THE EXPERIENCE OF DISABILITY AS EXPRESSED THROUGH LITERATURE AND THE ARTS

I. Who Am I? (5 min) (Personal Introduction) (Presentation title slide)

A. I am a psychologist by training. I've worked much of my professional life in a department of family medicine, first as a **teacher and researcher** of issues such as the doctor-patient relationship and family coping with illness.

B. More recently I've been directing **a medical humanities program,** about which more later.

C. I'm not an expert on disability. But in both professional and personal ways, disability has been a part of my life.

D. At the start of my career, I worked in the **Division of Physical Therapy at Stanford University Medical School,** as part of an interdisciplinary team to help patients who had experienced strokes, amputations, spinal cord injuries readjust to home life after hospitalization

E. For 10 years I facilitated **support groups for parents of developmentally delayed children** with Down Syndrome and other chromosomal anomalies, autism, cerebral palsy

F. I've also conducted several **research projects examining the attitudes of Latino families of children with physical disabilities** such as polio, cerebral palsy, spina bifida, and other congenital anomalies

G. More recently, I have worked with Dr. Mosqueda conducting modified **life history interviews with older persons with disabilities**

H. On a personal level, my son was diagnosed with **ankylosing spondylitis** 5 years ago**,** which my husband and I consider a disabling condition because of his living with some chronic pain and certain functional limitations; but my son would never describe himself as disabled.

II. **Why Literature? (Slide 2)**

A. About 5 years ago, I **began using literature to teach** medical students and residents about the patient's experience of illness and the doctor-patient relationship so what I have to say emerges from that context

B. When I first told my colleagues what I wanted to do, they were very excited, and told me: "Great! We need **evidence-based strategies** to help students master the professional literature." I had to gently inform them that when I used the word literature, I was referring not to the scientific literature, important as that is, but to imaginative literature – fictional accounts, short stories, plays, first-person narratives, poetry.

C. My colleagues tended to smile politely and back off quickly, especially when they heard about the poetry. (I hope you all will be a bit more tolerant!)

D. An important part of what medical students – and I'm assuming students in other health professions as well - are expected to learn is comprised of **technical and informational knowledge (Slide 3)**. But many of us in this room know that in this process something may be lost **(Slide 3a – TS Eliot)**

E. So students must also acquire **knowledge and skills (Slide 4) of a different sort**:

1. appreciation for other perspectives and points of view
2. understanding of illness within the context of the lived life of the patient
3. ability to listen as well as talk to the patient
4. the capacity for empathically imagining the patient's experience

F. Teaching these different ways of knowing is difficult

1. Students are reluctant to consider learning from sources of knowledge other than those from the scientific domain
2. One might say metaphorically, that although students think they see clearly, too frequently they remain blind to the possibilities of new understandings

G. One approach to conveying such "hard-to-teach" clinical competencies is the use of literature (Slide 5) which, because it focuses on the particular, the subjective, and the personal, is more likely to engage students' emotions as well as their intellects than are traditional didactic materials

III. The Uses of Literature

A. Why is reading a poem or a short story different than reading a journal article? (Slide 6) What can literature give us, and help us understand, that science cannot?

B. As **Einstein** observed, "Science can tell us the what, but not the why" **(Slide 7)**

C. It has been frequently observed that there are **two modes of thinking, the logico-scientific and the narrative (Slide 8**).

Both scientific and narrative thinking are useful for achieving certain ends, but they differ in important ways from each other. Science is all about determining truth, but can anything be truer than the truth? **(Slide 9: Jewish proverb). Narrative emphasizes the primacy of storytelling in the way we construct and make sense of our experience.** I will briefly consider three questions pertinent to health professionals and their patients to which narrative thinking, as expressed through literature, provides answers that differ significantly from those provided by scientific thinking.

