

EYES WIDE SHUT: TEACHING MEDICAL STUDENTS ABOUT PEOPLE WITH DISABILITIES

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Whatever is real has a meaning.

Michael Oakeshott,
philosopher

Introduction

Medical school is a place where students learn to become doctors. While an important part of what they learn is comprised of technical and informational knowledge, they are also expected to acquire knowledge and skills of a far different sort: appreciation for other perspectives and points of view; understanding of illness within the context of the lived life of the patient; the ability to listen as well as talk to the patient; and the capacity for empathetically imagining the patient's experience.¹ Teaching these different ways of knowing is difficult because students, while willing to absorb new knowledge, often are reluctant to fundamentally reconsider basic assumptions and beliefs. In effect, although they think they see clearly, too frequently their eyes remain closed to the possibilities of new understandings. To overcome this resistance, medical educators have experimented with different innovative methods to convey such "hard-to-teach" clinical competencies.² One such approach is the use of literature (poetry, stories, personal narratives) which, because it focuses on the particular, the subjective, and the personal, is more likely to engage the student's hearts as well as minds³ than are traditional didactic materials.

Description of course

At the University of California-Irvine College of Medicine, I teach an elective offered to both undergraduate premedical majors and first and second year medical students that examines the illuminating intersection of literature and medicine. The class exposes students to a range of medical issues and conditions, from the doctor-patient relationship to the patient's experience of illnesses such as cancer, heart disease, and AIDS. The goal of the course is to help students enlarge their ways of thinking about health and illness, doctors and patients. Within the course one unit focuses on literature by and about persons with disabilities.

Why disabilities?

Treatment of physical and mental disability traditionally has been considered an "unglamorous" aspect of medical practice. As Nancy Mairs points out in her essay "On Being a Cripple"⁴ (one of our required readings), physicians are made uncomfortable by diseases and conditions they cannot cure and often cannot ameliorate. In this situation, the role power inherent in being a doctor is challenged by a sense of helplessness and perceived failure. Physicians first blame the limits of medical science, then the disease, themselves, and at times, the patient.

Because of the prevalence of such attitudes, few if any students in my class state that their career plans include the care of persons with disabilities. However, as we talk, they discover such neat avoidance of "these people" may not be possible. If students are considering careers in family practice, for example, will they not inevitably encounter patients who need an annual physical but who also have multiple sclerosis, or patients with the flu who also are blind, or mentally retarded? If students envision themselves as geriatricians, will they not care for patients crippled by arthritis, or who have experienced debilitating strokes or are "cardiac

cripples?" Pediatricians see infants born with Down syndrome, spina bifida, or cerebral palsy and counsel their families. And unfortunately, having a disability is no protection against developing cancer, heart disease, or any of the conditions addressed by other medical subspecialties. Students begin to realize that their choice of medical specialty will not necessarily shield them from patients with disabilities.

We regard the essays, stories, and poems we read as opportunities to open our eyes and try to see with fewer preconceptions persons who have a disability in their own words, through their own eyes.

This awareness often engenders a further discussion examining the invisibility of disability in contemporary society.⁵ Not as future physicians, but simply as people, the students examine their personal experiences with disabled individuals. Students may mention a grandparent who has suffered a stroke, or a college roommate who was blind. They often remember classmates in elementary or secondary school who were "mainstreamed," but they rarely knew them or were friendly with them. More commonly, students discuss impersonal contacts, such as seeing someone at the mall in a wheelchair or watching a group of individuals with mental retardation ascending a bus. What is striking in these discussions is how little connection usually exists between these future physicians and persons with disabilities.

Issues

These in-class disclosures lay the groundwork for our readings, which are approached in the following manner. Since most students have had little close contact with persons with disabilities, we discuss literature as a way of discovering the "voices" of these individuals⁶ on a more personal basis. We regard the essays, stories, and poems we read as opportunities to open our eyes and try to *see* with fewer preconceptions persons who have a disability in their own words, through their own eyes.

Otherness

The primary awareness we address at this beginning point of the class is the pervasive sense of persons with a disability as "other."⁷ It is difficult for students to articulate this experience directly, apparently out of fear of being perceived as prejudiced against persons with disabilities. However, eventually they do talk about how it is "natural" to feel nervous in the presence of people who are "different," or how "difficult" it is to understand the experience of someone whose life is presumably so at odds with their own. With such disclosures as an introduction, we are then able to talk about the psychological and societal functions of otherness.

