

Book Review: The Thing Inside my Head: A Family's Journey through Mental Illness, by Lois Chaber

Reviewed by S. Evelyn Stewart, M.D.

Dr. Stewart is a clinical and research psychiatrist at Massachusetts General Hospital and the OCD Institute at McLean Hospital. She is also a member of the OCF's Scientific Advisory Board.

This book provides a non-fiction account of a young woman named Sybil Macindoe, written posthumously by her mother. The book is written as a compilation of narratives and photos written and collected by Sybil herself, her mother, her sister Molly, and mental health professionals involved in her treatment for obsessive-compulsive disorder (OCD) and anorexia nervosa in the 1980's-90's. This sad, moving collection walks the reader through the helplessness and confusion that families often experience in the face of undiagnosed and misunderstood mental illness through to Sybil's eventual suicide. The reader's emotions are intensified by the fact that Sybil does not realize for some time that her illness has a name – obsessive-compulsive disorder-- a treatable disease. Too late she begins to recognize some of her thoughts and behaviors as symptoms of OCD and one is left to wonder whether a happier outcome might have occurred with current day treatment approaches, or with earlier diagnosis and increased public awareness of this disorder.

Of note, the appearance of Sybil's OCD is very severe in comparison to most cases, and is complicated by a co-morbid eating disorder, anorexia nervosa. For example, although cognitive-behavioral therapy and medications are the 'gold standards' of treatment, only a minority of OCD-affected individuals require hospitalization as was the case for Sybil. Moreover, reported suicide rates in OCD alone are not as substantially elevated as for some other illnesses such as bipolar disorder, body dysmorphic disorder or schizophrenia.

However, this book is full of insightful pearls of wisdom and teaching points for those dealing with OCD, whether in themselves, among loved ones, or when working with patients/clients. As demonstrated in the early treatment experiences of Sybil's family, clinicians are often unfamiliar with the varied symptoms of OCD, which can delay its diagnosis and management and occasionally lead to inappropriate blame. In addition, observing the behaviors of individuals with OCD can be very deceiving, since behaviors do not necessarily reflect associated internal emotional struggles that take place within individuals' minds. Illustrating this, an excerpt from Sybil's writings sharply contrasts her external and internal states during a prolonged period of muteness. During this time she was being fed through a nasogastric tube, considered to be catatonic, and was appeared to be mentally disconnected from the world around her. In contrast, her subsequent journal entry reflects her awareness of this external world and her awareness of her losing struggle to fight the "voice that she thought was God (her OCD)" by stopping her continuous rituals.

The tragic outcome of Sybil's life story is not the conclusion to this book. Rather, the final component of this family's 'journey through mental illness' is spent in reconciling their experiences to create this work that aims to guide others in their own struggles. Lois Chaber explores the potential origins, exacerbating factors, treatment attempts and potential alternatives that may have resulted in a different outcome. In Sybil's mother's words, "we are confident she would have wanted sufferers, families and care givers, among many others, to learn and benefit from this cautionary tale....she wanted to touch people's hearts not only with her sufferings but also with her brave struggles against them."

I recommend this book to clinicians and others wishing to gain a deeper, intimate understanding of some of the experiences faced by those suffering with severe OCD. I would balance the sorrow in Sybil's story with optimism, arising from the knowledge that books and works like these have and will continue to raise public awareness for OCD. This book in turn has supported research efforts to develop improved treatments aiming towards a cure. I applaud the courage that Sybil's mother demonstrated in sharing her family's story, and would encourage parents reading this to contribute to this cause by becoming involved in OC Foundation activities.

