

BOOK REVIEWS

Six Autobiographies and Two Realistic Fiction Books as Tools to Engage Students in Neurobiology of Disease: A Guide for Instructors

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In this review, we discuss seven books, which we have utilized as compliments to textbooks in a Neurobiology of Disease course. These books describe neurological and psychiatric disorders from the viewpoint of the patient and include both fiction and nonfiction. We incorporate these texts in our course to engage a wide variety of students. For neuroscience and psychology students, these texts provide a more humanized view of the disease or disorder and a context for descriptions of symptoms or treatments. For students who take the course to fulfill a general education requirement, these texts are meant to make complex issues in science feel more accessible and relatable. Additionally, class discussion of these books facilitates the destigmatization of mental health issues. Here we present

reviews of various books we have used in this approach and describe the educational value of each. We highlight the reasons why each book was chosen and identify particularly relevant or challenging sections of each book. We also offer points of consideration to aid educators in evaluating whether a book is appropriate for use in their own classrooms.

Key words: Pedagogy; Human Perspective; Mental Health; Suicide; Depression; Obsessive-Compulsive Disorder; Schizophrenia; Bipolar Disorder; Tourette Syndrome; Alzheimer's Disease; Major Depressive Disorder; Autism Spectrum Disorder (ASD); Anti-NMDA Autoimmune Encephalitis

For the past 4 years, we have supplemented the textbook material (Meyer & Quenzer, 2013; Zigmond et al., 2014) in our regularly-offered Neurobiology of Disease course with autobiographical accounts written by patients who have some of the diseases that we teach about. We also use two realistic fiction stories written from the perspective of individuals with diseases we cover. Previously, guides for instructors have been created for how to incorporate original research (see Harrington et al., 2015), short patient case studies (Handelsman et al., 2004; Herreid et al., 2012; Wiertelak et al., 2016; Prud'homme-Généreux, 2016; Cook-Snyder, 2017), or cinema (see Wiertelak, 2002; Boyatzis 1994) in college classes. Our goal is to provide a similar instructor's guide to include longer, book-format autobiographies and fictional accounts of patients. In creating this review, we share how we use autobiographies and novels as well as provide specific assignments and general ideas for instructors who wish to use autobiographies (either those we use or others) in their classes.

Substantial research has demonstrated that students learn best when they are able to connect material to relevant stories, including their own life experiences and/or interpersonal narratives (Ambrose et al., 2010; Aoun, 2017). Additionally, it has been shown that presenting students with case studies and personal stories helps them excel in challenging, original research-oriented classes (Cooke-Snyder, 2017). We are inspired, in part by research showing that biographical portrayals of scientists improve overall grades in science classes for all students (Schinske et al., 2016; Hoh, 2009).

Here, we review relevant aspects of the stories we use, how they are used, the value they provide, and other considerations related to their use in a classroom setting. Our hope is that these accounts will allow other instructors to make informed decisions about the value of including either these specific books or other such resources in their classes. All the books we have required and/or recommended for our students can be seen on the sample course syllabus (Supplementary Materials 1). Although there are eight books we review here, we cycle through topics and therefore through these books, typically requiring 3-5 books per semester. For each required book, we assigned questions for the students to complete (Supplementary Material 2). On the day each assignment is due, we spend 30-50 minutes in class discussing the book in question.

For each book, we report how they are used in our class as well as instructional considerations and homework questions we assign students (Supplementary Material 2). In this course, the readings account for a small fraction of the final course grade (about 2% of total course grade from these homeworks and 2% of course grade for participation in discussions). The exams in the course assess student knowledge about the diseases being studied and about experimental evidence and methods used to study the diseases in human patients and in animal models, not the books. However, we believe from our time in class and interactions with students that the students find these stories to be interesting and valuable in deepening their understanding of the diseases and in motivating them to learn the course material.

Our approach is not totally novel, as others have presented review and recommendations on the use of biographies in classrooms (King, 1987; Solas 1992; Powers, 1998; Lom 2005; Mori & Larson 2006; Monuszko 2014). Additionally, several sources have used cinematic portrayals in pedagogical contexts in neurobiology and psychology courses to help students make a connection with neuroscience or biology material (Hyler & Moore, 1996; Wedding & Boyd, 1999; Stewart & Chudler, 2002; Wiertelak, 2002; Mead, 2007; Chamany et al., 2008), and comic books have also been used similarly (Hosler & Boomer, 2011). Relevant to those who wish to supplement their teaching with cinematic portrayals, three of the books we review here have since been made into movies (*Front of the Class*, *Still Alice*, and *Brain on Fire*) and one has been made into a play (*The Curious Incident of the Dog in the Night-Time*). In the context of books related to neuroscience of diseases, several reviews of individual books are available for instructors to draw on (see: Bernd, 2002 and Hales, 2003).

Our primary goal in using these books is to motivate students to learn about the biology of these diseases and provide a human context for them. Often, authors of memoirs and realistic fiction write with the intention of educating the general public about their experiences while also informing people who have these diseases about the challenges, realities, and successes they have had in their lives (Steele & Berman, 2001; Cohen & Wysocky, 2005; Wortmann, 2012; Alter, 2017).

Savvy students (and instructors) will note in our syllabus (Supplementary Material 1) that student engagement with the books is not required to earn a good grade in the course. We should be clear that understanding the life stories of people with the disease is not an explicit learning objective of our course. Students know they will not be tested on the life stories of the people in the books and they may, if they wish, just read or skim enough to answer the pre-discussion questions. Despite this, more than half the students raise points in discussions that go beyond the minimum amount needed to complete the assignments. Also, judging from conversations with students and from formal course evaluations, at least 10-20% of our students choose to read the entire book, and a large majority find the books and discussions to be valuable even if they may not read every one entirely.