Psychological function of "otherness"

Defining persons with disabilities as "other" creates a sense of distance between them and the students; therefore, it creates a sense of safety. Frightening occurrences such as blindness, quadriplegia, cerebral palsy, aphasia happen to other people, not people like themselves. Thus "otherness" as a construct insulates students from the fragility and vulnerability that disability might otherwise engender. Students are often characterized by the kind of logical yet supremely irrational thinking described in Tolstoy's *Ivan Ilyich*⁸ (also a required reading for another component of the course), when the protagonist cannot apply the concept of death to himself personally. "The syllogism—Caius is a man, men are mortal, therefore Caius is mortal—had always seemed to him correct as applied to Caius, but by no means to himself." It is much more comforting to think that the possibility of disability and dysfunction is a risk run by others, but is not relevant to oneself.

Societal function of "otherness"

"Otherness" is a construct of exclusivity. It places persons with disabilities outside the circle of individuals who "belong" in society. Otherness relegates these persons to the margins, where they may be tolerated or rejected at society's pleasure. By maintaining constructs of otherness toward persons with disabilities (as well as other minority and disadvantaged groups), society promotes homogeneity and certain standards of belongingness. We read a poem by Audrey Shafer,⁹ a professor of anesthesiology at Stanford University, that comments on the isolation of being an "oddy" within the communal structure: "How horrible to grow up/ringed by stares." Students begin to see that, in some respects, they think of themselves as "insiders" and persons with disabilities as "outsiders."

Shame and guilt

As the anthropologist Robert Murphy points out in *The Body Silent*,¹⁰ a poignant and unflinchingly honest portrayal of his own progressive paralysis resulting from a spinal tumor, the societal message to persons with disabilities reverses the normal sequence of guilt and shame. In most circumstances, a socially deviant action on the part of an individual produces guilt (a private, self-generated emotion). Discovery of the action results in punishment, accompanied by shame (the sense of public censure). For persons with disabilities, on the other hand, the societal stigma attached to disability first creates shame, discrimination and bias produce forms of punishment, and the consequence is ultimately a sense of guilt—the individual with a disability begins to feel somehow responsible for the opprobrium and punishment visited on him or her by social attitudes and institutions. Students try to imagine what it is like to be ashamed not of what you have done, but of who you are.

Sadly, social stigma is not necessarily restricted to anonymous members of society. Within the family itself of a person with a disability, a difficult choice, often barely conscious, must be made. Do we incorporate the disabled individual into our family unit, and therefore risk suffering the rejecting consequences of what Erving Goffman ironically called “courtesy stigma,”¹¹ in which the ignominy heaped on the person with a disability is generously extended to members of the family as well? Or do we join with society in subtly rejecting our disabled family member as somehow not representative of or belonging to the family? This struggle is affectingly portrayed in the work of Kenzaburo Oe, the Nobel prize-winning Japanese author whose first son was born severely brain-damaged. Over the course of several novels,^{12, 13} Oe chronicles a journey from rejection and loathing of his child to acceptance and gratitude. This issue is also sharply delineated in a poem “Retarded”¹⁴ by the medical anthropologist Howard Stein, in which a stalwart, God-fearing, salt-of-the-earth mid-Western family keeps the secret of their son, institutionalized for years with Down syndrome, and is manifestly relieved at his death. Examples of families lovingly and proudly embracing offspring with disabilities are found in Christopher Nolan’s semi-autobiographical novel *Under the Eye of the Clock*,¹⁵ as well as in poetry such as “Space”¹⁶ and “Song for My Son,”¹⁷ all examining a mother’s devoted relationship to a son with cerebral palsy.

In their own voices

The class moves from considering the stigmatizing views of society to understanding persons with disabilities from the widely varied perspectives of the persons themselves. At this juncture, we move from somewhat didactic, political perceptions to more personal visions. This part of the readings is essentially an exercise in empathic imagination.¹⁸ By listening and looking carefully, we hope to grasp more accurately and more feelingly what persons with disabilities would like us to know. Several themes emerge.

