

## INVITED COMMENTARY

# The idea of epilepsy. A medical and social history of epilepsy in the modern era (1860–2020)

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When we need historical facts about epilepsy we look them up in “The Falling Sickness”, Owsei Temkin's outstanding history of epilepsy, a work with few parallels in other medical specialties. However, time is moving on, and a need has long been felt for a similarly scholarly work to cover more recent developments. Simon Shorvon has now taken up the challenge with 630 text pages compared to Temkin's 395, which immediately indicates the increase of detail we are met with.

Temkin, who was not a neurologist and wrote his book in 1945 considered wise to write it up “the point where the historical perspective ends and the present debate begins” which he placed around 1880. Shorvon, who is a neurologist, deliberately includes the present debate and covers the period from 1860 to 2020. There is, thus, a fundamental difference in the two authors' approach.

Shorvon divides what he calls a “long century” into five periods named “The birth of modern epilepsy” (1860–1914), “Epilepsy in the age of catastrophe” (1914–1945), “Epilepsy and the new world order” (1945–1970), “Epilepsy in a globalized world” (1970–1995), and “The epilepsy floods are too recent” (1995–2020). To this chronological

order, he adds an order of four perspectives on epilepsy which are resumed for each period, i.e. science, medicine, society, and the person with epilepsy. Where multilingual Temkin was cosmopolitan, anglophone Shorvon is encyclopedic at least for the first three periods whose description is truly outstanding. It is amazing how many details about persons, exchanges and disputes the author knows, and he tells them with elegance and humor that make these chapters not only enlightening but also most pleasant reading.

The focus, as the title indicates, is on the development of ideas and concepts about epilepsy, including those that have been abandoned. That they once were influential is reason enough to discuss and analyze them if we want to understand history. This applies particularly to the competing psychiatric concepts of the first period, an era that also provided the fundamentals of the neuropathology of epilepsy. The modern nosology of epilepsy starts with Jackson, and surgical therapy of epilepsy with Horsley, whereas the prevailing image of epilepsy was that of patients who lived in asylums or epilepsy colonies rather than well-functioning individuals in the community. The

Disclosures: The author held the ILAE offices of Secretary General (1993–2001), President (2005–2009) and Past President (2009–2013). He established ILAE's distance education program Virepa, founded and co-directs the Baltic Sea Summer School on Epilepsy and teaches at the Latin American Summer School on Epilepsy. He is founder and co-director of the Prof. Peter & Jytte Wolf Foundation for Epilepsy, Bielefeld (Germany).

I confirm that I have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

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end of the period saw the birth of the field's most important professional organization, the International League against Epilepsy (ILAE) in Budapest 1909, which is described with entertaining detail.

In the second period, the eugenic movement that started in the USA but soon became global had far-reaching consequences for people with epilepsy in many countries, with more or less enforced sterilization programs, most extreme in Nazi Germany. For Shorvon, this is a prototypical example of the damage that can be caused by enthusiastic adoption of immature scientific theories. At the same time, in this period, pharmacotherapy of epilepsy moved from chance discoveries to targeted drug development, and the role of the EEG as the major diagnostic tool was established. Especially regarding the latter, I know of no better narration.

For the author, the history of epilepsy reflects to some extent general history which becomes most visible in the 3rd period, "Epilepsy and the new world order" (1945–1970). He documents how an international epilepsy community was re-established after the disruption caused by the two World Wars primarily due to North American activities, wherewith the leadership moved to the USA in parallel to the raise of their political power. The central figure in this development was Lennox and, in spite of a critical view of his strong commitment for eugenics and even defense of euthanasia in certain cases, Shorvon concludes that he was "the greatest clinical epileptologist of the twentieth century". Perhaps not everybody will agree with this, especially outside the anglophony where Lennox was less influential, and those of us who consider patients' subjective seizure experiences and their spontaneous counteractions as equally important as the objective signs will look for inspiration elsewhere. But the most interesting aspect of this is perhaps that the crown goes to somebody who already died in 1960, in the middle of the "long century". Is this because we need some distance to perceive a person's greatness or is it because the very concept of the greatest someone is not in synchrony any more with an era where the great innovations in medicine and science result from the work not of individuals but teams and increasingly global networks?

