DISABILITY AS OTHERNESS: IMPLICATIONS FOR THE DOCTOR-PATIENT RELATIONSHIP

- I. One question that interests me is how physicians position themselves in relation to patients with disabilities
- II. As Nancy Mairs, a well-known essayist who has ms, writes in her essay "On Being a Cripple," persons with disabilities makes **physicians uncomfortable** because they cannot cure or fix the problem (Slide).
 - A. From our discussions, I think this is probably less true of physiatrists than physicians in other specialties.
 - B. But the meaning of disability has implications for the doctor-patient relationship no matter in which specialty.
 - C. The meaning I'd like to consider today is disability as "otherness."
- III. Our way of understanding the world is based largely on Cartesian logic and especially on its dualism
 - A. For example, although it is probably more realistic to think of a continuum of ability to disability that is fluid and impermanent, with people moving easily between the two and often participating in both aspects simultaneously.
 - B. But we tend to think of ability (normality) and disability (deviance) in categorical, either/or terms
 - 1. Normalcy (a variant of the Ideal body) Michelangelo (Slide)
 - 2. Disability (a variant of the Deviant body) self-portrait (Slide)
 - C. This dualistic thinking leads to other dualisms:
 - 1. Good/bad
 - 2. Desirable/undesirable
 - 3. Doctor/patient
 - 4. Self/Other

IV. The Construct of Otherness (Slide)

- A. "Otherness" is a construct often studied by social psychologists.
- B. **Definition:** It is the identification of someone or a group of persons as not-self, outside your boundary of identity.
- C. Psychological function of otherness
 - 1. Defining certain persons or groups of persons as "other" creates a sense of distance between them and the individual doing the boundary-setting, thus establishing a sense of safety
 - 2. The construct of otherness insulates the non-disabled from the fragility and vulnerability that disability might otherwise engender

D. Societal function of otherness

1. Otherness is a construct of exclusivity

- 2. 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.
- E. But otherness designations also create in-groups, out-groups, shunning, shaming, avoidance, and attack.

V. Reactions of Otherness triggered by perceived threats to self

- A. Loss (roles, relationships, work, function, identity, meaning, purpose)
- **B.** Randomness (suffering is not predictable)
- **C.** Chaos (the universe is out of control)
- D. Disability can produce all these feelings, not only in the person experiencing disability, but in the person observing the effects of disability
- E. In "The Stroke Patient," the narrator fears he has lost his old identity, and wonders "maybe I really am/someone else..." (**Slide**)

VI. VI. One way of using otherness designations is by consigning persons with disabilities either to Less-than-Human or More-than-Human categories (Slide)

- A. Negative stereotypes and assumptions about persons with disabilities
 - 1. Association of moral perversion and evil with disability
 - 2. Assumptions of mental incompetence
 - 3. "ugly laws," still on the books in some Southern states till the 1970s
- B. But sanctification of disability is merely another form of distancing and objectifying
 - **1.** Once persons with disabilities are perceived as "more-than-human," they necessarily become relegated to a non-human category
- C. Vassar Miller, the great Catholic poet who also had cerebral palsy, comments on both tendencies in her bitingly satiric poem "Spastics" (Slide)
- D. Irving Kenneth Zola speaks of the perceived "potentiality" to overcome disability and succeed as yet one more burden inflicted on persons with disabilities by able-bodied society (**Slide**)

VII. The Physician-Patient Relationship (Slide)

- A. Modernist view of disease, disability, doctor-patient relationship (Slide)
 - 1. Body as machine/disease as malfunction/goal is restoration
 - 2. Doctor is expert and authority; stance one of detachment
 - 3. Patient is passive object
 - 4. Goal is "normality as far as possible"
- **B.** This quest for normalcy is well-illustrated in the play "The Elephant Man" by Bernard Pomerance
 - 1. 19th century historical personage Joseph Merrick, known as the Elephant Man
 - 2. Suffered from Proteus Syndrome, resulting in severe facial, skin, and musculoskeletal deformities
 - 3. Exhibited for money as a freak

- 4. Eventually was "rescued" by a physician Frederick Treves and spent the rest of his brief life in London Hospital, the "pet" of aristocratic English society
- 5.. Treves' goal was to make Merrick as normal as possible in the parlance of the times
 - a. a gentleman
 - b. a Christian
- 5. But Treves develops doubts about the validity of his enterprise when he realizes that Merrick's unique identity has been swallowed up in the pursuit of normalcy.
- 6. He remarks bitterly about Merrick's pursuit of baptism: "He is very excited to do what others do if he thinks it is what other do."
- C. But sometimes it is not possible to restore normalcy and sometimes it is not desired by the patient (Slide)
 - 1. Especially from individuals who have known only disability, such as persons born blind or deaf or with cerebral palsy, we should consider this possibility of fullness rather than emptiness
 - 2. DeafArt poster celebrates deaf culture
- D. The postmodernist view of illness, disability, and the doctor-patient relationship stresses:
 - 1. Unity of mind/body
 - 2. Limits and fallibility of physician, as well as physician expertise
 - 3. Patient expertise and testimony
 - 4. Instead of detachment, closeness through witnessing and solidarity
- E. Jack Coulehan's poem "Irene" shows a physician who chooses to move closer to his stroke patient, attempting to be a witness to her suffering, to express solidarity with her, and to find the person lost behind paralysis and aphasia (Slide)

VIII. Witnessing and solidarity with the disabled other come about through an effort to see more clearly, uncluttered by fear or threat (Slide)

A. A three step process

- 1. Learning to see others as wholly human (Slide)
- 2. Learning to see ourselves in others
 - a. Through the exercise of empathic imagination, we realize that "we" are "they"
 - b. Karen Fiser poem about watching a woman in a wheelchair navigate a glass door expresses this sense of solidarity (**Slide**)
- 3. Learning to see the disabled other as healer, as well as sufferer
 - a. Raymond Carver's short story "Cathedral"
 - **b.** A blind man, Robert, visits the home of a woman friend whom he has not seen for many years
 - c. He ends up watching late night television with her cloddish and insensitive husband, who narrates the story
 - d. When Robert asks the husband to describe the Gothic cathedral appearing on the screen, he is completely at a loss for words

- e. 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
- f. At one point, Robert tells the husband to close his eyes and continue drawing (Slide)
- g. The narrator reports this event as a moment of transformation. "Blind," he is seeing, perhaps for the first time in his life
- h. As health professionals, we need to consider adopting this stance of solidarity with our patients with disability.