Notes Narrative Medicine

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1. What Narrative is and what Medical Narrative is.

*Looking, listening, and examining*

Narrative is a spoken or written account of connected events; it is a story, a representation of a particular situation or process in such a way as to reflect or conform to an overarching model. As such is distinct from dialogue and it follows literary conventions such as frame, time, plot, and desire.

Narrative has a social dimension: we connect with ourselves and with others through narrative.

Medical Narrative is “medicine practiced with the narrative competence to recognize, absorb, interpret, and be moved by the stories of illness.”[[1]](#footnote-1) In this sense Narrative informs Narrative Medicine by creating a frame, a time, a plot, and a desire for the stories of illness.

“The storytelling is really where the medicine is… There is nothing that I can think of, there is no kind of testing, there is no sort of physiology or pharmacology that is more essential to clinical skill than the ability to elicit, interpret and communicate someone else’s story.”

Suzanne Koven, MD, primary care doctor and writer-in-residence in the Division of General Internal Medicine, Massachusetts General Hospital.

“[I]llness unfolds in stories, that the care of the sick is an art form, and that multi-disciplinary inquiry is the starting point for new knowledge and fresh practices.”[[2]](#footnote-2)

“[D]ifference between the patient’s experience of illness and the doctor’s attention to disease.”[[3]](#footnote-3)

“She taught me a grand lesson in patient care: that it is possible to talk with patients, even those who are most distressed, about the actual experience of illness, and that witnessing and helping to order that experience can be of therapeutic value.”[[4]](#footnote-4)

2. Social dimension of disease and how Medical Narrative approaches this

Narrative Medicine also seeks to incorporate the social dimension of Narrative: singularize the care of the patients, recognize professionals’ ethical and personal duties toward the sick, and to bring about healing relationships with patients, among practitioners, and with the public.

“[A] form of health care that recognizes suffering, provides comfort, and honors the stories of illness.”[[5]](#footnote-5)

Bring the social dimension of disease.

3. Where you can find Medical Narrative taking place and what does that mean

Modern movement towards introducing Narrative (and literature) in Medicine.

Ultimately, the goal of Narrative Medicine is to listen to the patient’s story.

4. Listening to the patient’s story

How do we listen to the patient’s story? We accompany the patient in her journey.

Previous medical model: therapies utilized shared beliefs: not that much of a gap between knowledge of person and healer; Doctor and patient shared theory of disease: shared understanding of how treatment would effect disease; whether doctor, midwife, herbalist, neighbor; likely great confidence, at baseline, that treatments were appropriate or effective.

a. Biomedicine and the biomedical patient

Biomedicine: 19th Century bacteriology—little change in medical practice

1940s antibiotic era

Biomedicine approaches the patient’s story as

* Instrumental
* Acts upon the patient
* Is driven by the physician’s agenda

Who is the patient? No longer in danger of death by infectious disease we have an aging population that lives longer lives with one or multiple chronic illnesses.

“It is hard not to contemplate future illness, especially when we are assailed on television and in newspapers and magazines with warnings about weakened bones, compromised arteries, impaired sexual function, and the ominous presence of “precancerous” lesions. Innovation in screening and diagnosis propel many of us into a world of anxious patienthood, while promising, paradoxically, to allay our consequent fears of the immanent cancer, cardiovascular disease, or diabetes gestating silently in our bodies.”

People have always had a narrative about their own bodies and diseases and it was only when the known-diseases were ruled out by family members and patients that people would contact a physician. Even then, their narratives about their bodies gave the clues for treatment.

But in biomedicine the patient is a foreign in her own body, marked by diseases and policies that, aside from being valuable heuristic concepts, they reflect a new social dimension of disease plagued with algorithms, screening practices, treatment protocols—not to mention reimbursement schedules and drug-company research and marketing strategies. In a world of ever-expanding screening and often symptomless disease, the sick role is increasingly contingent. A problematic mammogram or raised cholesterol enlists a previously healthy woman or man into the world of sickness.

Doctors who don’t listen: patient advocacy movements of the 60s – 90s

b. Narrative Medicine and the narrative practice of medicine (will provide a model)

Narrative Medicine approaches the patient’s story as

* Mutuality
* Collaboration
* Being with, accompanying

Listening to the patient’s story means understanding 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

Why Do Patients Tell Stories?

* To get better
* Way of orienting self in world of illness
* Way to make sense of one’s life, see it as meaningful
* Show capacity for change
* Power of person over circumstance
* Negotiation with physician over the meanings of disease and course of treatment

Furthermore, it gives the patient a possibility for 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.

Models for Thinking about Illness Narratives[[6]](#footnote-6)

Chaos

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

Restitution

* Find-it and fix-it
* Person restored to pre-illness life
* Highly desirable for both patient and physician

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

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

The Physician’s Role in Testimony

* 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

Epiphanic/ Transformative

* Moments of miracles

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

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

“[I]llness has a meaning; and to understand how it obtains meaning is to understand something fundamental about illness, about care, and perhaps about life generally.”[[7]](#footnote-7)

1. Rita Charon, “Preface” in *Narrative Medicine*, vii. [↑](#footnote-ref-1)
2. Columbia Universtity’s Program in Medical Narrative [↑](#footnote-ref-2)
3. Arthur Kleinman, *The Illness Narrative*, xii. [↑](#footnote-ref-3)
4. Arthur Kleinman, *The Illness Narrative*, xii. [↑](#footnote-ref-4)
5. Rita Charon, “Preface” in *Narrative Medicine*, ix. [↑](#footnote-ref-5)
6. Arthur Frank, *The Wounded Storyteller*, 1995. [↑](#footnote-ref-6)
7. Arthur Kleinman, *The Illness Narrative*, xiv. [↑](#footnote-ref-7)