Enrollment varies by semester from 20 (in summers) to 50 (in the academic year). In early offerings with this format, we engaged the entire class in discussion. Because of the number of students, this format kept us from ensuring all students participated. In more recent offerings, we have broken the discussion time into smaller groups of 8-12 students, with graduate TA's and/or trained undergraduate discussion facilitators to lead the sessions. Although we don't have direct measures, our own observations and course evaluations indicate that the value gained in inspiring students to be curious about neurobiology is worth the work on their part (and ours) in reading and discussing these memoirs and fictional accounts.

Paradoxically, by not using strong grade-based incentives, we seem to succeed in motivating many students to read the books for their own sake. We are upfront with

the students that the purpose is to provide them with interesting and relevant personal accounts to motivate them to learn the biology of the diseases and that we hope that they choose to read the books for the intrinsic enjoyment the books provide. While some students only read the bare minimum, these students still gain a small window into the life of someone with each disease. Even with heterogeneity in student engagement, the value the books provide is apparent to us in the in-class discussions as well as in conversations with students.

IMPORTANT CAVEATS

We are not physicians or licensed mental health professionals. In this review, we discuss briefly how we handle discussions with students about mental health and other sensitive issues. Before adopting any of the teaching practices we describe here, we strongly advise that instructors consult their institution's student support services and make sure all guidelines are followed. Additionally, instructors should seek out guidance from mental health professionals, consider having such professionals attend class, and they may wish to seek training in mental health first aid (National Council for Behavioral Health, 2018).

Furthermore, making available a clinician to answer student questions about suicidal ideation and dramatization can be crucial. It is also important for clinicians to discuss that people can have suicidal ideation but not have attempts. Ideation or even dramatic behaviors of self-harm without attempts may serve as coping strategies until patients receive proper care. A major concern for clinicians is the graphical depiction or glamorization of suicide in the media. On the other hand, discussing and normalizing the concept that these thoughts can occur helps, as does normalizing the need to seek professional help (J. Schreiber, M.D., personal communication). One of us (DJB) has also spoken to the class about his own experience with mental illness in order to help normalize such discussions (Brasier, 2016).

This review represents our own individual practices and does not necessarily reflect the practices or policies of our home institutions, and neither have our practices nor this article have been reviewed or endorsed in any way by our home institutions. Talking about mental health can be helpful for students when done effectively and appropriately (American Foundation for Suicide Prevention, 2018). However, when done without proper training or without consultation with licensed care-givers, it can result in unintended negative consequences and potentially put students at risk for serious, possibly life-threatening complications.

In our syllabi, we also tell students that class discussions are not an appropriate time for group therapy (Supplementary Material 1). In discussing what this means with students, we say something along the lines of:

"To ensure that all students are able to focus on the course material, any personal experiences should be de-identified in class discussions and all students should refrain from offering personal advice or recommendations about private mental health concerns. Remember that while we ask all students

to be respectful of one another, confidentiality cannot be guaranteed.”

In other words, we explicitly encourage students that if they want to share an experience about a sibling, friend, etc., that they just say “someone I know”, even if it’s about themselves. In addition to protecting confidentiality, this also ensures that discussions focus primarily on the biology of the diseases and the relationship between neurobiology and disease symptoms.

Lastly, it is likely in a class of 30 or more students that one or more individuals will have experienced serious psychological condition within any given thirty-day period, and there is an even greater likelihood that some students will be in active treatment or still be recovering (CDC, 2017). We believe that the loosely structured discussion time for each story helps students think through the emotionally challenging material. We spend time before each discussion considering how to ensure all students’ voices are heard and how to positively reframe any comments that may be off-putting to other students in the class. This raises the risk that some students may be in a position where reading vivid accounts of mental illnesses, especially suicidal thoughts and/or traumatic life events (including rape in one book – *The Day the Voices Stopped*) might work against the students’ best medical interests. In order to mitigate the possibility of this, we provide students with advanced information about the potentially triggering aspects of each book and with information about local and national mental health support services (see last page of Supplementary Material 1). We also provide every student the option to opt out of any assigned reading (see second-to-last page of Supplementary Material 1). Students are not asked to describe their reason for opting out, and opting out of one or more readings has no impact on their course grade as students are not tested on material from the books. Any book could, in principle, be contraindicated for a student, but the most likely are *Triggered*, *The Day the Voices Stopped*, *An Unquiet Mind*, or *The Noonday Demon* (Wortmann, 2012; Steele & Berman, 2001; Jamison, 1995; Solomon, 2001).

ALTERNATIVE BOOKS

To be fair to all students, we require that a student who opts out of one reading instead choose from a menu of other possible books or suggest a book on their own, with *ad hoc* homeworks and brief discussion with the instructor about the substitute book chosen. The menu of books we offer to students includes:

