Personal Insights into Neurological Disorders

May 9, 2017

Introduction:

Over the last 25 years there have been many books, and book chapters, written by individuals diagnosed with a variety of neurological disorders about how their injury or disease affects their life. I realized that many of these first-person accounts provide unique and insightful points of view of clinical conditions that are frequently encountered by physical therapists. I have integrated readings from some of these books into a course, Human Neurobiology. This course is the first neuroscience course in the physical therapy curriculum and is designed to introduce the students to the human nervous system at both cellular and systems levels, linking structure to function. So, there is anatomy and physiology, and some pathology, and it is all placed in a behavioral context. This reading exercise helps the students make a connection between what they have been leaning in the classroom and lab and the experience of the patient, from the patient’s perspective. Most importantly, it is a reminder to the students that the patients they will be working with are more than their diagnoses, and that patients have insights into nervous system function not necessarily covered in a textbook.

This activity breaks from the traditional lecture or lab experience by getting the students to stand in front of the class and read short passages from selected books. The students who have been assigned to read seem to take more ownership of the discussions that follow the readings. It is not unusual for students to borrow one of the books that was used in class so they can read the whole book when they have a break in their schedules.

Here is a list of some of the books that have been used for this exercise in the past (the first 6 are the ones that have been used most often):

1. **An Unquiet Mind**, A Memoir of Moods and Madness by Kay Redfield Jamison (1995). This is a first-person account of bipolar disorder from a world-renowned researcher/clinician who suffers from this disorder. Given the social stigma of mental disorders and their prevalence in our society, this book and the author’s insight into some of the challenges she has faced have proven useful as teaching tools. The students read the *Prologue* (5 pages).

2. **Thinking in Pictures, and Other Reports from My Life with Autism** by Temple Grandin (1995). Here is a book written by someone with autism that provides us with a first-person description of what it is like to be autistic. She has a newer book out, **The Autistic Brain,** which I have purchased but have not yet read that is probably another excellent choice. The students read 3 pages from chapter 2, *Diagnosing Autism*.

3. **Moving Violations, A Memoir of War Zones, Wheelchairs and Declarations of Independence** by John Hockenberry (1995). The author, a writer and news correspondent for NPR and ABC, writes about many aspects of life following a spinal cord injury. His description of a situation where his loss of sensation resulted in a severe burn is not only an example of beautiful writing, but of anatomically-correct beautiful writing. The students read 5 pages from chapter 4, *The Cutting Board*. The students also read

4. **An Anthropologist on Mars** by Oliver Sacks (1995). Dr. Sacks has written several books about interesting patients he has seen over the years, and in each case providing insight into brain function and the deficits that result following specific lesions or diseases. In this book, he has a chapter about his friend/colleague who is a surgeon with Tourette’s syndrome. The students read 5 pages from the chapter titled *A Surgeon’s Life*. There are some interesting insights into personal space issues that can accompany Tourette’s syndrome.

5. **The Diving Bell and the Butterfly** by Jean-Dominique Bauby (1997). Bauby “wrote” this book one letter at a time after suffering a brainstem stroke that resulted in locked-in syndrome. The students read the chapter titled *Bathtime* (3 pages).

6. **My Stroke of Insight** by Jill Bolte Taylor, Ph.D. (2009). Dr. Taylor, a neuroanatomist with a research interest in mental illness, writes about how it “feels” to have a stroke, and describes some of the challenges faced by those recovering from a left-hemisphere stroke from the perspective of a brain scientist. The students read the first 6 pages from Chapter 13, *What I Needed the Most*.

Other books that have been used from over the years:

A Nearly Normal Life (1999), by Charles L. Mee (first person account of life after polio)

My Year Off (1998), by Robert McCrum (first person account of life after a CVA from the perspective of a literary editor)

The Spirit Catches You and You Fall Down (1998), by Anne Fadiman (complicated cultural differences come to light when an infant is diagnosed with epilepsy; not a first-person account but insightful nonetheless)

Phantoms in the Brain (1998), by V.S. Ramachandran (also not a first-person account; neurological consequences of limb amputation and some clever therapeutic approaches; a great introduction to neuroplasticity)

Almost any book by Oliver Sacks.

Learning Objectives:

The primary objective of these readings is to sensitize students to the patient’s perspective, and to the fact that patient’s will be their teachers. Specific, measurable objectives will depend on which books you choose, but here are examples from the books listed above:

1. Describe the symptoms of bipolar disorder and how they can interfere with a healthy life. Given that there are relatively effective treatments for bipolar disorder, explain why some patients will not take their prescribed medications.

2. Define “autism”, discuss some behaviors associated with this diagnosis and explain the significance of a diagnosed condition that is expressed across such a broad spectrum (from mild to severe).

3. Describe the functional consequences of a complete spinal cord injury in the mid-thoracic region. List some of the limitations, not related to movement, that can result from this type of injury. Explain the dangers associated with a complete loss of sensation in a body area.

4. Discuss the symptoms of Tourette’s syndrome and explain how someone with this diagnosis can become a surgeon.

5. Define locked-in syndrome. Over the course of a 24-hour day list those activities that the individual will need assistance with. Explain how it is that the individual can be completely intact cognitively following this kind of injury. How does locked-in syndrome differ from coma in terms of pathology and functional deficits?

6. List 5 of the most important personal behaviors that Dr. Taylor found helpful during her recovery.

Description:

This exercise can be done in either a lab or lecture period. Students volunteer to read short passages from 5-7 books that I have pre-selected. Prior to the reading there is a brief introduction to the specific neurological condition that is the subject of the book. This introduction takes 1-3 minutes. I highlight where the student starts reading and where they finish; each reading takes about 3-6 minutes. Following the reading I wait for comments and ask for questions. If there are none, I ask the students what they found surprising about the patient account and whether they had previously considered this aspect of the patient’s situation. This has led to some surprising personal accounts that students have had during clinical experiences and with friends or family. I also ask questions that relate to the objectives for that reading.

Evaluation of student learning:

There are multiple choice questions on the corresponding exam taken from the objectives that have been written (as stated above, specific objectives will depend on which books are selected). Even though this activity is much different from the rest of the course (or perhaps because this activity is different) the students have responded positively. A handful of students each year seem to resonate with this activity and borrow one or more books to read in subsequent semesters.

Anthony E. Kincaid, PhD, PT

Professor

Creighton University

akincaid@creighton.edu