NARRATIVE MEDICINE

I'm here to talk with you today about the stories we hear in medicine, what they mean, how we can understand them, and how we can respond to them. In doing so, I will be drawing on a field of study called narrative medicine.

I. Definition

A. Narrative medicine has been defined as the ability to critically understand and be moved by the patient's story.

B. One of the principle tenets of narrative medicine is the importance of listening to the patient's story.

1. **Different ways of listening**
2. **Listening medically – identifying the signs, symptoms, and information to make the differential**

a. In its baldest form, the relevant facts are what we learn from medical listening:

b. The king died. The queen died.

3. **Listening narratively – hearing the patient's "history of present illness" as a story**

a. Drama, comedy, tragedy

b. Character, plot, beginning and ending

c. The king died, and then the queen died of grief.

II. Ways of Listening

A. What is narrative listening?

B. Arthur Frank, a Canadian medical sociologist, suggests that we listen not "to" the patient's story, but "with" the patient's story.

1. The difference in preposition has the intent of reducing distance between speaker and listener:
2. Activities that are done "to" someone suggest

a. Instrumentality on the part of the doer, and passivity on the part of the one acted upon.

c. Acts upon the patient

b. Listening to driven by physician's agenda

3. On the other hand, when we do something "with" another person, there is a sense of mutuality, collaboration, and

a. Most important, a sense of being with, accompanying, rather than doing to.

b. Allows the patient's agenda to emerge

III. Why Listen Narratively?

A. When you listen narratively, you are able to:

1. Understand more deeply why the patient is telling the story

2. Empathize more deeply with the meaning of patient's experience

3. Develop emotional connection with the patient

4. Appreciate the whole person of the patient

5. Create the possibility of helping the patient construct a better story

IV. Functions of Pathography: Why Do Patients Tell Stories?

Pathographies are first

A. To get better

B. An attempt by individuals experiencing illness to **orient themselves in the world of sickness.**
   1. Susan Sontag, a contemporary philosopher who underwent her own experience of cancer, referred to "the kingdom of the sick."
   2. 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

C. **Symbolic integrity** – seeing one's life as meaningful

D. **Sense of movement** – capacity for change, power of person over circumstance

E. **Telling stories and listening to stories as moral actions**
   1. Illness sets ill person apart
      a. Stigmatizing, isolating
      b. Loss of control
      c. Loss of self
   2. Storytelling joins patient to others in their shared vulnerability through the common bond of suffering.
   3. Storytelling is one way of recovering the voice that illness and treatment have taken away.

V. Understanding the Elements of a Story

There are several important elements of a narrative to consider, and I think as clinicians these will not be unfamiliar to you:

A. Frame –

1. Context

2. Historical, cultural, socioeconomic factors

B. Voice, point of view, audience –

1. Whose voice is being heard? Whose voice is being overlooked?

2. Who is the narrator of this story?

3. Whose point of view is represented? Whose is omitted?

4. Who is the intended audience? The physician? A family member?

C. Who are the main characters in the story? Of course the patient is important, but who else is a major character? Sometimes, for example, with certain patients, we discover that the grandma, who we never see in the office, is calling the shots. Maybe you assume the doctor is a major character; but in fact, the doctor plays only a peripheral role in this story.

D. Time – what role does time play in the story? Maybe time is pressing: the patient has only a short time to live; or only a few days to make an important medical decision. Maybe it is the transition in time that is important – the time before the diagnosis of

cancer vs. all the time after the diagnosis. What haunts the patient about her past? What are her hopes for her future?

E. Plot – what is the plot? For example, brilliant intern diagnoses disease missed by other doctors and saves patient's life. Or, patient suffers a debilitating disease but in the process becomes closer to family and friends.

F. Theme – in contrast to plot (what happens), themes deal with larger philosophical issues. For example, a theme could be man's inhumanity to man; or it could be the transcendence of the human spirit; or it could be good vs. evil

F. Desire – Desire is the fuel that drives most stories. What is the patient's desire? To be rescued from disease? To pretend that disease never happened? To preserve their dignity?

VI. Narrative Typologies: Is It a Good Idea to Categorize Stories?

A. I'm going to discuss different types of patients' stories, but I first want to ask, is this even a good idea?

B. Categorizing a story

1. Just like labeling a patient, always carries the risk of reducing and minimizing the person's experience to some kind of recognizable box.
2. So within categories, we always want to make space for variability, deviance, and difference.

C. But categorization can also be useful in

1. Helping us making sense of patient stories

2. Helping us decide whether the patient's story is appropriate to their illness and its trajectory

VII. Models for Thinking about Pathographies (Stories of Illness):

A. Frank:

1) **Chaos** – anti-narrative, pile-up of calamities; hopelessness
2) **Restitution** – find it and fix it; cure; person restored to pre-illness life; not all illnesses can be molded into this model
3) **Quest** (journey) – runs risk of romanticizing illness
4) **Testimony** – This word, "testimony," evokes narratives emerging from the Holocaust as well as other incredibly horrific circumstances.
    a. The idea of testimony is that voice is somehow given to the unspeakable; that non-dominant, non-normative discourses come to light.
    b. Offers testimony to a truth that is generally unrecognized or suppressed; witnessing always implies relationship
    c. Not just about self, but about self in relation to others; involves a listener. To properly resonate with illness narrative, the listener must contemplate her own complementary vulnerability and suffering; must see similarities, not differences

d. The response to testimony is not problem-solving or judgment, but "witnessing." This means a willingness to be fully present with the story of the other; to treat it with utmost respect, in no way diminishing, dismissing, negating, or trivializing the story.

5. Epiphanic/Transformative
   a. Moments of awe and miracle

VIII. Helping the Patient Construct Better Stories

A. Helping the patient construct a better narrative is always a risky business.

1. First, it runs the risk of presumption – an occupational hazard for physicians.

2. In effect, to say to the patient "I know better than you do what your story should be."

3. In such cases, we run the risk of forcing a story on patients that will make us feel less anxious.

B. So sometimes it is better just to listen, to witness

C. But sometimes, while listening carefully to the patient, you begin to realize that there are

1. Elements of a different, better story within the patient, struggling to emerge.
2. And it may be possible to strengthen that narrative.

VIII. What does a better narrative mean?

a. A narrative that makes more sense to the patient,
b. Provides more meaning,
c. Even brings some hope and happiness.

IX. Ways of strengthening preferred stories

A. Clinical empathy

1. Understands and resonates to patient's story
2. Keeps own perspective so may offer patient new possibilities
3. Offer alternative/complementary possibilities

B. Collaborative revisioning and reconstructing

1. Exploring different visions of self
2. Supporting preferred elements

X. Conclusion:

A. Listening with rather than simply to the story;
B. Being aware of narrative elements such as voice, character, time, plot, theme, desire;
C. Recognizing whether a story is whether a story is a narrative of chaos, restitution, quest, testimony, epiphany;
D. and whether that story makes sense for the patient and the patient's situation;
E. witnessing the patient's truth;
F. On occasion humbly collaborating with the patient to seek a better truth
G. May all improve the practice of medicine