1. **What is the Nature of Experience? (And, in the health professional-patient context, how do we best understand the patient's reality?) : Abstraction vs. Particularity (Slide 10/Slide 11 – seeing)**
   - **a.** Logico-scientific – Particulars of personal experience are eliminated in favor of abstractions, generalizations, systems of classification and diagnosis
   - **b.** Narrative – emphasis is on particulars of individual experience (
2. **Whose Point of View and Voice is Important?: Omniscient vs. Patient (Person)-Centered (Slide 16/Slide 17)**
   - **a.** Logico-scientific – the patient's point of view is subjective, therefore suspect; the patient's voice often disappears from the medical record

b. Narrative – the patient's point of view is subjective, therefore essential to help the physician develop an empathic stance toward the patient

3. **How Should We Position or Place Ourselves in Relation to Others (and in particular to the patient-other) ?: Distance vs. Engagement (Slide 12/Slide 13 -**
   a. Logico-scientific – Emphasis is on objective stance, detachment, distance
   b. Narrative – requires emotional engagement and participation in the event

IV. Why Disability? (Slide 18)

A. All of this might tell us something about why it is important to look at literature as well as science to learn about illness and suffering, but what interests me about disability?

B. When I first began teaching medical students, I discovered that **few** of them **imagine that their career plans will include the care of persons with disabilities**

C. Treatment of physical and mental disability traditionally seems to be considered an **"unglamorous" aspect of medical practice (Slide 19)**

D. As Nancy Mairs, a well-known essayist who has ms, writes in her essay "On Being a Cripple" (one of our required readings), **physicians are made uncomfortable by diseases and conditions they cannot cure (Slide 20)** and often cannot ameliorate

E. In fact, it is my belief that teaching about patients with disability is an example of the literary term "metynomy," in which **the part stands in for the whole (Slide 21)**: (medical example – the spinal cord injury in room 9); in other words, the psychological and interpersonal issues aroused in students in dealing with persons with disabilities are very similar to the dynamics that can occur in any doctor-patient (or health professional-patient) relationship; and these are precisely the kinds of issues that we can effectively reflect on through the use of literature

V. What Are Some of These Psychological and Interpersonal Issues? (Slide 22)

A. Disability as Otherness (Slide 23)

1. The first issue I address with students is the pervasive sense of persons with disability as "other."

2. Difficult for students to articulate this experience openly, out of fear of being perceived as prejudiced

3. Eventually, they talk about how it is "natural" to feel nervous in the presence of people who are "different," how "difficult" it is to understand the experience of "people like that"

B. Psychological function of otherness

1. Defining persons with disabilities as "other" creates a sense of distance between nondisabled persons and persons with disabilities; therefore, a sense of safety

2. The construct of otherness insulates the non-disabled from the fragility and vulnerability that disability might otherwise engender

C. 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

D. To illustrate this concept of otherness, I have students read the play **"The Elephant Man"** by Bernard Pomerance

a. 19th century historical personage Joseph Merrick, known as the Elephant Man
b. Suffered from Proteus Syndrome, resulting in severe facial, skin, and musculoskeletal deformities
c. Exhibited for money as a freak
d. 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

E. What is the proper antidote to this reaction of otherness?

1. Is it, as many well-intentioned students think, making persons with disability as "normal" as possible?
2. This is what Dr. Treves attempts in this excerpt from The Elephant Man
3. **Reading: Elephant Man** (three characters: Bishop, representative of religion; Treves, representative of science; and Gomm, the hospital director, a bureaucrat who nevertheless sees more clearly than most the questionable benefits of normalcy)
4. In this reading, Bishop Howe wants to make Merrick a good Christian; Dr. Treves wants to make him a normal man "as far as is possible"; later, however, while the Bishop is excited by Merrick's religious progress, Treves questions its legitimacy, suggesting it is more a function of Merrick's longing for acceptance than any real spiritual awakening. He is beginning to have doubts about the wisdom of trying to make Merrick "like everyone else."

VI. What is Normal? (Slide 24)

A. Art series: Michaelangelo – Hooper – Picasso **(Slide 25,26,27)**

1. Idealized (male) body vs. clearly disabled (female) body
2. But what are we to make of Picasso? – conscious distortion of conventional perception in order to force us to think differently about the human body; nothing to do with disability, everything to do with normality

a. Poem: "Handicapped" – Phillip Dacey **(Slide 28) Comments**
b. Are there other ways of understanding disability?