- *The Ghost in My Brain: How a Concussion Stole My Life and How the New Science of Brain Plasticity Helped Me Get It Back* (Elliot, 2015), which describes concussions and traumatic brain injuries. This book includes significant discussion of advances in neurological treatments.
- *Darkness Visible: A Memoir of Madness* (Styron, 1990), which is a frank account of depression and includes significant reference to suicide but can be empowering for individuals with mental illness because it is widely credited as having launched efforts for public awareness of mental illness (Fulham, 2014).
- *The Diving Bell and the Butterfly: A Memoir of Life in Death* (Bauby & Leggatt, 1997), which describes locked-in syndrome.
- *ADHD and Me: What I Learned from Lighting Fires at the Dinner Table* (Taylor & Honos-Webb, 2007), an autobiography of ADHD in adolescence.
- *Fixing My Gaze: A Scientist's Journey Into Seeing in Three Dimensions* (Barry, 2009), an autobiography written by a neuroscientist about her own experience with strabismus and late-in-life development of stereovision. This book also provides a great introduction to critical periods in sensory systems and we recommend it for classes in systems neuroscience.
- *Heal Thyself: A Doctor at the Peak of His Medical Career, Destroyed by Alcohol – and the Personal Miracle That Brought Him Back* (Ameisen, 2009), an autobiography of a physician who goes against medical advice to use baclofen to treat and recover from alcohol dependence. This book does include periods of inpatient psychiatric care, as well as a good introduction to neuropharmacology written for a lay audience.
- *Permanent Present Tense: The Unforgettable Life of the Amnesic Patient, H. M.* (Corkin, 2013, reviewed by Monuszko, 2014).
- Instructors wishing to have shorter biographical accounts may consider the works of Oliver Sacks, (e.g., *The Man Who Mistook His Wife for a Hat*, Sacks, 1998).

Each of the above books has its own considerations, which we do not review here, and this list is by no means exhaustive. Some of the books we review below are fairly “safe” in that they have a low likelihood to cause unintended challenges for students who have experienced mental illness personally or in close family and friends (Cohen & Wysocky, 2005; Haddon, 2003; Genova, 2007; Cahalan, 2013). We recommend that the menu of options appropriate for a course be provided to students who opt out of any reading. These options should be provided in time for the student to consider substitutions on their own and consult with health providers if they wish.

One final consideration and caveat that students should be aware of is that each story is one example and that the same disease may have different courses and outcomes in different patients. Related to this, it should be made clear which stories are fictional and that the memoirs represent one person’s own perspective on their own disease, which may at times be unreliable (see Söderlund et al., 2014).

REVIEWS OF BOOKS WE RECOMMEND

Triggered: A Memoir of Obsessive-Compulsive Disorder

Fletcher Wortmann (2012)

Disease or Disorder: Obsessive-Compulsive Disorder
Genre: Memoir

Summary

Fletcher Wortmann describes his childhood and college years living with obsessive-compulsive disorder (OCD). From the beginning of his story, Wortmann’s symptoms were not stereotypical, visible compulsions like frequent

handwashing. Instead, he experienced violent intrusive thoughts, such as ideas about a coming apocalypse, intrusive sexual thoughts, and religious fears about punishments by God for specific actions.

In the introduction to his memoir, Wortmann points out that his OCD was misdiagnosed as depression when he was in high school; it wasn't until he had an emotional breakdown in college that he was properly diagnosed with OCD and treated for it. The memoir then opens with a thought experiment designed to convey aspects of the thought process that defines OCD. The remainder of the chapter describes Wortmann's childhood and how that created the basis for his disorder. Even at a young age, Wortmann had frequently changing obsessions that resulted in him creating massive collections of both knowledge and tangible items, and a constant obsession with the apocalypse. Religion played a role in Wortmann's life, creating a focus for many of his obsessions and directly affecting his lifestyle. By the time he was in third grade, Wortmann experienced his first "full-blown bout of OCD".

In high school, Fletcher Wortmann experienced suicidal impulses as an extension of, in his words, his intrusive thoughts. It was at this time that he was diagnosed with depression and prescribed antidepressants. The bulk of the memoir examines Wortmann's experiences in college with sex, close interpersonal relationships and OCD. He begins a relationship with a girl who has her own mental health problems, and how that relationship exacerbates his OCD. By the time their relationship ends, he says, "There was only the obsession."

Interestingly, Wortmann's physicians never diagnosed him with OCD until after he learned about the disease and diagnosed himself; which was later confirmed by a different medical professional. Shortly after his diagnosis, Wortmann held a razor to his wrist and began to cut himself. His mother found him with the razor at his wrist and had him admitted to a psychiatric hospital to receive treatment. The remainder of the memoir describes in (often graphic) detail the difficulties in treating his OCD with exposure response prevention therapy. Wortmann's symptoms do not completely disappear, but the focus of his obsessions changed from violent intrusive thoughts to obsession about obsession. In the end, Wortmann graduated college, continued therapy, and became a part-time tutor and writer.

Value and Considerations

One of the values in reading this memoir is the honesty with which Wortmann writes. He uses language that is accessible to the layman instead of complex medical terms. This honesty lends itself to the genuine tone of the story; the reader understands that these experiences actually happened, and it puts a proverbial face to the disorder. In addition, Wortmann uses humor to his advantage – for example, describing his childhood cat as "mounds of doughy flesh." Some of the humor is dark, particularly towards the end of the memoir, so readers should be aware that this book is not meant to be funny. The memoir is particularly accessible for many college students as most of the events depicted happened to Wortmann while he was in college. Because of this, students have reported to us that the

college student perspective makes the story feel more relevant to them.

However, one of the more negative aspects of this memoir is the bitter tone in which it is written and the large amount of vulgarity in the book. Early in Wortmann's description of his symptoms, he says that he "will not allow the disorder to sterilize my writing." The first example of this is when Wortmann recounts his suicidal impulses as a high school student. His brusque and unsympathetic language, while not necessarily graphic, may leave an acrid taste in the reader's mouth. More sensitive readers may also find some descriptions Wortmann uses disturbing, such as how he talks about his girlfriend's self-harm, scars, and eating disorder, as well as multiple detailed descriptions of his own suicidal ideation. Another negative aspect to this book is how heartbreaking it is at some points; for example, Wortmann loses multiple family pets over the course of the memoir. While they weren't major characters, they were important to him, and their deaths are written poignantly enough that readers empathize with how sad the situation was.

