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BRAIN
BOOK REVIEW

Disease, disorder, condition or enigma? Epilepsy and its modern history re-examined

Medical history, more than anything else, also reflects and embodies social history. Not surprisingly, therefore, following an initial start by physicians turned historians during the late 19th and early 20th centuries, the field has since been increasingly dominated by professional historians and sociologists, often in multi-author publications, most notably when dealing with conditions involving social or mental health. Thus, it is a pleasant surprise to welcome a new medical and social history of epilepsy, written exclusively by a single neurologist with long and extensive practical experience in the field; a monograph that, despite its medical origins, certainly fulfils its title's promise.

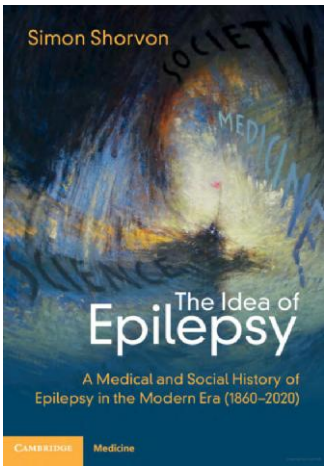
This book, by Simon Shorvon, Emeritus Professor of Clinical Neurology at UCL Queen Square Institute of Neurology, focuses on epilepsy in the modern era (1860–2020) and thus largely glosses over the earlier history, which is well covered by the thus far unsurpassed classic monograph by Oswei Temkin.[1] Nevertheless, where relevant, earlier scientific or social trends are referred to in the first chapter of the second section of the book, covering the birth of modern epilepsy (1860–1914), 1860 being chosen because that period hallmarks the birth of modern neurology.

In five chapters, further covering the epochs 1914–45, 1945–70, 1970–95 and 1995–2020, Shorvon extensively examines the progression of knowledge and the development of ideas regarding the essence, causes and consequences of epilepsy. These are considered not only from the perspective of medicine, but also from that of science in general, and in the context of social, economic and cultural developments of the time. Highly relevant but often ignored, the new findings are also considered from the perspective of the person with epilepsy.

This chronological section is preceded by an introductory section where Shorvon uses the metaphor of the 'Voyage of the Good Ship Epilepsy' to elaborate on this multidisciplinary and multi-perspective approach, as well as on the structure of the book that—to a large extent—mirrors that of Robert Burton's *Anatomy of Melancholy*,[2] a book that Shorvon considers to 'have set the standard against which all other disease histories should be matched'.

Also included in this introductory section is a discussion of the 'Concept of Epilepsy'. This is a welcome addition to a history of an entity that, over time, has been considered in many different ways: either as a singular disease or as a set of symptoms reflecting different causes; as a neurological affliction or as a mental disorder; and as an inherited and unalterable deficit or as a treatable disorder. Over the years, epilepsy has been seen with very different eyes and has known may different definitions.

This issue of definition is comprehensively covered in chapter 5 of section 2 (pp. 517–22), and Shorvon's approach largely reflects the current 'conceptual' definition of epilepsy as '(a) disorder of the brain characterized by an enduring predisposition to generate epileptic seizures and by the neurobiological, cognitive, psychologic and social consequences of this condition'.[3] Nevertheless, a comprehensive definition of epilepsy as a concept, disease or entity remains elusive and, in this introduction, Shorvon even poses the question of whether 'epilepsy', distinct from 'epileptic seizures' really exists, an as yet unanswered question which, however, well reflects the broad and often philosophical approach that is evident throughout this impressive work.



The Idea of Epilepsy.
A Medical and Social History of Epilepsy in the Modern Era (1860–2020)
By *Simon D. Shorvon*, 2023
Cambridge University Press £64.99
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Thus, the chapter on the 19th century not only highlights in great detail the development of the modern medical concept of epilepsy as a disorder of the brain through the pioneering works of Sieveking, Delasiauve and others up to the works of Reynolds, Gowers, Horsley, Ferrier and ultimately Hughlings Jackson, but also discusses the societal trends and their impact. The same era, however, that saw the birth of neurology and of localization in the brain was also characterized by controversies concerning the evolutionary teachings of Darwin and the resulting theories and practices of Social Darwinism and Eugenics. Their disastrous consequences—not just for epilepsy but for society as a whole—are given ample consideration in this and following chapters, culminating in the T4 Nazi killing program of people with epilepsy and other 'Lebensunwerten', a black page in this history, not to be forgotten since these theories to some extent still prevail.

For each epoch, Shorvon provides a thorough analysis, not just of the advances in the understanding of epilepsy and its underlying mechanisms brought about by new technologies—first EEG and X-ray, and then CT and MRI—but also of the way in which these technologies led to new concepts, terminologies, diagnostic criteria and classifications of epilepsy and epileptic seizures.

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One continuing thread throughout all epochs is the controversial and not yet fully clarified relation between epilepsy and seizures on one hand and mental deficiency and deterioration, psychiatric disorders, personality traits and disturbances and socially deviant behaviour, including crime and aggression, on the other. Successive, at times overlapping or contradictory, views and theories are addressed, including the still hotly debated issue of the 'Epileptic Personality'.

