Narrative Medicine in Practice

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Definition

- Narrative medicine is the ability to critically understand and be moved by the patient’s story.
  - Rita Charon, M.D., Ph.D.

- One of principle tenets of narrative medicine:
  Listening to the patient’s story

- Different ways of listening
  - Listening medically - identifying the signs, symptoms, and information to make the differential
  - Listening narratively - hearing the patient’s “history of present illness” as a story
    - Drama, comedy, tragedy
    - Character, plot, beginning and ending
What is Narrative Listening?

- Listening *with*, not *to* the patient’s story
- Listening *to* the patient’s story
  - Instrumental
  - Acts upon the patient
  - Is driven by the physician’s agenda
- Listening *with* the patient’s story
  - Mutuality
  - Collaboration
  - Being with, accompanying
Why Listen Narratively?

- When you listen narratively, you are able to:
  - Understand more deeply why the patient is telling the story
  - Empathize more deeply with the meaning of patient's experience
  - Develop emotional connection with the patient
  - Appreciate the whole person of the patient
  - Create the possibility of helping the patient construct a better story
Functions of Pathographies (Stories about Illness) or Why Do Patients Tell Stories?

- To get better
- Orientation
  - Way of orienting self in world of illness
- Symbolic integrity
  - Way to make sense of one’s life, see it as meaningful
- Movement
  - Show capacity for change
  - Power of person over circumstance
Why Do Patients Tell Stories?

- **Moral action**
  
  - Illness sets person apart
    - Stigmatizing, isolating
    - Loss of control
    - Loss of self
  
  - Through storytelling, patient becomes joined to others through the common bonds of suffering, vulnerability
  
  - Storytelling is a way of recovering the voice that illness, diagnosis, and treatment have taken away
Narrative Typologies:
Different Types of Stories

- Is it a good idea to categorize patient stories?
- Risk of labeling: minimizing, reducing
- Importance of creating space to allow for individual variability, complexity, and difference
- A way of making sense of stories
- A way of deciding whether the patient's story is well-matched to the patient's circumstances or whether another story needs to be told.
Models for Thinking about Pathographies*

- **Chaos**
  - Pre-narrative; anti-narrative
  - Pile-up of calamities
  - Isolation and alienation
  - Frightening to both patient and physician
  - No relationship between doctor and patient

The Scream
Edvard Munch
Iona Potapov, the sledge-driver, is all white like a ghost. He sits on the box without stirring, bent as double as the living body can be bent. The misery which has been for a brief space eased comes back again and tears his heart more cruelly than ever... His misery is immense, beyond all bounds. If Iona's heart were to burst and his misery to flow out, it would flood the whole world, it seems, but yet it is not seen. ... Iona drives a few paces away, bends himself double, and gives himself up to his misery. He feels it is no good to appeal to people... He can bear it no longer...
Models for Thinking about Pathographies

- Restitution
  - Find-it and fix-it
  - Person restored to pre-illness life
  - Highly desirable for both patient and physician
Restitution: Role of Physician
Today I woke up really sick
Mommy took me to the doctor quick
He gave me pills
He checked my poo
Before I knew it
I was good as new!

- 3rd year medical student
  Pediatric clerkship, 2003
Models for Thinking about Pathographies

- **Quest (journey)**
  - Reluctant hero receives a call
  - Encounters trials and challenges
  - Endures much suffering
  - Accomplishes mission and returns to help others
  - Uplifting; emphasizes acquisition of wisdom
  - Can be overly romanticized
The Wizard of Oz

Dorothy, Toto...

And the Tornado!
The Wizard of Oz

Threatened by evil demons and monsters

Assisted by friends...

...and guides
Journey: Role of Physician

Help from the local medical doctor:...