Students who themselves have personal or close interpersonal experience with mental illness may find that these accounts hit too close to home. There is a risk that this memoir may cause the students to experience an unwelcome (and possibly unhealthy) reliving of past or ongoing challenges. As described above, we therefore allow students to excuse themselves from the reading either before they start or after they have begun, and substitute another book that is less likely to be clinically significant for them (see "Important Caveats" and "Alternative Books" above).

The Day the Voices Stopped: A Memoir of Madness and Hope

Ken Steele, Jr. and Claire Berman (2001)

Disease or Disorder: Schizophrenia

Genre: Memoir

Summary

Ken Steele was a publicly influential mental health advocate until he passed away in 2000. In the latter years of his life he consulted with medical professionals and politicians about mental health treatment and policy (Goode, 2000). *The Day the Voices Stopped* is his memoir, written late in his life and published a few months after his death at age 51. In the book, he describes his initial schizophrenic break in high school. Steele experienced significant and worsening auditory hallucinations that included multiple voices which berated him and urged him to take his own life. He also recounts the unfortunate response from his parents who didn't understand what he was going through and broke off contact with him for years.

As a young adult with schizophrenia and no family connection, Steele found himself lost in New York City. He spent years as a male prostitute, during which time he was abused and raped numerous times, stories which he recounts in significant (but not pornographic) detail. Through this narrative, the reader is brought into the terrorizing life Steele led. Although Steele had some healthy

friends and personal supporters at times, a large amount of his time was spent homeless or in halfway houses. He also suffered in poorly run mental hospitals in which he spent much time restrained and over- or mis-medicated.

During a time when he was out of a hospital, Steele, with some deception (for which he felt guilty), landed a job as an assistant cook at a small private club. Although he was still plagued by voices, Steele was able to slowly rebuild a life for himself. He realized, however, that he couldn't fully function without proper professional care, so he returned to one of the inpatient facilities where he had previously been treated, now under new direction and with caregivers who provided better care for his condition.

With the help of his new physicians and therapists, Steele was able to quiet the voices in his head. As described in his obituary, "Mr. Steele was best known as the founder and publisher of New York City Voices, a newspaper focusing on mental health issues, and as the creator of the Mental Health Voter Empowerment Project, a national effort to register the mentally ill, who are often ignored by politicians" (Goode, 2000). Towards the end of the book, he describes his reconciliation with his family and emphasizes that though much work is needed to change public perceptions of mental illness, he is optimistic about the future.

Value and Considerations

This memoir is, in many ways, the most difficult for us as a teaching tool. There are many risks involved and considerations to be mindful of.

First, students reading this story are likely to, at times, be pessimistic about the state of mental health care, particularly after reading the descriptions of Steele's early institutionalization. Although Steele describes the many changes that psychiatry has seen in the last few decades, we still recommend that, if possible, instructors take time to bring in professionals from local inpatient clinics to discuss the reality of inpatient psychiatric care. This may avoid propagating negative perceptions about inpatient care, especially in case students may find themselves in need of psychiatric care during or after their college careers. In addition, this effort to demystify and destigmatize inpatient psychiatric care can be valuable for students who may have peers in need of such care, thus providing a more supportive community environment surrounding psychiatric care (J. Schreiber, M.D., personal communication).

Second, it is important to provide an honest depiction of life with mental illness through various degrees of recovery. While Steele's story is particularly poignant, it is not necessarily the only course for someone with schizophrenia. Instructors are encouraged to partner with in-patient care providers to allow a more accurate and modern picture of psychiatric care to be discussed in class (J. Schreiber, M.D., personal communication).

Third, like *Triggered*, this book features frank accounts of suicidal ideation and suicide attempts. For students who have lost someone to suicide or who themselves are living with mental illness that includes suicidal thoughts or past attempts, reading this book may not be appropriate. Additionally, the account of rape may not be appropriate for students who have personal history or know someone who

has been a victim of sexual assault. Students should be made aware of these considerations before reading the book, and decisions about whether it is appropriate should be made by the student and their health care provider (without a requirement to explain why to the instructor).

Despite these significant considerations, this book has the potential to dispel many myths about schizophrenia. Steele's ultimate recovery from a life spent homeless, hospitalized or in halfway houses, to a respected public figure can be valuable to some students who are concerned about the effect of their own mental illnesses on their lives. Additionally, because it is likely that every student will know someone with mental illness, the frank characterizations provided in this book help remind students to be aware of their interactions with others. Despite the many considerations, this is the one book that we feel best accomplishes our goals in teaching with memoirs and realistic fiction: helping students see a human side to unfamiliar or misunderstood diseases and motivating them to learn more about the biology of the disorders we teach.

An Unquiet Mind: A Memoir of Moods and Madness

Kay Redfield Jamison (1995)

Disease or disorder: Bipolar Disorder

Genre: Memoir

Summary

Though she suffered mood swings throughout her life, Dr. Kay Redfield Jamison was not diagnosed with bipolar I disorder (then called manic depression) until she was an assistant professor in psychiatry at UCLA and experienced severe manic and depressive episodes. The prologue to her memoir outlines her illness and the consequences she and others like her face. As a child, Dr. Jamison was incredibly "mercurial". She was initially diagnosed with depression in adolescence, which she points out is a common erroneous diagnosis that many patients with bipolar get early in life. When she went to college, her mood swings started to become more severe, often affecting her school work and lifestyle. The bulk of her memoir tracks her life from this time to publication.

