PATIENT STORIES

1, TITLE SLIDE - My deep thanks to my old colleague Dr. Sosa-Johnson for giving me this wonderful opportunity to share my thoughts with you about storytelling in healthcare.

2. 5 QUESTIONS SLIDE –

This afternoon, I'd like to examine briefly what storytelling in healthcare means, review what a story is, why patients tell stories and why they matter, consider barriers to physicians hearing patient stories, and finally describe how a narrative approach to listening can improve patient care and physician wellbeing.

Ultimately, my goal is to help you figure out WHAT TO DO with patients' stories.

4. EVERYTHING IS HELD TOGETHER SLIDE - We all know that stories are important. Sometimes, in fact, they are the most important thing.

But what do we mean by a story?

4. WHAT IS A STORY? SLIDE - Traditional narratives are expected to share 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 also 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. In fact, this forward movement is what often gives stories their meaning, so they aren't just going round and round in a circle.

5. FOR SALE BABY SHOES SLIDE – Doctors often worry that patient stories take up too much time. But stories can be very short. Perhaps the best-known literary example of one such short short story is attributed, probably apocryphally, to Ernest Hemingway: For Sale. Baby Shoes. Never Worn. An incredibly poignant, sad story.

The stories of illness that arise between patient and doctor are sometimes just simple sentences, throwaway lines that can easily be overlooked or ignored in the interaction.

6. DOMINANT MEDICAL STORY: RESTITUTION SLIDE - Although doctors may sometimes be suspicious aout the value or relevance of patient stories, there is one type of medical narrative that both physicians and their patients are eager to tell, what the medical sociologist Arthur Frank labeled the restitution narrative. Patients like this narrative because it promises them that, with the expertise, authority and knowledge of physicians, their life previous to illness can be fully restored. In the restitution narrative, the patient is saying, "My body is broken, can you fix it?"

7. RESTITUTION STORY SLIDE - 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, often 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! There is resolution in the sense of a desired and worthwhile outcome.

Not only patients, but physicians also 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.

8. BROKEN STORIES SLIDE - But 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. While restitution narratives also recognize this biographic disruption, it is necessarily defined as temporary, transitory, with the ultimate result being to retore the patient to their pre-illness life.

Yet we know that illness often triggers a profound loss of personal identity and a sense of meaninglessness. Sometimes personal values and beliefs are thrown into serious question. And often there is no quick or tidy resolution of these issues.

These patients often must tell stories that have little resemblance to restitution stories.

9. OTHER NARRATIVE FORMS SLIDE - These are stories of chaos, ambivalence, nonadherence, pain and suffering. 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 resolution, no solutions.

These stories do not ask the doctor to fix their body but to help them find a new story.

11. WHY PATIENTS TELL NONCONVENTIONAL STORIES SLIDE – Yet despite pressures from the healthcare system and society in general NOT to tell these unconventional stories, patients persist in trying to give these stories to physicians. WHY?

I'd like to mention two reasons: the value of resistance and the value of connection.

12. STORIES SEEKING RESISTANCE SLIDE – Individuals who are ill may lose ownership over their own illness event. Of course, we know that illness itself can be traumatizing. Ironically, the healthcare system can inadvertently retraumatize patients by telling them their stories are unimportant or inaccurate – their suffering isn't really suffering after all.

By telling their story in a way that makes sense to them and reflects their subjective reality, patients are engaging authentically with questions of pain, trauma, and the disruptions of self. Their narratives describing a different reality from the restitution narrative push back against dismissal and erasure. In this way, patients can become advocates for themselves.

13. STORIES SEEKING CONNECTION SLIDE - Stories come into being through relationship with others. Ultimately, all stories seek connection. Researchers agree that any serious illness is an isolating, sometimes alienating experience. Patients can end up feeling alone, misunderstood, not seen or heard. Sharing the traumatic experiences of illness can build community, including with their physicians.

But connection is complex because authentic stories may be perceived as threatening by others, including physicians. Without a story that moves toward resolution, connection may be thwarted.

When we tell a story to others, we are not only sharing that story. The story is making a claim on others, including physicians. The nature of this "claim" can be purely instrumental (cure me) but the more consequential claims require the receiver to change or to grow in some way (in other words, what is the story asking of the doctor not as an expert but as a fellow human being?). It is in seeking to honor this claim that meaningful connection develops between doctor and patient.