This chapter tells the development of the pharmacotherapy of epilepsy with growing awareness of the necessity of evidence-based treatment, and the rise of the pharmaceutical industry from modest beginnings to its present power. Modern epilepsy surgery also has its roots in this period which in addition saw an increase of experimental epilepsy research as well as first attempts of the ILAE to establish international classifications of seizures and epilepsies. It is also the era where lay organizations like the International Bureau for Epilepsy (IBE) began to change the societal aspects of epilepsy,

and Shorvon gives welcome attention to the influence of literature and film, and to authors like Margiad Evans who started to write about their own epilepsy experiences. Treatments giving an active role to patients such as lifestyle hygiene and self-control of seizures, however, are not discussed.

The prevailing Anglo-Saxon perspective (for which as a *captatio benevolentiae* Shorvon apologizes in the Introduction) gets the more clearly felt the closer we come to the present time. It becomes too much in the fourth period "Epilepsy in a globalized world" which only adds details of Australia, India and Zimbabwe whereas the major parts of both Asia and Europe, and entire Latin America are missing, including significant names from these regions. The author's ambition to write this monument of a book alone, which works admirably in its first three chapters, sadly fails here. French readers are privileged as they can supplement "Une histoire de l'épileptologie francophone" (2007) by Anne Beaumanoir & Joseph Roger.

The move from history to a chronicle of present issues continues in the last chapter and the epilogue "The separation of the wheat from the chaff". For this part, the author decided "to avoid describing in any detail the personal contribution of any living individual"—certainly a wise decision but it deprives the text of some of the human flavor including the occasional bit of gossip which are not the smallest charm of the earlier chapters. However, Shorvon does not hesitate to share his opinions with us, and they are of particular interest in two fields where he was personally much involved, i.e. the ILAE as a long-standing Executive member, and scientific publishing where his earlier role as Editor-in-Chief of *Epilepsia* has given him unique insight.

When Shorvon qualifies the present ILAE as an inward-looking bureaucracy the background is that the team who in 1993 came in charge, and to which we both belonged, intended to make the League the central forum for free international exchange of ideas and promotion of science and education. He is not fond of the Vanity Fair around classifications, definitions, guidelines and what not which filled much of the ILAE agenda in the last two decades, and it is refreshing to find him discuss abandoning the idea of epilepsy at all, at the very moment when an ILAE task force has decreed that this most heterogeneous conglomerate of different conditions should be considered a disease. Of the recent initiatives of the international epilepsy organizations, the only worthwhile in Shorvon's view is the Global Campaign against Epilepsy of ILAE, IBE and WHO. There can be little doubt about its importance, but it could be argued that the introduction of semi-independent regional structures and their manifold educational initiatives was more important as they attracted young talent and established a generation

of well-trained professionals in parts of the world where they had largely been missing. That these developments receive little attention is my most serious criticism of the book.

Regarding scientific publishing, the author paints a gloomy image. The number of publications and journals have exploded but the quality of publications, declined. “It is no exaggeration to say that any paper, no matter how bad, was likely to find publication somewhere.” Flawed methodology, biased reporting, salami publishing, failure to report contradicting results, even fabrication of results are the prevalent problems. There is truth in that but the diagnosis is incomplete when nothing is said about publishing houses, no less problematic than pharmaceutical industries, with large profits made on the unpaid work of authors and peer reviewers, and the growing practice of imposing hefty “publication fees”. In addition, correction seems needed of the impression, perhaps unintended, that the increase of publications is predominantly due to malpractice whereas much of it really is part of epilepsy’s success story coming from young professionals in the “new” regions whom we have encouraged to do research as one of the best ways to create expertise.

Caveats in spite of their obvious benefits are attached to pharmacotherapy where new drugs are much more expensive but not much more effective than older ones, and to epilepsy surgery where increasingly complex and expensive protocols lack regulatory oversight and controlled assessment, and the long-term results not always fulfill expectations. Attention is given to new developments in epilepsy genetics, precision medicine and neurostimulation

whose definite place in the practice of epilepsy it is too early to determine.

Some readers will probably feel that the author would have done better had he followed Temkin’s example not to include the most recent history with its conflicting opinions, but that would have deprived us of his account of the newer sociocultural history, of what today it feels like to have epilepsy. In the period described, reduction in prejudice and stigma, new openness about epilepsy and more accepting public attitudes have resulted from sociological research, public education and legislation, and are amply reflected in literature, film and social media. This appears as “the most significant and beneficial development in the lives of people with epilepsy and in many ways of greater importance than any scientific or medical advances”. I would not want to miss this statement.

Whatever one may think of the book’s last chapters, its first parts covering the period from 1860 to about 1980 are a marvelous achievement that is enough to ensure this exceptional work a prominent place in any epilepsy library.

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