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## Book Review

**Sacred lives: An Account of the history, cultural associations and social impact of epilepsy.** Ian Bone, Honorary Senior Research Fellow at School of Medicine, University of Glasgow, Copyright 2020. [www.sacredlives.co.uk](http://www.sacredlives.co.uk); [ianbone@sacredlives.co.uk](mailto:ianbone@sacredlives.co.uk). ISBN: 978-1-8380367-13

*Sacred Lives* is an encapsulating journey, contained within a relatively sparse 363 pages, that seeks to shed light on epilepsy throughout the ages. The word epilepsy is derived from the ancient Greek *epilepsia*, meaning 'to seize, or take hold of that which was beyond an individual's control. (p 5). The ancient Greeks considered epilepsy to be a form of "spiritual possession, but also associated with the condition of genius and the divine" (p.6) This helps us understand the religious demonization of this condition and the ability, or lack thereof, of science, technology, media, and the arts to debunk the myths of this "hidden disability".

From cover to cover, *Sacred Lives* explores the lives of writers, artists, musicians, and scientists, as well as the public and legal systems vis-a-vis their impact on this condition. The book explores how epilepsy is seen: in the past vs the present, art vs science, and myths vs truths.

Unlike previous books about the history of epilepsy, including Temkin's classic treatise "The Falling Sickness: A History of Epilepsy from the Greeks to the Beginnings of Modern Neurology" (2nd ed. rev., Baltimore and London, Johns Hopkins Press, 1971), Dr. Bone has written the book from two voices; first, as a neurologist treating this patient population, and secondly, but maybe more importantly, as the father of a son with epilepsy. This allows for invaluable insight into the societal and personal challenges of these individuals and their families. It is a fascinating, accessible read, providing a wealth of knowledge, whether one has a personal connection to epilepsy, is a researcher, artist, historian, advocate for social justice, or is part of the general public. He delves into topics ranging from scientific advancements, to a discussion of the artists who were thought to have epilepsy or had a personal connection to it. It also goes on to tackle more complex social determinants of health with a discussion of the mistreatment of these individuals by the legal system, and the pros and cons of various social media platforms and their ability to influence societal perception of this complex health condition. Social media is now a leading resource of health information, where individual opinions can be shared, allowing for uninformed information to be readily spread with negative consequences. It speaks of the imperative of epilepsy organizations, the medical community, and epilepsy specialists to provide some means of oversight to ensure correct information is being distributed.

The question remains, has anything really changed about attitudes toward people with epilepsy over the course of time? This

is best reflected by the following quotation, 'The history of epilepsy can be summarized as 4000 years of ignorance, superstition and stigma, followed by 100 years of knowledge, superstition and stigma.' Kale R (1997) Bringing epilepsy out of the shadows. *British Medical Journal* 315, 2.

The book is divided into five parts: Part I: "History, classification, and causes of epilepsy" from ancient times to the present, sets the groundwork for how epilepsy has been stigmatized through the ages. Hippocrates in 400 BCE broke from this dogma, proposing that epilepsy was not caused by the spirits or was of divine origin, "but rather that it was a medically treatable problem that originated in the brain" (p. 7). Unfortunately, the next 2000 years did little to alter public perception, but instead sustained a framework for ongoing prejudice and discrimination, that largely silenced the voices of those who live with this condition. In the 19th century, with new scientific advances, including diagnostic testing, treatments, and genetics, there began a new scientific understanding of epilepsy. Unfortunately, societal perception remained rooted in the past.