She faced immense challenges as she initially refused treatment or did not follow recommended doses for her medication. As time passed and her mood swings became more severe and disruptive, she began to take lithium, the standard treatment for bipolar disorder. Her illness contributed to her separation and divorce from her husband, though he remained a supportive figure in her life. During her manic periods, Dr. Jamison spent exorbitant amounts of money, resulting in financial troubles, and become extremely hyperactive, getting only a couple hours of sleep a day, spending the rest of her time reading research papers or trying, somewhat unsuccessfully, to write her own papers.

Dr. Jamison's depressive episodes were as dangerous as her manic periods. During one particularly bad depressive episode, she became violent and attempted suicide; she did not die from this attempt, though it did take her a while to recover from it. A recurring thread through the memoir is Jamison's struggles with taking her medication consistently. Later in the memoir, she directly addresses

medication and how important it is for patients with bipolar disorder to maintain their medication and therapy regimen, lest they fall back into the swings of mania and depression. At the time her memoir was published, Dr. Jamison had some control over her illness, thanks to treatment, and had established her career as a researcher who studies mood disorders.

Value and Considerations

One of the great benefits of this memoir is the clinical perspective that Dr. Jamison brings to it. Her dual perspective as both a patient and clinical researcher bridges a common misperception that some students have – that a clinician cannot really understand what a patient is going through because clinicians never experience mental illness. Another significant benefit of this memoir is her example of how a mental illness, while it may affect one's life, is not the end of someone's career. Dr. Jamison, once she maintains her treatment plan, goes on to write the book (literally) on bipolar disorder and becomes very successful. Her clinical training is evident in this memoir, particularly when she discusses statistics related to bipolar disorder and emphasizes the importance of maintaining a treatment regimen. Additionally, this memoir provides a valuable portrayal of a successful female scientist (Hoh, 2009; Schinske et al., 2016).

Jamison also proves that a diagnosis does not have to define a person, which provides a valuable counter-point to the more difficult course of illness experienced by Steele in *The Day the Voices Stopped*. Similarly, Dr. Jamison's work helps break some of the stigma that surrounds discussions of mental health and illness. For example, at one point, Jamison was considering having children and her physician advised her against it, frankly telling her that the genetics of bipolar and the likelihood that she wouldn't be able to care for her children would make having kids a poor decision. Our students appreciate this representation of improper medical care as an opportunity to discuss how properly-treated patients with mental illness can lead productive family lives and successfully raise children.

Dr. Jamison does not censor herself in her memoir. In the prologue, she says she is tired of hiding who she is, and makes it clear she will be honest in this book. She describes, in incredible detail, her thoughts and actions during both manic and depressive episodes, including a suicide attempt. Because of this, sensitive readers may find it difficult to read certain parts of this book. Her tone throughout the memoir, though, is not as bitter and angry as Wortmann's, nor is it as optimistic as Steele's. The memoir is clearly being written retrospectively, which brings a level-headed and self-critical tone to it as the older Jamison looks back on her actions.

There are small sections that are written as vivid flashbacks, putting the reader in whatever moment Dr. Jamison depicts. The writing style of the book can be poetic, which some students have told us makes it too abstract and difficult to read, although others find the beautiful prose to be enjoyable. Some parts of this particularly emotional memoir, such as when Dr. Jamison's lover is killed while on duty in the Navy, are incredibly sad. While she is eloquent

and well-spoken, reading this memoir can be mentally and emotionally exhausting.

As with the memoirs by Wortmann and Steele (discussed above), the potential for this memoir to cause distress for students is high, particularly if they or someone close to them have experienced severe depression, suicidal tendencies and/or bipolar disorder. Again, students should be aware of this before reading it, and provided with local hotlines if they find themselves in crisis (see the last 2 pages of Supplementary Material 1 and "Important Caveats" above). While the memoir may serve as a hopeful piece to some, it should be kept in mind that Dr. Jamison was able to seek treatment because she had a personal support network and the support resources of an excellent university/workplace. While her success in the face of her illness should not be belittled, there are many people in a similar situation who do not have access to such resources.

One other clinically relevant consideration that this book raises is patient non-compliance with treatment. We recommend that instructors discuss the reasons for this while being mindful that students may themselves be current or future patients and many may also be future physicians. We recommend emphasis be put on frank discussions between physicians and patients about side-effects, doses and treatment options. Understanding these factors are an important learning objective in our course and relevant resources are made available to students (e.g., Jin et al., 2008).

Front of the Class: How Tourette Syndrome Made Me the Teacher I Never Had

Brad Cohen and Lisa Wysocky (2005)
Disease or Disorder: Tourette Syndrome
Genre: Memoir

Summary

As a child, Brad Cohen had uncontrollable tics, several of which involved involuntarily making sounds others would consider disruptive. In his adolescence, he was diagnosed with Tourette Syndrome, a neurological disorder that was virtually unknown outside the medical community in the 1980's. Cohen tells the story of his youth and young adulthood, describing the difficulties and barriers he encountered because of his tics. While some did not believe his diagnosis, others did. Cohen's mother began to gather as much information as she could. She and Cohen quickly became advocates for those with Tourette Syndrome, initially by educating their own community.

Cohen began to advocate on a national scale from childhood, going so far as to participate in the Sally Jesse Raphael Show, though he was not permitted to remain on stage the entire time with the other Tourette Syndrome patients because his symptoms were more severe. There is a particularly moving passage in which Cohen speaks to his entire elementary school about his disorder, with overall positive reception by his teachers and fellow students.

