3+LISTENING TO PATIENTS' STORIES HTH PRESENTATION

SLIDE 1: Thanks so much to Allyson, Lexi and the HtH club. As the original faculty advisor, it is wonderful to see how the club has flourished and how committed you all are to becoming physicians and health care professionals attentive to the whole person of the patient. A little about myself - I have recently retired from the School of Medicine, where I taught medical students and residents for over 40 years. I also founded and directed the Program in Medical Humanities, which draws on the arts and literature to deepen understanding of both patients and physicians and their relationship to each other.

SLIDE 2: OVERVIEW –
Why patient stories matter
Our expectations about what stories should look likf/narrative conventions
Illness disrupts our lives/and in a way breaks our life stories
- **Restitution stories - the most comfortable narrative in medicine**
- **Other (less comfortable) illness stories**

Next I'll talk about how medical education teaches one way of listening to patients (medical) and how we sometimes need additional, narrative ways of listening
Close reading exercise

SLIDE 3: EVERYTHING IS HELD TOGETHER WITH STORIES –

Human beings have been called the storytelling animal. Stories have individual, familial, group and cultural significance.

QUESTION: THINK ABOUT THE STORIES YOU KNOW BEST – THEY PROBABLY COME FROM YOUR FAMILY, YOUR CULTURE, YOUR FAITH, YOUR FRIENDS. CAN ANYONE BRIEFLY SHARE A STORY THAT IS MEANINGFUL TO THEM?

We tell stories to ourselves (we are always narrating our lives), we share stories with others, we offer our stories to those we hope can understand us and help us.

We all know that stories are important. One of my favorite quotes from the novelist and essayist Barry Lopez says that sometimes stories are all that is holding us together.

Stories help us to make meaning of our own experiences and the world around us. We all build our stories around our expectations of what life is supposed to be. But it's important to remember that the stories that get to be told are always connected to people's ability to exercise power.

SLIDE 4: WHAT IS A STORY?

We grow up hearing stories and eventually telling stories, and we form ideas about what a story is "supposed to look like." Traditional narratives are expected to have certain elements: characters, plot, conflict or problem, rising action (the tension of the story), a climax, falling action, and finally resolution or solution. Stories are expected to have a theme, an idea that embodies the meaning of the story.

Stories also traditionally move through time, so a sense of forward movement, moving toward a goal, is essential in a traditional story.

SLIDE 5: DOMINANT MEDICAL STORY – RESTITUTION:

Because of our expectations about what constitutes a story, some stories are easier for us to hear than others – and some stories are easier for doctors to hear as well.

The medical story that is most comfortable for physicians follows a traditional narrative formulation. The medical sociologist Arthur Frank labeled this traditional illness story a restitution narrative. It promises that, with the expertise, authority and knowledge of physicians, the patient's life previous to illness can be fully restored. In the restitution narrative, the patient is saying in a rather mechanistic way, "My body is broken, can you fix it?" It's a model of healing kind of like car repair.

SLIDE 6: RESTITUTION STORY –

In broad outline, the restitution looks like this: A healthy, active person, the protagonist, goes skiing. They fall and break their leg, the conflict or problem. They feel pain, the rising action that culminates in their being transported to the

hospital, a dramatic climax. There, the knowledgeable doctor, a character as important as the patient, diagnoses the break and applies a cast. Time passes, the action falls, the patient does what the doctor told them to do, and soon they are back on the slopes. Problem solved!

Physicians like this story because it is the one they have trained for many years to recognize and handle. In hearing and responding to this story, the physician feels competent and successful.

SLIDE 7: BROKEN STORIES –

Not every narrative of illness and suffering follows the restitution trajectory.

Many scholars have defined illness as a biographical disruption that puts our life on a different path, perhaps forever. Our lives are following one story, then illness intervenes and that story is no longer possible. Our story has become broken.

QUESTION: CAN ANYONE GIVE AN EXAMPLE OF HOW AN ILLNESS OR SERIOUS MEDICAL EVENT DISRUPTS THE PATIENT'S LIFE STORY?

Stories that are broken often must be told differently. They often don't fit into familiar narrative conventions.

SLIDE 8: OTHER STORIES –

These are stories of chaos (substance use, mental illness), nonadherence, pain and suffering, personal tragedy, family violence, systemic injustice and racism. Chaos stories, for example, depict a shattered, disorganized experience. These stories may be circular, rather than linear. They may be fragmentary, full of gaps and silence, rather than coherent. They may have plenty of conflict, plenty of problems, but no easy solutions. These stories can make doctors feel frustrated, helpless, sometimes resentful, because they are not stories with an easy fix. These are stories that are sometimes discouraged from being told or judged negatively when they are told. Yet they are the stories some patients must tell.

QUESTION: WOULD SOMEONE LIKE TO GIVE AN EXAMPLE OF A NON-RESTITUTION STORY?

These stories do not ask only whether the physician can "fix their bodies," but whether the physician can help them craft a new story that makes more sense, helps them become more empowered, helps them be more connected, given their disrupted life circumstances.

SLIDE 9: DOCTORS ARE NOT ALWAYS TRAINED TO LISTEN TO ALTERNATIVE STORIES

Doctors are not always trained adequately to receive these alternative stories. Although great strides have been made in medical education, many doctors are still uncomfortable with and try to avoid narratives that are not restitution stories or some other narrative form that feels safe and familiar to them.

