (last, but not least) the history of medicine itself. In contrast, *Neurogenetic Diagnoses* by Carole Browner and Mabel Preloran is a rare example of work that examines the intersection of genetics and the neurosciences (in this case clinical neurology). Over the past two decades medical genetics and the neurosciences have both expanded rapidly. This expansion has precipitated a wave of social science research grappling with the effects of the 'new' genetics

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(e.g. Peterson and Bunton, 2002; Atkinson et al., 2006; Pálsson, 2007) and the neurosciences (e.g. Beaulieu, 2002; Pitts-Taylor, 2010; Pickersgill and Keulen, 2012). Yet there have been relatively few attempts at analysing the interrelationship between the two. The dual focus of *Neurogenetic Diagnosis* on neurology and genetics, therefore, makes it very well positioned to develop insights on the changing dynamics of what it means to be a neurological patient in the emerging era of genetic and genomic medicine. Interested in the effect of the increasing availability of genetic technologies in medical practice, the authors use ethnographic methods to explore the introduction of genetic testing of adults with movement disorders in the United States. Like *The Neurological Patient in History*, *Neurogenetic Diagnoses* is structured in distinct parts of two chapters, only here the chapters follow the 'patient's journey', starting with initial symptoms, searching for answers, medical examinations and tests, receiving a diagnosis, and finally 'living with' a particular condition.

Rather than discuss each book separately, this review takes their shared concern with the subject of 'the neurological patient' as its focus. More specifically, it draws on key cross-cutting themes that highlight the different forms of knowledge and ways of knowing that constitute the patient's view in the context of clinical neurology. This is done in three sections. The first explores the role of diagnosis, as a process and a category (Jutel, 2008), in the making of particular types of patients. The second examines the blurred boundaries between experiences of 'living with' illness and biomedical knowledge. The third focusses on ethical issues around the articulation of the patient's view, in particular the question of 'whose' experience is taken into account and in what way.

### **Making patients: diagnosis, knowledge and hope**

Neurological conditions are notoriously hard to diagnose, often progress over long periods of time and, in many cases, have no cure. As a number of neurological conditions are, at least partly, hereditary, people living with undiagnosed neurological symptoms are increasingly able to turn to these tests as a means of seeking a diagnosis. Elucidating this 'search for answers' is the focus of the first part of *Neurogenetic Diagnoses* (pp.21-48). The authors follow the experiences of two women (Liz and Ana) as they undergo genetic testing which they hope will result in diagnoses that explain debilitating neurological symptoms. In Liz's case, the results for hereditary ataxia (a condition that causes degeneration in the brain and

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spinal cord) are inconclusive (pp.23-36). In Ana's, the test for the gene for Huntington's – the disease her father died from – is 'positive' (pp.37-48).

Browner and Preloran's in-depth portrayal of these two women's diagnostic odysseys highlights the time and effort people living with 'medically unexplained symptoms' expend in order to receive a diagnosis (Nettleton, 2006). It also shows how, paradoxically, in cases where people are already experiencing significant health problems, a seemingly 'negative' diagnosis can provide a sense of hope and control, whereas, no diagnosis – *not knowing* – is perceived as extremely disempowering. This is evident in Liz's disappointment at her lack of a diagnosis, and Ana's description of hers as 'strangely liberating' (p.39). Moreover, Ana's test result had a number of wide-ranging consequences. It turned her symptoms, previously categorised by medical practitioners as mental health problems, into a 'legitimate' medical condition, opening up new avenues of support. More importantly, it confirmed her long-held beliefs about her condition, enabling her to rethink her past experiences and current family relations in the light of this new diagnosis. The latter, therefore, not only turned Ana into a new type of patient, but significantly, into a new type of person – someone carrying the gene for Huntington's disease, with everything that this implied for her.

As many of the neurological conditions for which genetic testing is being made available have no effective treatment, the strong desire to *know* expressed by many of the patients who took part in this study highlights how knowledge can be a form of therapeutic intervention in its own right. Yet, an interesting finding was that many medical practitioners thought there was little or no benefit in providing genetic tests if the results of these tests were not medically actionable. This contrasted with the patients' desire to know, as well as the views of some specialists, who believed that *any* diagnosis, even if it did not lead to treatment or cure, was better than none (pp.98-109). In the words of one neurologist:

Saying that we don't know [what you have] closes the door to hope and we have to recognize that hope is nourished in the trust our patients have for us, for our knowledge and experience. Saying we don't know and showing no willingness to look for answers fuels uncertainty and after a while patients lose hope and they decline. (Browner and Preloran, 2010, p.103).