Part II, "Epilepsy in the arts", highlights key individuals in literature, the visual arts, cinema, television, music, and theater. Within the arts, epilepsy has been portrayed for its dramatic effect; in this context, seizures have been associated with rage, violence, madness, demonic possession, or used for enhancement of plot and character development. In general, it is used to depict an individual as being vulnerable, weak, villainous, or a victim. Gender bias oftentimes can play a role in this development. "Women with epilepsy are generally portrayed as vulnerable and deserving of sympathy, whereas men with the condition, unless they developed epilepsy as a result of an accident or serving in a war, are flawed and often criminal." (p. 151)

The discussion of how epilepsy is portrayed in all forms of the arts highlights the need to engage those directly with epilepsy, to shed light on the reality of the condition. Fortunately, a few contemporary artists with epilepsy have come forth, with visual representations of their experiences, revealing the complexity and heterogeneity of this condition. The art becomes a narrative to inform and educate a wider audience. Unfortunately, many choose to remain silent, which only serves to keep epilepsy in the shadows, rather than allowing their art form to become a means to educate the public and highlight their positive contributions to society.

Part III, "Epilepsy in the media" from print to online. This section highlights the explosion of social media platforms, which have been utilized to market, influence, and educate the public. Social media has the bandwidth to reach a large and diverse global population. Individuals can become better informed about health-related issues; yet, the ability of false information to be easily spread without oversight can have negative consequences.

Part IV, "Epilepsy in society" explores the legal system and discrimination in the workplace and ends with a comprehensive dis-

discussion on the stigmatization of epilepsy. The author points out that many of the laws designed to protect those who are disadvantaged or disabled are written by lawmakers without the expertise or understanding of the health-related issues at hand. There is a fascinating discussion on the “binary legal concept” of sane and insane. This concept has been used to incriminate individuals with epilepsy, by making use of a flawed distinction of epilepsy automatisms (brief unconscious behaviors that cannot be voluntarily suppressed) as being sane or insane. “Because epilepsy arises in the brain, which is considered to be ‘out of control’, its resultant automatisms are legally classified as insane.” (p. 263). The last section concludes with a thorough review of the psychosocial issues of epilepsy. The concept of “stigma coaches” is presented. Are parents’ part of the equation for the ongoing stigma/discrimination by concealment of their child’s condition to friends, family, educators, and the public, resulting in overprotection and isolation? Is the individual to be blamed for internalizing and externalizing that epilepsy is bad or something to be ashamed of? Do physicians contribute to the problem by not properly addressing the seizure experience as epilepsy? These issues have been addressed in Schneider and Conrad’s book entitled, “Having Epilepsy: the Experience and Control of Illness” (Temple University Press, 1983). All of these issues make it more difficult for the individual to accept the diagnosis and take control. Without ownership of “their epilepsy, as part of them and, having done so, deny it to others as grounds for devaluing definitions and treatments... Disclosure was the key to reducing felt stigma and thus minimizing enacted stigma”. (p. 281)

Part V concludes with “A personal account of living with epilepsy”, told through Dr. Bone’s eyes, as both the parent of a son with epilepsy and also a neurologist. His honesty in addressing his own anxieties and decisions when trying to understand what was best for his son is a heartening reflection of what any parent of a child with a chronic illness confronts. Dr. Bone addresses the need for the integration of the “medical model (the control of seizures) and the social model (the mitigation of societal consequences)”.

*Sacred Lives* is a call to action for physicians treating the population with epilepsy, educators, employers, the general public,

social media platforms, the film and television industry, as well as persons with epilepsy, their families and caregivers to break what has become a vicious cycle of ongoing misinformation. Until the medical model aligns with the social model, we as a society perform a disservice in enabling those with epilepsy to live to their full potential.

*Sacred Lives* spoke to me personally. As a neurologist and mother of an adult son with epilepsy, I have also had to address the complexities of the medical side of this disease as well as the psychosocial intricacies of this condition. Dr. Bone takes this complex, misunderstood condition, and through history, medicine, the arts, media, the legal system, and personal reflection, brings this hidden disability out of the shadows. There are few if any books or authors that have taken on this challenge, integrating science with the arts to reveal the profound social/medical implications of this condition.

“Epilepsy, like sex and death, must be made speakable...It is only then we can begin to banish the ghosts that for so long made it mysterious and threatening.”(P. 281)

#### **Declaration of Competing Interest**

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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