

NARRATIVE MEDICINE LBVA

2. Slide Everything Held Together with Stories

You know, there is so much in medicine that pushes toward disintegration and dissolution – illness and disease, for sure, but also, tensions within families, between doctors and their patients, within teams and across specialists.

It is our stories that can hold us together and bring us together.

Stories matter – all of our stories, those of patients, family members, doctors, nurses, medical students. They all matter.

Cleveland Clinic video – Has pretty much everyone hear seen this great video? The point is that everyone has a story. Mostly when we see people, or interact with people, we don't know their stories – certainly not their full stories – but the stories are there, influencing both patients and doctors.

3. Definition: Narrative Medicine

Narrative medicine seeks to acknowledge the primacy of stories in patients' and families' lives. From the physician's standpoint, narrative medicine is the capacity to understand *and be moved by* the patient's story.

Narrative medicine involves *listening* to the patient's story

4. Different Ways of Listening

Of course, there are different ways of listening:

Listening medically – goal is to reach a differential

Listening narratively – hear the HPI as a story: drama, comedy, tragedy; characters, plot, beginning, middle, and end

5. What is Narrative Listening?

Listening *with*, rather than *to*, patient's story

Listening to - is an act of extraction – pulling out the elements that are important, make sense to you, the physician; it's driven by the physician's agenda

Listening with – involves mutuality, collaboration, honoring the pt's agenda, being present

6. Who Has Time to Listen to Patient's Story?

So let's be real. Who has time to pay attention to the patient's story?

It's important to remember that not all stories are novels. Some are short stories – VERY short stories!

In literature, there's a genre called 6 word stories; most famous one: Hemingway

Often stories can be conveyed in a single sentence: Examples

7. Why Listen Narratively?

Even listening to a 6 word story takes time, so what's the value of thinking about your patients' stories? Medical educators have suggested that listening narratively can help us...

Understand more deeply why the patient is telling the story – what is the important thing they are trying to convey to you?

Develop emotional connection with the patient – once you've received someone's story, it draws you closer to them

Appreciate the whole person of the patient – you begin to understand the patient within the context of his or her life, hopes, and fears

Create the possibility of helping the patient construct a better story – I will say more about this later on

8. Why Do Patients Tell Their Stories?

To get better, to heal

To understand what's happening to them; to understand the kingdom of illness (Sontag) and their place in that world

9. Connection:

Illness sets person apart; it is stigmatizing, isolating; loss of control/loss of self

With storytelling, patient becomes joined to others through shared bonds of suffering, vulnerability

Storytelling is a way of recovering the voice that illness, diagnosis, treatment take away

10. Different Types of Stories

Social scientists/literary scholars have identified different ways of classifying narratives

Important to remember that not all patients tell the same story even though they might have the same disease

Same patient may tell different stories about their illness at different points in time

Most stories are not one type or other; contain many different elements within a single story

I'm going to briefly describe 5 types of illness narratives and how physicians can interact with these narratives.

While I'm focusing on pt stories, it's important to remember that doctors also tell stories about their patients, to themselves, to their colleagues, to the patient, and to family members; and the stories of patients and doctors interact with each other.

11. Restitution: Find it and fix it; patient goes skiing, breaks a leg, has it set in the ED, and in 6 weeks is back on the slopes good as new.

A highly desirable story for both patients and doctors; when it is appropriate for the situation, it is a wonderful story for everyone to tell

12. Restitution: Physician Response

Yes, of course find it and fix it

But don't over promise; be ready to let go of this story when it's no longer appropriate

13. Chaos Stories

Broken stories, characterized by isolation, hopelessness, fear; frightening for everyone touched by the story, doctors and patients alike

14. Chaos Stories; Physician Response

Tendency, especially for find it/fix it physicians, is to instantly "fix" patient; that's what the patient wants, but they also want their subjective experience recognized