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The authors' emphasis on how different medical practitioners and patients perceived the value of knowledge differently invites us to question the contemporary nature of hope and its relationship to medical diagnoses and emerging technologies – and to knowledge more generally. Unfortunately, in spite of its inclusion in the long title, the concept of 'hope' remains relatively unexamined in *Neurogenetic Diagnoses*. Wider work on hope, such as that of Cheryl Mattingly (2010), is briefly mentioned, but the authors' own theoretical contribution to extant social science research on the topic (e.g. Miyazaki, 2006; Novas, 2006; Brown, 2011) is never really developed.

New technologies have long been recognised as playing a key, sometimes disruptive, role in disease classification and diagnosis (Rosenberg, 2002). And it is clear that the genetic tests analysed in *Neurogenetic Diagnoses* are not only intervening in clinical neurology, but are creating new relations and forms of patienthood with relevance in and outside of clinical contexts. When read alongside *The Neurological Patient in History*, however, the genetic tests explored by Browner and Preloran emerge as a continuation, rather than disruption, of technologies for diagnosing neurological conditions. This is particularly evident in Chapter 1 by Steven Casper (pp.21-43). Casper discusses a number of tools and techniques developed during the 19<sup>th</sup> and early 20<sup>th</sup> centuries to diagnose neurological conditions. Through a nuanced analysis of how tacit knowledge was encoded in textbooks, routinized and institutionalized as part of the neurological exam, Casper draws on Foucault (1976) to argue that the aim of the neurological exam was to make invisible pathology visible; turning 'the patient's body into a machine of its own revealing' (p.33). While genetic tests of the kind discussed by Browner and Preloran were obviously not available during this period, these tests, like the ones described by Casper, seek to diagnose disease by looking inside the patients' body. Yet in searching for distinctively genetic diagnoses they defy any simplistic localisation of disease as inside or outside the body, in an individual or their family.

Although Casper's chapter is the only one in *The Neurological Patient in History* to focus explicitly on practices of clinical diagnostics, the *effects* of diagnosis resonate throughout the volume. These are numerous and by no means easy to pin-down, ranging from legal ramifications (e.g. Chapter 3 by Marjoria Perlman Lorch), through to the creation of patient organisations (e.g. Chapter 5 by Jesse F. Ballenger) and the shaping of patients' sense of self

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(e.g. Chapter 7 by Stephen Jacyna). Furthermore, while Casper focuses on physical tests in the clinic, other factors that blur the boundaries between the patient's experience and medical knowledge constantly slip into the discussion, including the patients' psychology, occupation, environment, and family relations. Thus, as in *Neurogenetic Diagnoses*, one is left with an appreciation of the power of diagnosis to make particular types of patients, combined with an awareness of how no one medical test or category can accurately encompass what it means to 'live with' a neurological condition, diagnosed or not.

### **Perspectives on 'living with' neurological conditions**

While the first part of *Neurogenetic Diagnoses* focuses on processes of diagnosis, the second looks at the lives of patients who have received a 'devastating' neurogenic prognosis (pp.49-80). This section explores the experiences of two men, diagnosed with Friedreich's ataxia and Spinal Muscular Atrophy (SMA) respectively. In both cases, the receipt of a diagnosis affected how the men perceived themselves and their relationships with others (particularly family members), resulting in their making radical, in some cases pre-emptive, changes to their lives. The strategies they developed, both practical (changing jobs, moving country) and psychological (rethinking their past, adjusting expectations), for coping with their deteriorating health are presented through detailed, often very moving, descriptions and interview excerpts.

In a number of places the men's interpretations of their conditions differed from those of the medical practitioners (e.g. pp.66-67). This is treated by the authors as a reflection of the difference between 'disease', as medically diagnosed organic condition, and 'illness', as the personal experience of being unwell. This is a well-known distinction that, with a few rare exceptions (Mol, 2002), is often reproduced in social studies of medicine. From this perspective, the patient's view, usually solicited via in-depth interviews, maps on to the concept of 'illness', while 'disease' is left under the jurisdiction of medical professionals. It is hoped that by contrasting differing interpretations of 'illness' and 'disease', patients and practitioners can develop a better understanding of each other's positions, enhancing communication and, ideally, health outcomes. This, clearly, is an admirable aim; however, as amply illustrated by the empirical material contained in both books, the ways that patients *actively draw on biomedical knowledge* and develop subjectivities *based on*, rather than *in*

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*opposition to*, it, highlights the contingencies of the above distinction and brings its analytical validity into question.