Cohen attended college knowing he wanted to be the compassionate, understanding teacher he never had. Once he finished school and had his teaching certificate, he began to interview for jobs. During interviews, Cohen was honest

about his disorder. Though no one could or would say it outright (the Americans with Disabilities Act prohibits job discrimination based on disabilities), Cohen presents a convincing case that his struggles finding a job were because of his disease. After twenty-four schools turned him down, Brad Cohen finally got a position just outside of Atlanta, Georgia, teaching second and third grade. He received several awards for new teachers, which eventually set him on a course to become assistant principal of his elementary school.

Value and Considerations

This is a particularly heart-warming and memorable book. Brad Cohen's optimism and how he uses his disorder to educate others is encouraging. Cohen works with the Tourette Syndrome Association, through both national and local chapters, and he started his own foundation and summer camp for children with this syndrome. Unlike some other disorders, the symptoms of Tourette Syndrome cannot be easily hidden; that put Cohen in a unique position to use his symptoms as an opportunity for discussion. For example, one point in the memoir where discussion can naturally start is the recollection of Brad's school presentation, where his disorder is explained to the entire school during an assembly. This moment serves as a gateway to discussing public opinions, judgments and treatment of adults and children with Tourette Syndrome. This book is the least likely of any we recommend to be triggering for students; the most emotionally trying part is a story of a young student of Cohen's who dies of cancer.

This book is appropriate for all readers because of Cohen's positive tone. In fact, his perseverance and determination to live as normal a life as possible is encouraging for any young reader who may be facing similar circumstances. There is also an underlying message throughout the memoir about accepting others for who they are and not bullying them for conditions they cannot control. Because this memoir is optimistic and upbeat, the weight of Brad's condition on his life is not felt by readers the same way as in other memoirs. This reflects Cohen's uniquely optimistic personality: he approaches the most negative aspects of Tourette Syndrome with resolve to succeed. While he does address bullying, he does not dwell upon the negative aspects of this syndrome.

Still Alice

Lisa Genova (2007)
Disease or Disorder: Alzheimer's Disease
Genre: Fiction

Summary

Author Lisa Genova creates a story so rich readers would be forgiven for forgetting its fictional nature. *Still Alice* is a fictional account of a woman and her family dealing with the lifestyle changes that early-onset Alzheimer's Disease brings. The main character, Alice Howland, is a cognitive psychologist and linguistics expert working at Harvard University when the novel begins. She teaches, runs a lab and travels to conferences like many academic researchers. In the first half of the novel, Alice displays subtle, early

symptoms associated with dementia, including memory loss and disorientation; later, she is diagnosed with a rare, single-gene form of early-onset Alzheimer's Disease.

Genova's novel follows how Alice's disease affects her career and family life, with her three adult children and husband coming into conflict and confronting the difficulties of caring for a loved one with Alzheimer's Disease. Alice must face a rapidly deteriorating mental state, and creates a suicide plan so that she will not burden her family once her memory is gone and she can no longer live on her own. The book is structured so that each section represents a month, which allows the reader to follow the time course of Alice's illness. Genova's use of the first-person perspective humanizes Alzheimer's, pulling readers into an emotionally charged and deeply personal account that often reads as though it is nonfiction.

Value and Considerations

One of the advantages to this well written novel is that it makes the subject of Alzheimer's Disease more accessible to readers who may not be inclined to pick up a memoir or other piece of nonfiction. The information that Genova includes about Alzheimer's is reasonably accurate considering its non-technical nature. An important plot point, the genetic basis for the disease, is written so that it can be used to start a discussion about genetics and the role that it plays in early-onset Alzheimer's. This includes a comparison of rare, Mendelian alleles that can essentially guarantee a disease, with more common risk-factor alleles that only increase chances of a disease.

It is clear that Genova thoroughly researched the disease in order to create her characters and their stories, but this novel lacks the personal reflection that a memoir would bring. Genova also invents an experimental drug for clearing amyloid plaques that does not exist. However, this can be a launching point for discussing real experimental treatments, such as tau and amyloid immunotherapy (Lannfelt et al., 2014; Pedersen & Sigurdsson, 2015).

Although Alice plans to take her life when her symptoms become severe, the discussions of suicide and self-harm are less graphic than those in *Triggered*, *The Day the Voices Stopped*, or *An Unquiet Mind*. Although many of our students have had family members with Alzheimer's, none have found the book distressing so far, and those who have spoken to us about their family experiences seem to find the book cathartic. However, instructors should still be mindful that this may not hold true for all potential readers.

The Curious Incident of the Dog in the Night-Time

Mark Haddon (2003)
Disease or disorder: Autism Spectrum Disorder (ASD)
Genre: Fiction

Summary

In this fictional account, Mark Haddon introduces a possible view of the world through the eyes of an autistic boy, Christopher Boone, as he strives to solve the mystery of who murdered his neighbor's dog and why. Christopher is a British teenager and mathematical savant who idealizes Sherlock Holmes and is strongly committed to finding and

expressing the unvarnished truth. As Christopher follows clues and interviews suspects, he also navigates social interactions with strangers, adapts to new environments, and begins planning for his future. The novel is written as Christopher's journal covering his daily experiences with his family and school.

All events are described in first-person through Christopher's point of view, laying out his thought process as he tries to decipher the behavior of his peers and neighbors. Christopher's literal interpretation of the world creates a poignant perspective of Christopher's inner life for the reader.

