THE PATIENT'S EXPERIENCE THROUGH LITERATURE AND ART

Introduction: Thank you for inviting me to speak with you this afternoon. My name is, I'm a clinical psychologist by training, and for the past 25 years I've taught and conducted research at the UCI COM. I'm interested in how doctors communicate with patients, in the relationships between doctors and patients, and in the patient's experience of illness. In the past 5 years, I've focused on how we can use literature and art to give us insights into these questions, and that is what I'll be discussing today.

Objectives:

1. Literature and art can increase empathy for patients' experiences
2. Develop sensitivity to meaning
3. Stimulate imaginative and creative thinking about patients

Why Literature and Art? It's a legitimate question to ask.

The Nature of Illness: Illness is not a simple reality shared by patient and physician or patient and researcher, but rather quite distinct realities depending on who is doing the perceiving. If you think about it, patients, doctors, and scientists all have

1.**Different systems of relevances** – what matters; to the patient with cancer, what is relevant might be whether her surgery eliminated the possibility of recurrence; to the surgeon, what is relevant might be a cleanly performed surgical procedure; while to the researcher, the relative efficacy of two surgical approaches might be of most interest

2. **Different habits of mind** – how people think about things; the patient who is fatigued and tired may think primarily in terms of how these symptoms are interfering with his daily life; the physician may approach these symptoms in terms of a differential diagnosis; while the researcher may be interested in generating a testable hypothesis pertinent to these symptoms.

3. Finally, **distinct interpretational schemata**: a patient newly diagnosed with cancer may feel disbelieving, terrified, or hopeless; the oncologist may interpret the test results as consistent with stage II ovarian cancer; the researcher may see the patient as a likely candidate to develop cancer based on familial and genetic risk factors.

Students Must Learn Technical and Informational Knowledge
But What is Lost? (T.S. Eliot)

The Nature of Knowledge: The cognitive psychologist Jerome Bruner observed that there are different kinds of knowledge. One kind is

1) **Logico-scientific knowledge** – this kind of knowledge is dominated by biophysical understanding of illness and the apprehension of reality through empirical research. Logico-scientific knowledge emphasizes objectivity, facts, replicable procedures, universal rules, generalizability. It is derived from empirical research. In terms of health and illness, it leads to a biophysical understanding of disease.

For example, we can ask, what is the number one killer in this country, and we can answer that question through epidemiological studies, which find that the answer is heart disease. We can further ask, what is the physiology of myocardial infarction? What are the risk factors for heart disease? What is the relationship between stress and heart disease? How does gender influence risk? These are all questions that can be answered through empirical, bioscientific methods.

Logico-scientific knowledge can answer a lot of questions about the nature of reality but it does have some limitations. Notably, in the case of illness, logico-scientific knowledge ignores the particular, experiential aspects of illness, and the suffering it produces. In effect, logico-scientific knowledge subtracts the particular patient's experience out of the medical paradigm because it is idiosyncratic and unique, rather than categorical and universal. This suggests that there is a whole other set of questions that cannot be answered so easily through logico-scientific knowledge. For instance, what is it like to have a heart attack? What does being a coronary care patient mean to people? What is the nature of the suffering caused by becoming a heart patient? These are issues that can best be understood by seeking the voice of the patient, which Bruner observed is found in.

2) **Narrative knowledge** – the kind of knowledge we acquire from reflecting on and sharing particularistic experiences. Narrative knowledge assumes that realities are social constructed through language and narrative, and that multiple truths exist simultaneously. Narrative knowledge most often takes the form of story-telling, whether oral or written. It has been argued that narrative knowledge can best help us explore and understand questions of suffering and meaning, the kinds of questions that inevitably arise in the face of serious or life-threatening illness. Narrative knowledge leads to a biopsychosocio-cultural understanding of illness.

What is Truer than the Truth?

These Two Types of Knowledge Have Important Implications for Health Care

1. What is Important about Experience? (How can we best understand the patient's reality?)
    a. Logico-scientific: particulars of personal experience 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 are important?
    a. Logico-scientific: patient's point of view is subjective, therefore suspect; patient's voice disappears from the medical record
    b. Narrative: patient's point of view and voice are essential; multiplicity of voices in clinical encounter recognized
3. How should we position ourselves in relation to the patient-other?
    a. Logico-scientific: emphasis is on objective stance, detachment, distance in professional relationships
    b. Narrative: requires emotional engagement and presence in professional relationships

The Illness Experience

Meaning. The central meaning of serious illness is **loss** and the **separation** it entails. By loss I mean the loss of roles, relationships, competence, function -–loss of self, i.e., death; loss of wholeness, of certainty, of control, of freedom, of the future. In addition, illness creates absence of order and coherence; an experience that is painful, destructive, disorienting. Illness sets the ill person radically apart from others. Ill people are perceived as different, and may feel themselves to be different, than the non-ill. Often individuals with serious medical diagnoses do not want to disclose these to family, friends, and co-workers for fear they will be "treated differently."

