

MEDIA REVIEW

Shaken: Journey into the Mind of a Parkinson's Patient

Produced and directed by Deborah J. Fryer, Ph. D.
Lila Films, Inc.

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INTRODUCTION

Parkinson's Disease (PD) is an increasingly common disease that currently affects 1.5 million people across the country (www.parkinson.org). This brain disorder results from decreased dopamine production by cells in the substantia nigra. Lowered dopamine levels can lead to tremor, slowness of movement, rigidity, difficulty in walking, slurred speech, stiff facial expressions, and depression. The disease is progressive. While there are many therapies and, recently, surgical palliative procedures, there is no cure.

Unless they have a family member with PD, college students are apt to be ignorant of the condition, since the average age of onset is 60 years (www.parkinson.org). However, an increasing number of patients are developing PD at earlier ages (5-10% develop the disease at 40 years or younger). As our population ages, it is critical to promote awareness of PD and to underline the urgency of developing a cure.

To that end, Deborah Fryer has created an award-winning, moving and insightful 30-minute documentary about PD. The film uses the life of one patient to highlight the difficulty of living with the disease, the promise of Deep Brain Stimulation (DBS), and the bittersweet realization that while the surgery can dramatically improve life, the benefits are temporary, and that the surgery is not a cure.

DESCRIPTION OF SHAKEN

With unflinching honesty, humor and dignity, producer/director Deborah Fryer follows the story of Paul Schroder, a bright college graduate whose life's goals and dreams are cut short by the early onset of Parkinson's disease at age 33. By the start of the documentary, Paul has endured increasingly debilitating symptoms, such as tremor, stiffness and impaired balance. He suffers such terrible dyskinesias from his 21 pills a day that he has developed tennis elbow and has had to move back home to live with his 70-year old parents.

After a dozen years on expensive drugs, the quality of Paul's life is so diminished that bilateral deep brain stimulation surgery remains the only option for him. Fryer follows Paul from the moment he makes the decision that brain surgery is "preferable to sitting on the couch like a vegetable." We go into the operating room with him, and hear him singing songs and cracking jokes while a neurosurgical team probes his lobes listening for clues to his condition.

Viewers watch the doctors mapping their trajectory from Magnetic Resonance Images, expertly guiding the

electrode through white matter, missing the ventricles, going through the caudate and landing in the lima bean-sized subthalamic nucleus. "You've done everything you can with diet and exercise and medication," neurologist Dr. Vicki Wheelock, Associate Clinical Professor of Neurology at UC, Davis tells Paul on the day before his surgery. "And thank goodness we have this other option, but we're going to tell you right now, we are not really sure how this works."

Paul's transformation after the operation seems miraculous. He regains his dexterity and independence so fully that he is able to drive, go bowling and flyfishing, and most importantly, to smile again. He is able to decrease his medication by 50%, but when he develops an infection in his scalp, he has to have the electrodes removed, and he reverts to his previous state of alternately freezing and being dyskinetic. (Paul is planning to have the DBS electrodes re-implanted in April 2007).



Figure 1. Images from *Shaken*. Left: The neurosurgical team maps the trajectory of the DBS electrodes. Middle: Axial sections of Paul's brain. Right: Paul receives a lidocaine injection prior to surgery. (Pictures are provided copyright of Deborah Fryer, Lila Films Inc.)

A TALE OF TWO SCREENINGS

I was extremely fortunate to be able to invite Dr. Fryer to Denison University to screen *Shaken* and to speak about the making of the film. While her presence added enormously, I think the documentary would still be effective without that kind of introduction and follow-up.

The first screening was for my Introduction to Neurophysiology 349 course, which was a mixed junior-senior biology elective class. The students read Benabid (2003) to prepare; some had also read Bevan et al. (2006). The Benabid article was especially useful because it outlined the criteria for DBS, described why different regions of the brain might be stimulated, outlined different methods of localizing the target, and discussed clinical benefits and complications. By viewing the documentary, the students were then able to see the surgical team (neurophysiologist, neurologist, neurosurgeon and others) work through these same elements in Paul Schroder's

surgery and follow-up. The Bevan et al. (2006) article, which details current understanding of the mechanisms underlying both PD and DBS, allowed the best-prepared students to take their understanding to the next level, but overwhelmed others.

We were especially lucky in that the filmmaker also shared with the class sixteen additional minutes of raw footage of the brain mapping, electrode placement and electrode testing. Among other gems, such as manipulation of contrast mechanisms in the MRI, this footage enabled students to eavesdrop on the different sounds produced by layers of cells on the track followed by the electrode. While not available for purchase, this additional footage can be part of scheduled screenings.

Despite it being the day before the start of Spring Break, students were riveted, especially during the scenes of the brain surgery and its aftermath. Comments included: "the video was very touching", *Shaken* made "learning seem even more important than it usually does," "the film did a great job of combining both the scientific/medical aspects of Parkinson's with the emotional and psychological problems it causes," "the film provided a humanizing perspective," and that they "understood the disease so much more after seeing someone live with it on a daily basis." One pre-med student noted that "it is sometimes easy to get caught up in reading about the biological causes of a disorder and to lose sight of how greatly real people are suffering from these diseases. I thought that by focusing on one story, Deborah Fryer's film helped to show what it can be like to live with Parkinson's disease, as well as demonstrating the great hope and the great disappointment that can be associated with novel therapies." Several students mentioned that the film "presented an excellent case for why we need to continue with both basic and applied scientific research into Parkinson's disease and other progressive disorders" and that the film motivated them to "study the disease and try to find a cure."

The second screening (same day) was open to the entire Denison community and was not associated with any assigned reading. Again, audience members were very involved with the movie, several visibly moved. One professor commented, "Deborah Fryer's *Shaken* brilliantly captures the challenges associated with Parkinson's disease and its treatment. You don't have to be a neuroscientist or a Parkinson's patient to appreciate this film, you only have to be human." A student noted that "there was a good amount of scientific detail while remaining true to the personal nature of the subject." Another audience member commented on the dignity with which Fryer was able to capture Paul's life, and the warmth and humor which came through with the pathos of the struggles of Paul and his family.

In summary, this film is a useful teaching tool for helping undergraduates understand the impact of PD on patients and their families. Many students, especially those with a pre-health bent, will find the surgical scenes inspirational. Watching the movie in conjunction with reading a sampling of the literature can lead to a greater understanding of the brain circuits involved in PD and an appreciation of the

therapeutic value of DBS. In addition, the compassion with which the material is presented can remind students of the fundamentally patient-driven nature of their future profession.

HOW TO OBTAIN THE FILM

The film can be obtained from Deborah Fryer at Lila Films Inc., Boulder, Colorado, at www.lilafilms.com or (303) 442-1966.

REFERENCES

- Benabid AL (2003) Deep brain stimulation for Parkinson's disease. *Curr Opin Neurobiol* 13:696-706.
- Bevan MD, Atherton JF, Baufreton J (2006) Cellular principles underlying normal and pathological activity in the subthalamic nucleus. *Curr Opin Neurobiol* 16:621-628.
- www.parkinson.org. This website, run by the National Parkinson Foundation, is geared to patients and their families.

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