Christopher refers to advice from his social worker, Siobhan, though out the story, giving us a glimpse of the therapy and social training autistic children might receive. He often becomes hyper-focused on a particular detail and can become intensely upset when confused or stressed. The novel also touches upon the difficulties inherent in raising a child with autism spectrum disorder (ASD), and how that stress can affect a family. Haddon succeeds in providing an engaging and entertaining snapshot of what it may be like to have ASD, even though the author himself does not have this disorder. Although Haddon has done research into ASD, he intentionally does not explicitly use "autism" or related words in the book, emphasizing it as a work of fiction (Powell's Books, 2006).

Value and Considerations

As a novel written in the voice of a 15-year-old, this book is easy to read and comprehend. It is not intimidating or dense, which can be an advantage over nonfiction accounts or memoirs. Christopher is an endearing protagonist and certainly humanizes the experience of ASD. Additionally, his interactions with strangers and police officers demonstrate the lack of awareness and understanding of ASD among the general public. Though the novel is by no means technical, it does introduce some psychotherapy treatments and strategies used with autistic kids. It also shows some behaviors commonly observed in those with ASD. Christopher does not address the underlying cause or prevalence of ASD, nor any biological consequences of the disorder. As a novel by an author who does not have this condition, the book is an incomplete picture of the possible experiences of an autistic teenager. However, the topics and issues in the novel are presented in an engaging way.

ASD is a character trait of the protagonist, but the book is not written with the goal of educating about the disorder. It influences Christopher's choices and point of view, but he does not directly discuss the impact of ASD on his life in much detail, nor is the biology discussed. As such, the book provides more of a motivator for students to learn about ASD and to give a human (albeit fictional) face to the disease. We chose this book, in part, because it is stylistically very different from the others we review here. It therefore provides our classes with a break from the more scientifically rigorous or challenging books. Instructors who want a book on ASD that is more similar to the others we review here could consider Temple Grandin's autobiography (Grandin, 1995) or Grandin's biography (Montgomery, 2012) instead.

The Noonday Demon: An Atlas of Depression

Andrew Solomon (2001)

Disease or disorder: Major Depressive Disorder

Genre: Memoir and Compilation of Short Cases

Summary

Andrew Solomon interprets the biology, pharmacology, psychology and human experience of depression through a literary lens in his memoir, *The Noonday Demon*. As a professional writer with depression and anxiety, Solomon is particularly adept at creating analogies to further readers' understanding, striving to put depression into a framework that adults who have not experienced depression can understand. At a whopping 688 pages, *The Noonday Demon* can be intimidating, but it is an impressively thorough exploration of depression effectively organized into 13 chapters.

The author begins by offering his own experience with breakdowns and treatment, along with experiences conveyed to him by friends, family and interviewees. The personal stories anchor each chapter in honest biographical portraits that readers will find relatable and emotionally engaging. As the son of a drug company executive, Solomon provides insight into the development of pharmacological treatment of depression, bluntly addressing the advantages and disadvantages of various types of drugs. The book is full of interviews with clinicians, researchers, pharmacologists, experts and other sufferers of depression, which are chronicled in an extensive bibliography. With the skill of a humanities scholar, Solomon captures and explains much about the experience, origins and factors of depression.

Value and Considerations

As a teaching tool, *The Noonday Demon* provides personal stories which capture and convey the experience and consequences of depression better than a list of diagnostic criteria. Our students have expressed both relief and excitement at reading an eloquent articulation of experiences similar to their own, reminding them that they are understood and not alone when struggling with depression. Others said that the book helped them empathize more with depressed friends and loved ones. However, some portions of the book read like a dense dissertation or rambling personal journal entries, making it difficult for some students to extract the pertinent information and descriptions. Despite that, the author's literary style gives the writing a poetic and lyrical quality, earning acclaim and accolades including the National Book Award and consideration for the Pulitzer Prize. The book provides a wonderful balance between research findings, societal impacts and human interest, which is particularly helpful in a classroom of students with varying academic backgrounds.

As an in-depth work of nonfiction which resists categorization, *The Noonday Demon* covers a wide range of topics relevant to depression and offers many starting points for classroom discussion. Solomon addresses the role of cultural values, history, politics and identity in the manifestation of mental illness. These topics are not often

addressed in scientific works, but certainly influence the manifestation of depression. He also does not shy away from emotionally heavy material, including depression in the wake of traumatic experiences (e.g., massacres, sexual assault), comorbidity with drug addiction and suicidal ideation. Because the book was published in 2001, some of the research referenced is a bit dated. In the 2015 edition, Solomon added a chapter entitled, "Since", to update readers on relevant research findings and discuss the public's reactions to the book.

Rather than requiring the whole book, we employed it in our classrooms as a selection of chapters, including "Depression", "Breakdowns", "Treatments" and "Populations". "Depression" is the first chapter of the book, introducing the author's background with depression and anxiety and multiple descriptions of the experience of depression. This chapter was chosen to give a broad overview of the disorder, and provide the language and analogies for future class discussion. "Breakdowns" illustrates symptoms and triggers of mental health crises, and gives an account of what helped the author recover from breakdowns. It shows steps a patient might take during or in anticipation of a breakdown, as well as ways to interact and support someone struggling with depression. "Treatments" highlights various ways depression is treated, the proposed mechanism behind the treatment and evidence of its relative effectiveness. This chapter is more biologically oriented and facilitates discussion of the cellular and chemical basis of depression. Finally, "Populations" is included to acknowledge that depression has sociological and cultural underpinnings while describing how these factors influence the patients' experience, diagnostic criteria and treatment options. One motivation behind including this chapter is to engage students from a diverse socioeconomic and cultural background who typically might not see their values or experiences reflected in the story of a white American male struggling with depression. This selection of chapters makes the length and density of the book more manageable for the students and allows the instructor to choose the relevant points for their course. The book does not have an overarching storyline, so it is feasible to look at chapters in isolation.