So - be present

Acknowledge the patient 's vulnerability, suffering

Be willing not to diminish, negate, or trivialize patient's story

On the other hand, the physician will not help anything by becoming lost in this story; rather the physician is there to contain the pt's emotions; to let them know it is okay for them to feel panic, rage, despair

15. Resistance:

There are two types of resistance stories

- 1) In the first, the pt adopts a military metaphor – fighting disease; this can be useful at certain points in the course of an illness and with certain diseases; and less useful in others; a lot of doctors love this narrative, and frequently use it themselves
- 2) Second type – resistance is to doctor; it's harder when YOU are the tank!
Many doctors find these patients/families frustrating b/c they reject dr expertise

16. Resistance: Physician Response

In the first sort of resistance story, be prepared to help the patient recognize when it's time to change the story; find another metaphor

For the second type of resistance story, try to avoid defensiveness and escalation

Practice empathy – understanding the pt's perspective

Reframe and learn from resistance – resistance is FERTILE - a demanding parent becomes a committed advocate for their child

17. Quest Story

Reluctant hero receives a call

Encounters trials and challenges; endures much suffering

Finds friends and allies

Accomplishes mission and returns to help others

Uplifting; emphasizes acquisition of wisdom – patient is at center (vs. restitution story)

Can be overly romanticized

18. Quest: Physician Response

Recognize that the patient sees what is happening as a journey; be willing to be a companion and guide

Acknowledge pt's courage, wisdom

19. Transformative

Moments of miracle – large (birth); small (holding a pt's hand)

20. Transformative: Physician Response

Be willing to witness and celebrate with patient/family

Physician's role is one of humility and awe in the face of mysteries of the universe

21. Twisted Smile story

22. Twisted Smile story 2

What narrative elements do you see in this story?

- a) In the first few lines, we see in the surgeon's guilt the longing to have been able to tell a restitution story; we also see a yearning for restitution when the patient asks, "Will my mouth always be like this."
- b) When the physician answers yes, there is a moment of potential chaos. What will happen? How can patient, husband, and physician come to terms with this development?

- c) Then the scene is miraculously transformed – not by the surgeon, but by the husband, who affirms his enduring love of his wife with a kiss.
- d) There is a sense that this may be the beginning of a journey for the couple.

23. Helping Patients Construct Better Narratives

I want to return to a point I made earlier about helping patients construct “better” narratives
Helping pt construct a better story could be incredibly presumptuous, and is an idea that always has to be approached with a great deal of care and humility

Often it is enough just to listen or to witness another’s story – just by sharing their story, pts themselves sometimes begin to edit and revise the story in more congruent directions

But the definition of clinical empathy is that, while deeply grasping the patient’s story, the physician also may sometimes glimpse elements of a “better” story

What do I mean by “better?” A story that

Makes more sense for the patient; provides more meaning; gives more hope

Think about this story: “Insulin will cause me to go blind” – a caring doctor can hear this story, respect its logic, but gently offer the patient a more hopeful narrative

Think about this story: “Maybe a Phase One trial will cure my cancer.” After listening to the patient’s hopes and fears, the physician can help the patient find a story that allows the possibility of end of life and how that can best be lived.

24. Ways of Helping Patients Create New Stories

The physician should view herself not as the author (physician-centered) but as a collaborator or editor, facilitating the patient’s exploration of his or her own values and priorities; and helping the patient choose a story line that best supports what lies closest to that person’s core (pt-centered)

Always start with where the patient is – understand, respect, and resonate with their story

Although the subject of another presentation, it is worth mentioning again that the physician herself also has a story she is telling about the patient, and it is important to be aware of this story as well, to make sure it is in the best interests of the patient

25. Conclusion

In conclusion, when we think about narrative medicine, some things to remember might be:

Listen with rather than simply to the story;

Listen for the narrative elements of the story

Interpret whether that story makes sense for the patient and the patient’s situation;

Be willing to witness the patient’s truth;

Humbly collaborate with the patient to seek a better-matched truth if needed

In this way, narrative medicine results in true patient-centered medicine