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Life changed forever

One of the most difficult ideas for students to accept is the one expressed in Reynold Price’s book, *A Whole New Life*,¹⁹ an autobiographical account of his several years’ struggle with a malignant spinal tumor that left him a paraplegic. As the title suggests, Price believes unequivocally that when a previously non-disabled person crosses the line into permanent and significantly painful and/or limiting disability, that individual is, quite simply, no longer the same person he or she once was. This is not a valenced observation. Indeed, in Price’s accounting, despite his physical limitations and suffering, he personally is a much better human being and a much more productive writer than prior to his paraplegia. Nancy Mairs, in the essay “On Being a Cripple,” describes a similar evolution in her own personality after the onset of multiple sclerosis, noting that although, given the choice, she would much rather not have MS, nevertheless she is a more compassionate person as a result of contracting this disease. In *Broken Vessels*,²⁰ André Dubus writes with greater regret and anguish about changes in his life after the automobile accident that made him an amputee. Robert Murphy, clear-sighted about his losses, speaks of having undergone a “revolution in consciousness.” Finally, a short

story by Sue Miller, "Appropriate Affect,"²¹ suggests that the onset of disability (in this case, a stroke) can allow people to reclaim aspects of themselves that have been discarded or suppressed in order to conform to the demands of ordinary life. What is important in all these accounts is the requirement that loved ones and friends understand that the disabled person is no longer "the same old Joe only now he can't walk," but someone transformed. Students struggle with this insight because they perceive change as threatening, especially when it refers to alteration of the nature of the person. At this point in the class, they are convinced that the only way to accept persons with disabilities is to view them as "no different" than they were before acquiring their disability, no different than others, no different than the students themselves, except that now they have "the disability." It is anxiety-inducing for students to realize that should they themselves develop a serious disability, they too would be fundamentally changed by the experience.

Loss

Transformation connotes a positive experience, and thus may tend to minimize in the minds of students the devastating sense of loss that many people experience in undergoing a seriously disabling disease or medical event. Irving Kenneth Zola speaks movingly in his book *Missing Pieces*²² of a "sense of chronic loss" that he struggles against but does not completely overcome. Our readings on the aftermath of stroke, in particular, exemplify the great effort made to reclaim parts of the "old self" while exploring and understanding the restrictions and changes embodied in the "new self." As Arthur Kopit writes in the introduction to his play "Wings,"²³ "An explosion quite literally is occurring . . . the victim's mind, her sense of time and place, her sense of self, are being shattered if not annihilated." In "Eleven Steps"²⁴ by the internist, professor, and poet Jack Coulehan, the narrator recounts the fierce determination of a stroke patient to walk unassisted, only to be undermined by the well-meaning intervention of her husband. The poem "Stroke"²⁵ by Susan Rea conveys the terrible frustration that loss of communication inflicts on both stroke victim and family members, as well as its symbolic connotations of death. In "The Stroke Patient,"²⁶ the narrator fears he has lost his old identity, and wonders "maybe I really am/someone else . . ."

Sex

One of the most symbolically charged aspects of life is sex. The sexual desires and needs of persons with disabilities are frequently discussed, mourned, and embraced by writers who themselves have disabilities. Christopher Nolan makes no bones about his raging adolescent sexual feelings, and Nancy Mairs writes extensively about her own sexuality both before and after the emergence of symptoms of MS. Murphy, Zola, and Price all engage in extensive explorations of the relationship between their sexuality and their disability.

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Awareness of this insistency among the students leads to discussion about what one's sexuality might represent. Students suggest concepts of virility and fertility, but often conclude that the conscious pleasure in the sexual act, apart from its procreative function, is one of the things that defines us as fully human. Yet it is one of the first things of which the non-disabled world seeks to deprive persons with disabilities.²⁷ Some students confess that they have never really considered persons with disabilities as capable or interested in engaging in sex. Uncomfortably, they find their confusion mirrored in Raymond Carver's protagonist in the classic short story "Cathedral,"²⁸ who can't imagine how any woman could make love to a blind man without repugnance. In this regard, one of the most helpful writings we examine is Zola's "Tell Me, Tell Me,"²⁹ which meticulously and lovingly describes a sexual encounter between two disabled persons, of whom he is one.

Emptiness and fullness

Another key discussion point is the nature of disability itself. Buddhist philosophy suggests that in emptiness is found fullness, a seemingly paradoxical concept to the Western mind. The very language used to denote disability suggests loss, inability, lack, or absence. Yet, especially

from individuals who have known only “disability,” such as persons born blind or deaf or with cerebral palsy, we are asked to consider the possibility of fullness rather than emptiness. This point of view is brilliantly captured in the poem “Handicapped”³⁰ in which the so-called deficiencies of persons with disabilities are perceived as embodying a mysterious and powerful richness. In a poem about sign language, “Fingers, Fists, Gabriel’s Wings,”³¹ the poet sees the power and physical beauty of a mode of communication based on physical motion. The well-known poem “Monet Refuses the Operation”³² is a poetic rendering of the artist’s historically documented initial refusal to undergo cataract surgery. In the poem, Monet explains that the basis for his resistance to the operation is the fear that, without this distorted vision, he will lose both his unique style of painting and his harmonious view of the world. In Carver’s “Cathedral,” students come to see that the apparently non-disabled narrator is filled with limitations and unhappiness, while the blind visitor is a man with a rewarding and fulfilled life.