There is a chapter entitled "Suicide" (which we do not usually assign), and issues related to suicide and other serious aspects of depression are discussed at many places in the book (including in many of the chapters we do assign). As such, we recommend instructors bring the same considerations discussed above in *Triggered*, *The Day the Voices Stopped* and *An Unquiet Mind* to bear in discussing this book.

Brain on Fire: My Month of Madness

Susannah Cahalan (2013)

Disease or Disorder: Anti-NMDA-Receptor Autoimmune Encephalitis

Genre: Memoir

Summary

In *Brain on Fire*, Susannah Cahalan describes her abrupt, rapid, and frightening descent into madness. At the time,

she was a 24-year-old reporter for the *New York Post*. She was outgoing, confident, sharp and witty. After a few months on the job, signs began to appear that showed something was abnormal. First, after getting two bug bites, she became paranoid that her apartment had a bedbug infestation. Around that time, she also forgot about a crucial meeting with her boss, began deleting many of her old articles, and impulsively decided to go through her boyfriend's emails, all of which was uncharacteristic of her. She was experiencing persistent nausea, migraine and a "pins and needles" feeling that was spreading throughout the left side of her body. When she saw a neurologist, he determined that her MRI was normal and that it was likely a virus. With her increased moodiness, her friend's mother thought it was bipolar disorder.

After having a tonic-clonic seizure, the neurologist surmised that her symptoms may have had to do with her alcohol consumption (which he overestimated because he did not take her word about how much she drank). She began to experience more seizures, and increasingly, delusions and hallucinations that often came in the form of voices, as well as severe paranoia, including thinking that the hospital staff and the TV reporters were all talking about her. Cahalan started slurring her words and sometimes spoke in fragments of sentences or in unintelligible noises. Several doctors tried to piece together her symptoms of psychosis with her elevated blood pressure, heart rate, and white blood cell count. She became extremely thin and experienced concentration and memory difficulties.

After ruling out many infectious and autoimmune diseases and considering her normal CT and MRI scans, it was finally determined that she had an exceptionally rare disease known as anti-NMDA-receptor autoimmune encephalitis, that had only been discovered about two years prior by Cahalan's eventual physician, Dr. Dalmau, and his colleagues (Wandinger et al., 2011). After treatment with steroids, plasmapheresis, and IVIG to rid the body of the anti-NMDA receptor antibodies that were attacking her brain, she made a full recovery and eventually returned to her work as a journalist. Her family, boyfriend, hospital care team, and friends helped her to put together the pieces of her "month of madness," and she went on to write an article about it in the *New York Post*, titled, "My mysterious lost month of madness."

Value and Considerations

There are several benefits to using this book as a means for sparking a discussion about neuropsychiatric disorders. As Cahalan is misdiagnosed with many different diseases, this book can serve as a review of symptoms from different diseases discussed during a semester-long course on Neurobiology of Disease. It discusses parallels to bipolar disorder and schizophrenia, as well as the ways in which they differ from what the author experienced. Therefore, the reader does not just get an insight into anti-NMDA-receptor encephalitis but is also introduced to other disorders. In particular, the psychotic symptoms that Cahalan experiences can be used as a jumping-off point to discuss the NMDA/glutamate hypothesis of schizophrenia (Laruelle, 2014; Chang et al., 2014). Second, this memoir gives a

deeply personal, moving account of one person's experience with this disease. Additionally, for students who are aspiring physicians, this book can bring up questions about listening to patients, and how to evaluate whether they are being honest.

The author clearly discusses the science behind her diagnosis. She explains what the disease is, how it gave rise to her symptoms, and how her treatment was able to cure her. She also provides interesting and helpful information on the disease's prevalence and prognosis. Furthermore, the age of the author at the time that her disease manifested is similar to that of undergraduates, which may allow them to connect and empathize with her experience even more. Finally, the author's story illuminates a common theme in diagnosing neuropsychiatric disorders: that they are often hard to diagnose, especially when people experience symptoms that appear in more than one disorder's diagnostic criteria. Many times, it can also be difficult to identify the root cause of one's psychiatric symptoms.

While one valuable aspect of this book is that it shows how symptoms of psychiatric disorders can be caused by other underlying diseases. The flip side of this is that *Brain on Fire* describes the experience of someone who has a very rare disease. Therefore, some instructors may choose to use it as a teaching tool in a unit on rare diseases, but some may choose to omit it, preferring to expose students to the experiences of those with more common neuropsychiatric disorders. Additionally, the author's account of her symptoms becomes repetitive. While this was necessary to accurately convey as many details about her experience as possible, it may be easier and more time-effective for instructors to present her particular story in the form of a video (Susannah Cahalan has several interviews and talks online in which she talks about this experience (Cahalan 2012; Cahalan 2013b; Cahalan 2017) or as a case study to the class.

No major considerations arose that an instructor would need to address when assigning this book as a recommended or required reading in an undergraduate-level class. There is one scene describing a delusion the author has in which she believes her father has killed his wife and is potentially plotting to kill her. From a subjective standpoint, this would be the only potentially jarring scene of the book. There are no other parts that seem likely to be clinically counter-indicated for any students.

CONCLUSIONS

Although there are many considerations to bear in mind when using biographies, autobiographies and realistic fictional accounts of patient experiences with diseases in teaching about the neurobiology of disease or related subjects, these books can be valuable tools to help instructors spark and maintain student interest in material. In addition, they can be starting points for broader discussions about the impact of science on health care, as well as considerations that patients and physicians should be aware of in their lives and careers.

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