That is because most of medical training focuses on medical listening. If you've shadowed a physician or worked as a scribe, or been a patient, or gone with a parent or grandparent to the doctor's, you are already familiar with medical listening – when the doctor is listening medically, she asks directed questions targeting the patient's history of present illness and listens for medically relevant details. Medical listening has as its goal finding the problem and fixing the problem. Whereas the restitution story can be "solved" by medical listening, more complicated stories require not only medical listening but narrative listening.

Medical listening works less well with alternative stories because often there is not an obvious solution to the problem.

SLIDE 10: HOW CAN DOCTORS COMPASSIONATEY RECEIVE UNCOMFORTABLE STORIES?

Narrative listening is one way of shifting how doctors listen that respects sand empowers patients as well as help restore feelings of connection and purpose to physicians. Narrative listening involves finding the story that matters to the patient.

EXAMPLE: Maybe a family doc is counseling a patient about healthy diet choices. But until they can acknowledge that the patient's eating habits are embedded in longstanding family traditions and cultural practices; or until they hear that part of the patient's story is that they live in a food desert, they are not listening narratively. Rather than jumping immediately to fixing, narrative

listening asks the physician to spend a few minutes simply being present with the patient's story of suffering or confusion or helplessness, empathizing with and respecting that story. It is not so much a more time-consuming way of listening as a different approach to listening. It involves acknowledging the patient's right to tell their story in their own way and requires the physician to respect and honor this story. In essence, it means being willing for a few moments, to become a meaningful part of the patient's story rather than imposing a medical story on the patient.

SLIDE 11: MEDICAL LISTENING VS. NARRATIVE LISTENING

Comparing these two types of listening, we see that listening medically means listening *to* the patient's story. It means extracting information for a specific purpose, that is formulating a diagnosis and making a treatment plan. It is "doing something to" the patient in the sense of taking something that the physician needs. As in the restitution story, the physician directs the agenda, and re-authors the patient's story to translate it into medical language and structure and medical priorities, omitting everything the physician judges as tangential or unimportant. Although not the intent of medical listening, this approach can distance the physician from patient.

Narrative listening, by contrast, involves listening *with*. This means being fully present with the patient, being willing to accompany the patient in their suffering, hearing what matters to them. In a way, it means having the courage for a few moments to turn toward the patient's suffering, rather than away from it. It means connecting with the patient on a human level and collaborating with the patient to build a better, more healing story.

SLIDE 12: CONVEYING NARRATIVE LISTENING

It may be that for some of you, listening narratively sounds kind of intriguing, but still somewhat abstract. How do we actually go about listening narratively? To be honest, I think it is something of an art and something of a mystery. But there are several things that can help. One is learning to be fully present and attentive to the patient, even when feeling time-pressured or confused. Another is by conveying one or more of the following messages, whether articulated explicitly or conveyed through tone and nonverbal behavior, to the

patient, so that the patient knows that the doctor respects and honors their story.

i. **I see you, I hear your story**
ii. **I believe, accept, and value your story**
iii. **I will try to understand how you feel**
iv. **I care about you and what your story means to you**
v. **I can't always fix you, but I want to help you accept this story or help you find a better one**
vi. **I'm grateful you chose to entrust me with your story**
vii. **I want us to work together as we think about your story**
viii. **I stand with you in your story**

SLIDE 13: BENEFITS OF NARRATIVE LISTENING

When physicians listen narratively, both patients and physicians can benefit. Patients feel less isolated and more respected because their story has been heard. This connection leads to greater trust in the physician and changes the hierarchical nature of the doctor patient relationship by creating the opportunity to partner with the physician. Having their story validated also can lead to deeper understanding of how structural inequities affect their health. Ultimately, they will feel more empowered and healed.

For physicians, narrative listening gives them the opportunity to understand their patients more wholly and more deeply. They experience a person to person connection rather than a person to object relationship with the patient. Understanding the patient's story more deeply can also help the physician become a better advocate for their patient within the healthcare system. Connecting with their patient and advocating for their patient reduces physicians' feelings of helplessness and helps restore them to their original idealism.

SLIDE 14: SUMMARY - Listening narratively can help push back against structural forces in medicine that diminish the value of patients and lead to burnout in physicians. Patients need to have the courage to tell their stories as they want to tell them and physicians need to have the courage to listen with, not only to,

these stories. From this foundation of trust, patient and physician together can genuinely acknowledge pain and suffering and just "be with" this suffering; and when it makes sense seek to reframe these stories to help the patient endure and heal, including ways that acknowledge and resist larger societal forces of inequity and injustice.

SLIDE 15: DISCUSSION QUESTIONS

1. **What differences can you identify comparing *Maria* and *Medicine, Mortality and Reflexive Verbs?***
2. **What are aspects of medical listening that you can identify in *Maria*?**
3. **What are examples of narrative listening in *Reflexive Verbs*?**
4. **How did reading *Maria* make you feel? How did you feel reading *Reflexive Verbs?***
5. **What would you say about the doctor-patient relationship in *Maria*? In *Reflexive Verbs*?**