Chapter 7 of *The Neurological Patient in History*, in which Stephen Jacyna's analyses the letters written by the neurasthenic poet Robert Nichols (1893-1944) to his neurologist Henry Head (1861-1940), provides a striking example of how experiences of illness are shaped by medical categories and understandings (pp.167-183). This is a beautifully written chapter that illustrates the affection that can develop between patient and physician, and shows how strongly Nichols identified with his diagnosis. Rather than seeing his 'disease' classification as something forced on him, it was integrated into his experience of 'illness'. Judging by the letters, Nichols began, over time, to see himself very much as an 'expert patient' (foreshadowing the development of this concept in contemporary healthcare), offering advice to others and even signing off a letter as 'Robert Nichols, M.D.' (p.180). He described his first meeting with Head as 'the most important event in my life to date' (p.168) and affectionately addressed the eminent neurologist as 'Headlet' – a nickname that one struggles to imagine many neurologists today being too pleased with!

Similarly, Paul Foley's contribution on Encephalitis Lethargica (EL) in Chapter 8 draws attention to how blurred the boundaries between patient, researcher and medical practitioner can become (pp.184-214). EL, also known as the 'sleepy sickness', is a condition of unknown origin that causes patients to have Parkinsonism, visual disturbances, psychosis, extreme lethargy, and in some cases to enter catatonic states. Drawing on the self-reflections of patients, some of whom were also medical practitioners, Foley sketches out the role that reflection and self-analysis plays in grappling with unexplained and poorly understood symptoms – an alternative mode of 'looking inside' the body with a long pedigree in philosophy, psychoanalysis and psychology. The chapter also draws attention to issues around medical specialisation and the potential for conflicts and contradictions between different professional groups, in this case neurology and psychiatry. The significance of inter-professional collaboration and conflict is reiterated in Marjorie Lorch's discussion on the intersection of Medical and Legal aspects of Aphasia in 19<sup>th</sup> century Britain (pp.63-80) and Howard Kushner's on neuropsychiatry in Tourette's syndrome (pp. 129-166). In a more contemporary setting, this topic is addressed in Chapter 6 of *Neurogenetic Diagnoses*: 'The



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Neurologists' Conundrum' (pp.97-111). All of which serves to highlight that it is not only the patients' voices that are plural and multifaceted. Far from being monolithic, medicine itself is multiple, riven with its own divisions and contradictions.

So far, this review has foregrounded aspects of both books that illustrate how profoundly the patient's view is entangled with medical knowledge and practitioners, but, of course, people's articulations of how they live with illness are not limited to or contained within medical descriptions or contexts. Indeed, what makes illness narratives so compelling is how they foreground the personal, highly emotional, aspects of living with life altering conditions. The epistemic authority of the patient's experience as a source of knowledge emerges not in spite, but precisely because, of its highly emotive and embodied dimensions. Its authority is premised on the singularity of individual experience that can, even in an era of evidence-based medicine, influence healthcare decision and policy making (see Moreira, (2012)). Moreover, when reading about these experiences, whether in the form of interviews, letters or even drawings, one gets a strong sense of how becoming a subject-who-knows, a producer rather an object of knowledge, can transform the experience of being a patient.

### **The patient's 'view' and the ethics of representation**

As has hopefully been made clear, both books emphasise the importance of generating an understanding of neurological disease from the perspective of the patient, something that, in the context of contemporary medicine, where 'patient participation' has become de rigueur, is relatively uncontroversial. Chapter 2 of *The Neurological Patient in History* by Ellen Dwyer provides a salient reminder that this imperative to include the patient 'voice' did not emerge without a considerable struggle on the part of patients, their family and friends (pp.44-62). Situating her chapter within the history of medical experimentation (Lederer, 1995; Marks, 1997), Dwyer analyses how the people who took part in the Northwestern Plan for studying epilepsy in the United States during the 1920s and 1930s were treated and represented. The resounding silence of the patient's voice in this context contrasts sharply with the rest of the volume, drawing attention to how, in addition to the patient's view being shaped by medicine, medicine has been changed through the active engagement of patients.

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Given this history and prevailing ethical concerns about the objectification of patients, it is not surprising that social scientists have been reticent to problematize the subjectification of the patient. When this has been interrogated it has typically been in relation to issues of 'data collection': *whose* experiences become known (the question of representativeness); and *how* they become known (the question of methods). In relation to the former, one key concern is what happens to patients who are unable or unwilling to articulate their experiences (Pols, 2005) – an issue that is clearly relevant to many neurological conditions and one that is tackled by Jesse F. Ballenger in Chapter 5 'Disappearing in Plain Sight' (pp.109-128).