Initially epilepsy was considered as primarily a mental disorder with intrinsic mental deficiency or propensity to degeneration and associated with—either causing or resulting from—specific character traits, either 'genius' or 'criminal'. Psychiatric views then evolved, with the emergence of fashionable alternatives including Freudian psychoanalysis, and notably following increased awareness and understanding of the temporal lobe as the source of a specific type of epilepsy and seizures. Eventually, the general shift, not just for epilepsy but for psychiatry in general, into a more biological and organic-oriented field, offered a more nuanced view regarding the complex associations between seizures, seizure disorders, cognitive functions, and psychiatric disorders. New fields of study opened up into common pathways, and it was recognized that patients had different problems and could benefit from better, often psychopharmacological, treatment where indicated.

This shift from psychiatry to neurology and better (or maybe less bad) social understanding is also reflected in the sections on care. Psychiatric asylums made place for special institutions or colonies and in these places the initial emphasis on care eventually shifted to treatment, rehabilitation and even research. More recently, stays in residential institutions have been discouraged in favour of as full as possible intra-societal integration.

Neurological hospitals took over the clinical care and early research, and medical education followed as did treatments. Initially many substances were tried—including bromide (the first effective drug for a specific neurological disorder in Western medicine)—but few had any effect. Shorvon lists, in great detail, the many new drugs that became available to treat seizures, beginning with the barbiturates (1912) and phenytoin (1937), followed by a plethora of others, including carbamazepine, valproate and the benzodiazepines, now themselves considered 'old drugs' and succeeded by others. None of these new drugs, apart from lamotrigine, have shown true superiority, except with respect to side effects. Notably, they have also recently been renamed 'anti-seizure drugs', rather than 'anti-epileptic drugs' because the best they do is to suppress the seizures.[4] For the underlying epilepsy, so far no treatment is available.

In parallel with advances in neurological knowledge and medical technology, the neurosurgical treatment of epilepsy developed in a stepwise fashion, beginning in the period 1886–1900 with the pioneering work of Horsley in London. This was followed in 1935–60 by further progress with the work of Penfield and co-workers at the Montreal Neurological Institute. After a temporary dip, probably caused by the widespread introduction of carbamazepine, the pace picked up again from around 1980 onwards, stimulated by advances in neuroimaging.

The science of epilepsy during these epochs has changed enormously, starting in the private rooms of individual physicians or chemists, and shifting gradually to better organized and equipped hospital clinics and then to dedicated hospital and university laboratories, to the current immense worldwide and multidisciplinary activity we see today. As well as stimulating the formation of national and international clinical and scientific organizations and funding systems, this change unfortunately has also resulted in a relative overreach of industry-driven research and development, requiring control mechanisms that at present do not always appear to be sufficient to protect patients and society.

Despite all this progress, for approximately one-third of patients with epilepsy, seizures and their ensuing physical, psychological and social consequences remain largely refractory to all treatments. For many others with the condition (or even just the diagnostic label!) and their partners and families, having epilepsy—even if well-controlled—still results in social stigma and burden. While this has to some extent lessened over time, it has definitely not disappeared. Shorvon illustrates this aspect of self-experience and the burden of living with epilepsy in part with quotations from people living with epilepsy, but more extensively and in a highly illuminating way by analysing the presentation of epilepsy in literature and more recently film and television. Reproductions of 15 paintings by David Cobley, a former artist in residence at the Epilepsy Society's Chalfont Centre in Buckinghamshire, UK, further illustrate vividly these emotional effects of epilepsy.

To stimulate better knowledge and treatment, but also to reduce this psychosocial burden associated with epilepsy, many national and international organizations have come into being, including the International League Against Epilepsy (ILAE) and the closely associated International Bureau for Epilepsy (IBE), both with local chapters in most countries.

The development and current status of this 'Bureaucracy of Epilepsy' is discussed extensively in the third and final section of the book, including a comprehensive appendix on the ILAE/IBE. This third section offers a review of developments sketched out in the preceding chapters, as well as a look ahead at the various issues concerning epilepsy as a medical condition and as a challenge for individuals and for society as a whole. The section also includes two further appendices, one on the developments that have been 'good' versus those that have been 'bad' for epilepsy, and another on all the obsolete or failed theories and treatments associated with epilepsy. In this final section Shorvon expresses a not too optimistic view on the present status of the individual with epilepsy and the way society is dealing with the condition, the concept and nomenclature of which he, again, calls into question.

Despite its comprehensiveness the book has some weaknesses, most of them already acknowledged by the writer in the introduction. The emphasis is on the Anglo-Saxon perspective which does not so much affect the discussion of medical contributions from other countries, but certainly affects the discussion of social and political developments. Current sociocultural views will probably denote the book as representing a white-male-oriented history, but as such it reflects history in much of the Western world.

Possibly the most conspicuous and paradoxical weakness is Shorvon's wish to 'tell it all'. Throughout the book and for each time epoch he discusses epilepsy in a much wider context, effectively presenting not just a comprehensive history of epilepsy but also a broad history of medicine in its scientific, social and political context for the period 1800–2020.

This, combined with the intrinsic limitations of publication, results in some inconsistencies: some individuals get extensive biographies, others a brief sketch in a footnote, some just a reference; illustrations are few. The result is a beautifully produced book: small quarto, 760 pages, good quality paper, 1700 g, with its many tables, glossary, index and extensive bibliography. As such, it presents as a beautiful study book, perfect to work with on a desk; however, it is much more than a study book, it is a book to be read and read again in a comfortable position!

Cambridge University Press would be wise to consider this for a second edition.

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