Community

In a hermeneutic analysis of suffering, Dorothee Soelle describes three stages: chaos and isolation; lamentation; and solidarity with others.³³ This final stage is evocatively represented in the short story “Saint Ursula and Her Maidens,”³⁴ in which a group of women variously diagnosed with multiple sclerosis, rheumatoid arthritis, lupus, and ovarian cancer participate in a water rehabilitation class. As the class progresses, they learn to support each other with affection and humor against the insensitivity of the outside world and the ravages of their diseases. Zola’s book also chronicles examples of informal solidarity developing as a result of (or sometimes in spite of) a Dutch social experiment in the 1970s to create an intentional community for disabled persons.

Less-than-human to more-than-human

While such a reformulation of disability exerts a primarily beneficial corrective on student thinking, it does run the risk of sanctifying disability. One of the most common student responses to readings is the sentiment: “That person is so magnificent, so courageous. I could never adapt to such adversity in the same way.” While admiration and respect for others is a generally positive emotion, it is important to explore its downside: i.e., adulation as merely another form of distancing and objectifying. Once persons with disabili-

ties are perceived as “more than human,” they necessarily become relegated to a non-human category. Vassar Miller, a great Catholic poet who also has cerebral palsy, comments on this tendency in her bitterly ironic poem *Spastics*,³⁵ in which she mocks characterizations of persons with CP as saintly and pure, albeit stupid, unproductive (and asexual). Irving Kenneth Zola speaks of the perceived “potentialities” of persons with disabilities as yet one more burden inflicted on them by able-bodied society, further restricting them to certain unrealistic stereotypes. In “The Cost of Appearances,”³⁶ Arthur Frank comments on the price paid by persons with disabilities for maintaining a constant façade of cheerful courage and hopefulness. Nancy Mairs laments that, since developing MS, it is almost impossible for her to be treated “as an ordinary human being.”

We also begin to be able to see persons with disabilities as they are, neither less nor more than human, but also having been marked and changed forever by their encounter with disability.

Learning to open (and close) our eyes

By the conclusion of our literary unit on disability, we realize that our task, impossible to achieve completely, but critically worthwhile to approximate, is learning to see more clearly, sometimes by opening our eyes, sometimes by closing them. First, we must learn to see our self in others. Through the exercise of empathic imagination, we come to realize that “we” are “they,” that little separates us (and likely only temporarily) from persons who initially seem unlike us to the core. As Karen Fiser writes about watching a woman in a wheelchair navigate a glass door: “She is not what you feel yourself to be, but what you see you are . . . You know that you can never leave her now.”³⁷

We also begin to be able to see persons with disabilities as they are, neither less nor more than human, but also having been marked and changed forever by their encounter with disability. We further learn that definitions of disability and

ability are fluid, and that our understanding of the constructs themselves is better served by thinking less categorically and more flexibly. We also realize that we have tended to see the label of disability as an all-encompassing, all-defining category, rather than as simply one attribute of individuals and often, in their eyes, not the most important one. Finally, we see, in the words of one student, that we all have disabilities, "only some of us don't know it."

**Ultimately, we too learn that
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Crossing between worlds

Once these realizations and awareness have begun to develop, a final complex issue is explored. How can disabled and non-disabled persons bridge their respective worlds with mutual respect and caring?³⁸ Again we look to our literary readings for models. One of the most powerful images for the class is found in the short story "Cathedral." In it, a blind man, Robert, visiting the home of a woman friend, ends up watching late night television with her cloddish and insensitive husband, who narrates the story. When Robert asks the husband to describe the Gothic cathedral appearing on the screen, the husband is completely at a loss for words. In a scene charged with emotion, the two men begin to draw the cathedral together, the blind man's hand guiding the hand of the husband. At one point, Robert tells the husband to close his eyes and continue drawing. The narrator reports this event as in a moment of transformation: "It was like nothing else in my life up to now." And when the blind man suggests that the husband now open his eyes, in order to inspect his handiwork, he declines. Eyes wide shut, he is seeing, perhaps for the first time in his life. Ultimately, we too learn that sometimes, by shutting our eyes to the obvious, we can see beyond our narrow conventional sight. ♦

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