Suffering: The result of such loss is **suffering**. Eric Cassell, a contemporary physician and ethicist, notes that:

1) Suffering involves the whole person, can't be separated into the dualism of mind and body on which the practice of medicine is based
2) Suffering occurs when severe distress threatens the intactness of the person
3) Suffering can occur in relation to any aspect of the person

Meaning Revisited: Alleviation of Suffering. Suffering is produced and alleviated primarily by the meaning one attaches to one's experiences. Cassell notes that the primary way of attaching meaning to events is to tell stories about them. Relief from suffering comes from changing the meaning of the experience of the sufferer and restoring the disrupted connectedness between the sufferer and those around her.

Pathography: Today I'd like to talk about a particular form of narrative knowledge found in something called "pathography."

Definition: Pathography is a form of autobiography or biography that describes personal experiences of illness, treatment, and sometimes death.

Pathographies have existed throughout history, in the sense that people have always written about sickness, suffering, and death. The 17th century poet John Donne, for example, most famous for his line "No man is an island unto himself," wrote a long poem about his life-threatening bout of typhoid. But the late 20th century saw a proliferation of this literary genre, especially in terms of autobiographies, and scholars have speculated that this reflected a shift from modernism to post-modernism in the roles people assumed vis-à-vis their own sickness.

1) **Modernism** – In the modernist view, the body is a machine about which its owner, the patient, knows very little, while the doctor is the expert at fixing the machine. In this model, the patient is essentially the passive object on which the doctor acts to repair the body and thus return the individual as a productive, functioning member of society. Obviously, in this paternalistic "doctor- knows-best" model, a good patient is compliant, cooperative, follows the doctors orders, and tries to get well.
2) **Post-modernism –** In the post-modernist view, the body is an indivisible aspect of personhood. Doctors have expertise, but they are also fallible, and limited in their perspective. Patients too have an expertise about themselves

and their experience, and have an obligation to express this and share it with others.

Classic bio-pathography: Arthur Kleinman – The Illness Narratives
1.Narratives of illness illuminate how the life problems created by sickness are controlled, adapted to, and otherwise made meaningful
2) Kleinman emphasized that it is through narrative that patients make sense of and give value to their experiences
3) He stressed that interpretation of illness narratives is a core task of doctoring – a physician can't take care of a patient until he or she understand what the illness means to them - The doctor gets a powerful, concrete, rich sense of feelings, values, and beliefs that make up the actual experience of the sick person

Models for Pathographies:
Robinson – Narrative trajectories

1) **Sad** – basic downward slope across life
2) **Tragic** – positive line, then crashes down
3) **Heroic** – upward trend, with slight detour or blip for disease
4) **Transformative** – stable line, illness event, upward arc

Hunsaker Hawkins: Myths of

1) **Death and rebirth** - individual dies to their old way of life, and is reborn a new person. Typical of heart attack accounts – people recover and radically change their lifestyle
2) **Battle** – quintessentially modernist myth; illness is the enemy, treatment is warfare; problem with this is that the patient can become the battleground; goal is victory
3) **Journey** – hero; receives, and often tries to avoid, a call; encounters many trials and challenges, endures much suffering; accomplishes mission and returns to his land

Frank:

1) **Chaos** – anti-narrative, pile-up of calamities
2) **Restitution** – not all illnesses can be molded into this model
1) **Quest** (journey) – runs risk of romanticizing illness
2) **Testimony** – witness offers testimony to a truth that is generally unrecognized or suppressed; witnessing always implies relationship – not just about self, but about self in relation to others; involves a listener. To properly read illness narrative, reader must contemplate her own complemntary vulnerability and suffering; must see similarities, not differences

Functions of Pathography.
Pathographies are first

1) an attempt by individuals experiencing illness to **orient themselves in the world of sickness.** Susan Sontag, a contemporary philosopher who underwent her own experience of cancer, referred to "the kingdom of the sick." Many anthropologists have used the analogy that becoming ill is similar to entering a foreign country, with its own language, culture, and customs. Pathographies are also written to develop

2) **Symbolic integrity** – seeing one's life as meaningful
3) **Sense of movement** – capacity for change, power of person over circumstance
4) **Telling Stories and Listening to Stories as Moral Actions.** Illness sets ill person apart, but storytelling joins bodies in their shared vulnerability through the common bond of suffering. Through act of writing, ill person becomes healer as well as sufferer (**testimony)**. Storytelling is one way of recovering the voice that illness and treatment have taken away. Storytelling as testimony becomes a moral action, as does the act of listening through **witnessing**.

Listening to stories we can place ourselves in (a slice of) the lived experience of the patient, and understand, imaginatively perceive, and feel the illness experience as the patient understands, perceives, and feels it.

Specific "Knowledge" the Listener Can Develop:
Close, respectful attention - presence
Empathy, sensitivity to meaning of patient's experience
Emotional connectivity and engagement
Whole person understanding and appreciation

Chemotherapy
The Cancer Match
Senescent Heart
EKG
Spastics
The Stroke
Death Psalm
Living Will