B. **Emptiness and Fullness (Slide 29)**

1. The very language used to denote disability suggests loss, inability, lack, or absence
2. I remind students that in Buddhist philosophy emptiness is fullness

3. 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
4. Poem: "Fingers, Fists, Gabriel's Wings" **(Slide 30) Comments?**

C. **Loss… (Slide 31)**
1. Lest students become too complacent about the joys of disability, literature can also remind them of the core experience of loss in the lives of many people with a disability
2. 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"
3. In "The Stroke Patient," the narrator fears he has lost his old identity, and wonders "maybe I really am/someone else…"**(Slide 32) could skip**
4. Arthur Kopit writes in his play "Wings": "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" **Reading**

VI. The Less-than-Human/More-than-Human Continuum (Slide 34)

A. Students may begin our sessions by holding carefully concealed negative stereotypes and assumptions about persons with disabilities, but they may also run the risk of sanctifying disability
1. Common response to readings is the sentiment: "This person is so extraordinary, so courageous. I could never adapt to this terrible adversity in the same way."
2. Such adulation may be merely another form of distancing and objectifying
3. Once persons with disabilities are perceived as "more-than-human," they necessarily become relegated to a non-human category

B. Vassar Miller, the great Catholic poet who also had cerebral palsy, comments on this tendency in her bitingly satiric poem "Spastics" **(Slide 35)**

C. In his essay "The Cost of Appearances," Arthur Frank comments on the price paid by persons with disabilities for maintaining a constant façade of cheerful courage and hopefulness **(Slide 36)**

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 37)**

VIII. The Health Provider-Patient Relationship (Slide 38)

A. Thinking back to the 3 questions I posed earlier in the talk regarding logico-scientific vs. narrative modes of thinking, you might see that we have been focusing on the first two questions: what is reality? What is normality? And - Who should we listen to and what perspectives should we attend to?

B. Now is a good time to consider question #3: How do we choose to be in relation to patients/persons with disabilities?
1. Do we wish to see the person with disabilities as other?
2. Do we wish to try to make the person with disabilities "normal"?
3. Will we demean their joys or minimize their losses?

4. Will we unintentionally either debase or glorify this individual?

C. Isolation vs. community (Slide 39) – The choice is ultimately about adopting a stance of isolation, separation, and professional detachment from persons and patients with disabilities ; or engagement and sense of community

D. In a hermeneutic analysis of suffering, the social philosopher Dorothee Soelle describes three stages **(Slide 40) could skip**

a. chaos and isolation
b. lamentation
c. solidarity with others

1. **Reading:** Short story "Saint Ursula and Her Maidens,"
   a. A group of women variously diagnosed with multiple sclerosis, rheumatoid arthritis, lupus, and ovarian cancer participate in a water rehabilitation class
   b. 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

E. Solidarity in the professional relationship (Slide 41)

1. Jack Coulehan's poem "Irene" shows a physician who chooses to move closer to his stroke patient, attempting to find the person lost behind paralysis and aphasia **(Slide 42)**

F. Solidarity with the disabled other comes about in part as a result of our learning to see more clearly (Slide 43)

1. Learning to see ourselves in others
   a. Through the exercise of empathic imagination, we realize that "we" are "they"
   b. In the words of one student, we see that "We all have disabilities, only some of us don't know it" **(Slide 44)**
   c. Karen Fiser poem about watching a woman in a wheelchair navigate a glass door expresses this sense of solidarity **(Slide 45)**

2. Learning to see the patient-disabled other as teacher

a. Raymond Carver's short story "Cathedral" **(Slide 46)**

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
   g. The narrator reports this event as a moment of transformation. When the blind man suggests that the husband open his eyes, in order to inspect his handiwork, he declines. "Blind," he is seeing, perhaps for the first time in his life

h. We too can learn that sometimes, by closing our eyes to our assumptions and stereotypes, we can begin catch a glimpse of a reality that is truer than our narrow conventional truths