Awakenings has a message for all of us

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The recent film, AWAKENINGS, starring Robert De Niro and Robin Williams, is an adaptation of a book by the same name written by Dr. Oliver Sacks, a neurologist from New York. The movie is a tour de force, the acting pure genius, the story compelling and the message timeless, especially for physicians, no matter what specialty they pursue.

The book was written by Sacks in 1973, and depicted the patients he attended at a chronic care hospital. These patients were suffering from the effects of von Economo's disease – encephalitis lethargica. Some of these souls had been in a trance-like state for up to 40 years, after they were originally affected by the flu epidemic of 1918-19. In many cases the cause of the disorder was not recognized. These patients were considered to be suffering from some obscure psychiatric disorder (wasn't inflammatory bowel disease once considered in the same fashion?), and were relegated to the buck wards of hospitals or to a remote asylum. They were simply forgotten by the bulk of the profession, the detritus of an unremembered epidemic, a population of people scattered all over the Western World caught in an abyss of perpetual immobility and unconsciousness punctuated by bizarre tics, weird motor disorders, and outbursts of frenetic, chaotic and sometimes psychotic behaviour. There seemed to be no end in store for them except the final release of death. No research was considered, since the population with the disorder were dying off; they had no advocate to plead their case; and no one had a clue as to the reason for their almost metaphysical existence. They seemed to have received excellent, even dedicated, care from their attendant nurses and orderlies, but active medication was just not available.

Sacks was one of the few neurologists who recognized the link between this disease and Parkinsonism. He came upon this realization from careful, almost continuous observation of their behaviour. If there was ever a testament for training our students to observe their patients carefully, this is surely it. In addition, Sacks was trained as a researcher, and this training allowed him to put his observations together logically – another reason why those we train should be given research experience as part of their education. Sacks was also extremely tenacious – another attribute of a great scientist – he was reviled by the neurological establishment of the times, and suffered the humiliation and frustrations of so many of medicine's great innovators who dared to suggest that the current dogma was not correct – namely, Semmelweis, Selye, Lister... and the roster goes on, even in our enlightened times.

One problem that was that he wrote his reports in the classic biographical fashion using an old Hippocratic style, 'pathography' – ie, pathology plus biography – no charts, no graphs, no statistical manipulations – just a penetrating analysis of each case – something that the profession of that time (and our time as well) denigrated as 'not scientific'. However, he stuck to his guns and ultimately overcame the prejudice, jealousy and bitterness, especially after his reports of the amazing results of treatment with L-dopa.

And the results were astounding – as graphically portrayed in the movie by the amazing De Niro and his co-actors. The sleepers awoke and resumed their lives. Their tics, wild mood swings and akinesia disappeared, like a fog dissipated by the sun. His description of these amazing responses are beautifully and graphically illustrated in his book and equally in the film. Suddenly there was hope for these victims of 'Rip Van Winkle's syndrome'. The world, and Sacks, were astounded. But there were problems. Some patients could not cope with the fact that they had been 'away' for so many years; some suffered severe reactions to this social problem, but most of them did fine – in the beginning.

As we all witness in the chronic disorders we treat, after an initial, sometimes miraculous improvement, the drug's effects slowly start to wear off, the original symptoms and signs return, and new ones are added. Complications occur, and side effects may be devastating – sometimes more horrendous than the problems caused by the disease itself. We have merely to think of the problems we encounter with Crohn's disease to find a parallel with Sacks's patients. Initially most of our patients

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improve – the pain disappears, the diarrhea subsides and the bloodwork approaches normality. Indeed, we document these changes in our research efforts, in the so-called ‘activity indices’. We all know that in the vast majority of cases this improvement is not sustained – recurrences are almost the sine qua non of the condition; surgery is performed and the process is temporarily arrested, and then the whole cycle begins again – indeed, one knows that the symptoms will come back. In the meantime we are faced with added problems – shortened guts, various deficiencies, total parenteral nutrition and an open road for further complications – some of which we are poorly equipped to handle – much like Sacks’s experience.

Sacks also pondered the strange discovery that the brains of his dead patients did not help him to understand this most unusual disorder any better, for there was no correlation between the pathology and the degree of disordered function. Some, with the most bizarre movement disorders or even akinesia, he states, showed very little damage, whereas those with the most innocent form of the syndrome showed massive damage. How often do we see patients with the most terrible looking colons and terminal ilei very mildly affected by this terrible pathology? How often do we see patients with ostensibly minimal disease simply laid waste by their affliction? What lesson is there in this apparent dichotomy between pathology and function? What are we not measuring in our patients that distinguishes the survivor from the defeated? Sacks thinks it is something to do with the patient’s essential inner being, which he cannot predict or measure – and neither can we – but it must surely exist. Why do all research studies report that the placebo response in virtually any drug investigation, in virtually any disorder, is around 30 to 50%? What chemistry is unleashed by a bogus drug, in an individual who simply wants to get better? Or is it that facile? Do the patients that respond in this fashion have some inner control over their immune systems? Conversely, what mysterious mechanism is unearthed when, in the same studies, the side effects are as frequent as with the ‘real’ drug? What happened to Sacks’s patients that caused them to return to their predrug status? The scene in which De Niro is forcibly restrained from leaving the institution is particularly poignant, since his ‘recurrence’ and subsequent deterioration begins at that event. Did the patient decide that his newfound independence was a fraud – that it had no meaning? Did he will himself into his previous state? Did the other patients, witnessing his return to his pre-L-dopa state, also ‘give up’ and turn off the receptor responses to the medication?

Following the same argument – what are the predictors of ‘malignant’ Crohn’s or rheumatoid arthritis or diabetes? They all appear the same as their more benign counterparts under the microscope. What is the reason that, despite the sameness, no two diseases react in exactly the same way to the same treatment? And as an aside, what are our residents missing when they declare a patient ‘nonteaching’ because they have "seen those before”? What are we not seeing, not measuring, not recognizing? What are the patients thinking when they are told they have these disorders? Does knowledge of the disorder alter their responses, defying their pathologies one way or another? Did a sister die from one of the diseases? What does the patient’s own preconception about the disorder do to his or her response to treatment – or lack of response? How much good or damage does a compassionate physician or nurse, or the opposite, do to alter the course of the malady? An insightful quote appears in the book, attributed to the esteemed Louis Pasteur, when on his deathbed from an infectious disease he cried, "Claude Bernard was right – the germ is nothing – the soil is everything". Is this true – should we be paying more attention to the ‘soil’? Is this what is missing in our quest to cure our incurables – should we be better cultivators?

It is clear that not only did the patients awake in the movie, but Sacks did as well. He begins as a reluctant doctor whose research efforts had failed, and ends as a consummate clinician who ‘discovers’ something about himself along the way. He finds that there is more to patient care than cold science, laboratory results and statistics. He has contributed mightily to the understanding of one of the most mysterious disorders of our time and, like any good researcher, he leaves us with more questions than answers.
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