...and a specialist
I would hope that my doctor's authority and his charisma might help to protect me against... "soul loss," a sense of terrible emptiness, a feeling that your soul has abandoned your ailing body like rats deserting a sinking ship.... I would like my doctor to understand that beneath my surface cheerfulness, I feel... "the panic inherent in creation" and "the suction of infinity." ... He should be able to imagine the aloneness of the critically ill... I want him to be my Virgil, leading me through my purgatory or inferno, pointing out the sights as we go.
Models for Thinking about Pathographies

- **Testimony**
  - Offers testimony to difficult truths not generally recognized or acknowledged
  - Challenges conventional wisdom
  - Implies relationship - requires a listener
  - Painful for both patient and physician
Buchenwald
Testimony: Physician’s Role

- **Witnessing**
  - Must contemplate own complementary vulnerability, suffering
  - Must be willing not to diminish, negate, trivialize the patient’s testimony
  - Must see similarity, not difference with the patient
Literary Example: The Five Stages of Grief
- Linda Pastan

The night I lost you
someone pointed me towards,
the Five Stages of Grief.
Go that way, they said,
It's easy, like learning to climb
stairs after the amputation.
And so I climbed.

Denial was first.
I sat down at breakfast
carefully setting the table
for two. I passed you the toast -
you sat there. I passed
you the paper - you hid
behind it.

Anger seemed more familiar:
I burned the toast, snatched
the paper and read the headlines myself.
But they mentioned your departure,
and so I moved on to
Bargaining. What can I exchange
for you? The silence
after storms? My typing fingers?
Before I could decide, Depression
came puffing up, a poor relation
its suitcase tied together
with string. In the suitcase
were bandages for the eyes
and bottles of sleep. I slid
all the way down the stairs
feeling nothing.
The Five Stages of Grief (cont)

And all the time Hope flashed on and off in defective neon. 
Hope was a signpost pointing Straight in the air. 
Hope was my uncle’s middle name, he died of it. 
After a year I am still climbing, though my feet slip on you stone face. 
The treeline has long since disappeared: green is a color I have forgotten. 
But now I see what I am climbing Towards: Acceptance

written in capital letters, a special headline: Acceptance; its name is in lights. 
I struggle on, waving and shouting. 
Below, my whole life spreads its surf, all the landscapes I’ve ever known or dreamed of. Below a fish jumps: the pulse in your neck. Acceptance. I finally reach it.

But something is wrong. Grief is a circular staircase. I have lost you.
Models for Thinking about Pathographies

- Epiphanic/Transformative
  - Moments of miracles
Epiphanic: Role of Physician
I stand by the bed where a young woman lies, her face postoperative, her mouth twisted in palsy, clownish. A tiny twig of the facial nerve, the one to the muscles of her mouth has been severed. She will be thus from now on. The surgeon had followed with religious fervor the curve of her flesh; I promise you that. Nevertheless, to remove the tumor in her cheek, I had to cut the little nerve. Her young husband is in the room. He stands on the opposite side of the bed and together they seem to dwell in the evening lamplight, isolated from me, private. Who are they, I ask myself, he and this wry mouth I have made, who gaze at and touch each other so generously, greedily?

The young woman speaks. “Will my mouth always be like this?” she asks. “Yes,” I say, “it will. It is because the nerve was cut.” She nods and is silent. But the young man smiles. “I like it,” he says, “It is kind of cute.”

All at once I know who he is. I understand and lower my gaze. One is not bold in an encounter with a god. Unmindful, he bends to kiss her crooked mouth and I am so close I can see how he twists his own lips to accommodate hers, to show her that their kiss still works. I remember that the gods appeared in ancient Greece as mortals, and I hold my breath, and let the wonder in.
Helping Patients Construct Better Narratives

- **Risk of presumption**
- Sometimes better to listen, to witness
- Sometimes within one story, hear elements of a “better” story
- **What is a “better” story?**
  - Makes more sense
  - Provides more meaning
  - Gives more hope and happiness
Ways of Helping Patients Create New Stories

- Clinical empathy
  - Understands and resonates to patient’s story
  - Keeps own perspective so may offer patient new possibilities
- Offer alternative/ complementary possibilities
- Collaborative revisioning and reconstructing
  - Exploring different visions of self
  - Supporting preferred elements
Conclusion

- Listening with rather than simply to the story;
- Recognizing whether a story is a narrative of chaos, restitution, quest, testimony, epiphany;
- Whether that story makes sense for the patient and the patient’s situation;
- Being willing to witness the patient’s truth;
- On occasion humbly collaborating with the patient to seek a better truth;
- May all improve the practice of medicine.