Ballenger provides an eloquent description of how, since the 1970s, increasing numbers of people with Alzheimer's disease (AD) have written or spoken publicly about their experiences. Since the AD advocacy movement framed AD as destroying people's sense of self, rendering them incapable of speaking for themselves, narratives of living with AD provide a fascinating case for exploring what forms of knowledge are considered a valid and valuable part of the patient's view. A contradictory picture emerges from Ballenger's analysis. While narratives about dementia by people with dementia challenge contemporary ideas about personhood, they, are primarily written by people in the early stages of the disease and conform closely to the conventions of illness narratives more generally. This sparks an uncomfortable question: in uncritically valorising the patient as a knowing and articulate subject are we unwittingly promulgating one very particular version of patienthood and, indeed, humanity?

This question is addressed in various ways in *The Neurological Patient in History*; sometimes explicitly, as in Ballenger's chapter, and sometimes implicitly, as in Chapter 6 by Howard Kushner in relation to Tourette's syndrome (pp.129-166), another condition where the 'voice' and 'identity' of the patient is precisely what is at stake. But it also subtly permeates *Neurogenic Diagnoses*. For instance, as Liz's condition deteriorated, the researchers found it increasingly difficult to speak to her as she did not answer their calls or respond to their messages. Eventually, when they reached her, Liz explained that due to her worsening speech problems she no longer felt comfortable speaking on the telephone (p.33). Thus, the reader is made acutely aware of the fact that the experiences contained in the book, as in most social science research, are only those that can be communicated and shared.

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The experiences of caregivers and family members have often been omitted from medical history and sociology focused on the patient's view (Condrau, 2007), so it is worth noting that both books include an explicit emphasis on this. Drawing on the case of Jacques Raverat (1885-1925), who had Multiple Sclerosis (MS), and his wife Gwen Raverate (1885-1957), who cared for him, Chapter 4 of *The Neurological Patient in History*, by Katrina Gatley (pp.81-108), focuses on the interaction between patient and caregiver. Here, Gatley highlights the significance of informal care and the burden that chronic illness places on families. Based on Gwen's letters and drawings of her husband, this chapter opens up a very different 'view' of the patient, one based on the experiences of caring for rather than living with a neurological condition. Unsurprisingly, given that *Neurogenetic Diagnoses* deals with genetics, family and emotional ties are important themes here as well. While the opinions of caregivers are specifically brought to the fore in Chapter 5 (pp.83-96), the patients' stories are, throughout this book, situated in relation to their families, illustrating how family members respond to neurogenetic diagnosis in variable ways. This is particularly striking in Chapter 4, which discusses how three different siblings who all display symptoms of SMA, interpret the cause and effect of their condition very differently (pp.64-79).

## **Conclusion**

This essay began with a reference to Roy Porter's famous injunction for historians to pay more attention to the patient's view (Porter, 1985). Yet, Porter never really questioned what such a view might entail or whether and in what sense it was possible to gain access to it. In contrast, in his identically titled 'The Patient's View', David Armstrong argued that the patient's view was not simply what was *said*, but what was *heard*, and that what was 'heard' is a product of 'socio-medical perception' (Armstrong, 1984: p.743). Porter's and Armstrong's papers serve as apt illustrations of on-going epistemological tensions in how the figure of the patient is treated in the medical humanities and social sciences (Condrau, 2007). On the one hand, as a pre-existing subject whose experiences need to be represented; on the other, as subjects that are produced through the very discourse and practices that supposedly represent them (Armstrong, 1985). The first, broadly speaking, adopts a humanist approach, the second a constructivist or, following Foucault, genealogical one.

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While these two perspectives may seem incommensurable, this does not necessarily have to be the case, as shown in the preceding discussion. Patients, regardless of their specific condition, are mediated and shaped by medical knowledge, institutions and technologies, including ones that enact the patient as a knowing subject. At the same time, the experience of being a patient is always more than being identified with a particular diagnosis or disease and it is through foregrounding the embodied dimensions of the patient's experience that the notion of the patient's view has gained so much traction in social studies of medicine. As patients become increasingly involved in medical decision-making at all levels, it is essential that the patient's view is not positioned in opposition to medical knowledge, treated as its 'soft', subjective, counterpart or dismissed as simply a new star in the constellation of medical power. For it is only through acknowledging and further analysing the complex ways in which the patient's experience spans these different domains that it can be understood and incorporated into contemporary healthcare as a source of knowledge in its own right.

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