14. UTERINE SARCOMA SLIDE - I'd like to share a personal story of thwarted connection. In 2004, I was diagnosed with a rare uterine sarcoma. No one, including physicians, knew very much about this disease. There was little information about prognosis and survival. It was a terrifying experience. As the mother of three adult children and two (soon to be four) grandchildren, I struggled with my own mortality. Finally, I got up the nerve to ask my gynecologic oncologist about my chances of survival. He was an excellent and usually compassionate doctor. But that day he was very busy and running behind. Seated in the exam room, I said hesitantly, "Could I ask you a question?" "Of course," he replied, "but would you mind asking while I'm doing your pelvic exam?" On the exam table, my legs in stirrups, I could not bring myself to ask about how long I might live. I was too vulnerable, too afraid, and felt dismissed and dehumanized. My gyn-onc never asked me about my question. It was a missed opportunity for my doctor to connect more meaningfully with me.

15. OBSTACLES TO PHYSICIANS RECEIVING PATIENTS' STORIES SLIDE - What makes it so difficult for physicians to really hear and respond to patient stories?

16. SYSTEMIC AND STRUCTURAL BARRIERS SLIDE – Probably the most significant barriers to really hearing patient stories are systemic and structural, not personal. Most physicians are good people whose choice of profession is motivated by a sincere desire to help others. But systemic aspects of healthcare can make it difficult for them to realize their visions of the kind of physician they'd like to be. It is beyond the scope of this talk to analyze all the institutional barriers to listening carefully to patient narratives, but one example has to do with time. Physicians (and frequently patients) often complain that doctors do not have enough time to spend with patients. The problem of "no time" however is not primarily the result of talkative patients or ineffective, disorganized physicians. Rather, the institutional focus in the delivery of healthcare on prioritizing efficiency and productivity to enhance a financial bottom-line can lead to dehumanization of that care.

17. DOCTORS ARE NOT TRAINED TO RECEIVE THESE STORIES – Doctors are not always trained adequately to receive these alternative stories. Although great strides have been made in medical education, especially through such classes as Art of Doctoring, many doctors are still uncomfortable with and try to avoid narratives that are not restitution stories.

19. THE WOUNDED PHYSICIAN SLIDE - The effects of structural and systemic priorities as well as gaps in medical training are felt not only by patients, but by physicians. They have little bandwidth for listening to, learning from patients' stories, or incorporating them into their care of the patient. As a resident once told me when I asked why he seemed to avoid asking about his patient's story, "I'm afraid of opening Pandora's box. My own container is already full." Doctors want to help, but how?

20. HOW CAN DOCTORS RECEIVE PATIENT STORIES MORE EFFECTIVELY SLIDE - Despite institutional pressures that move them in one direction, individual physicians do have personal agency, they can can choose to integrate other more healing, more empowering elements into their practice for the sake of both their patients and themselves. It is possible to exert pressure from within to change the

culture of medicine. For the remainder of my time, I'd like to describe one way of shifting how doctors listen to patients that will respect and empower patients as well as help restore to physicians' feelings of connection and purpose.

21. LISTENING MEDICALLY SLIDE - In medical education, a certain kind of listening is taught. It is fact-based, reductive, driven by the physician, and intended to extract relevant information from the patient to form a diagnosis and treatment plan. A nonmedical example of such a "history" offered by the British novelist EM Forster is: The king died and then the queen died. From a physician's perspective, this history contains two facts and might suggest a contagious disease. Medical listening is essential to the care of patients so please hear that I am not criticizing the need for or utility of this kind of listening. But listening medically on its own is incomplete because, as we have seen, it often diminishes, ignores, or dismisses the patient's story.

22. LISTENING NARRATIVELY SLIDE – EM Forster alters his story subtly in the following way, and in doing so helps us to listen narratively to this tale of the king and queen. Listening narratively involves seeing the patient's story, rather than simply an assemblage of facts, signs and symptoms. In the medical perspective, it is perhaps sad but not relevant that the queen died of grief, unless it was due to broken heart syndrome. But from a narrative perspective, we see that the king and queen loved each other deeply. Perhaps, if the physician had known the story of the king and queen, he could have better helped her deal with her loss.

23. NARRATIVE LISTENING SLIDE - Narrative listening involves being present with patients as they tell their stories and giving them full attention. It acknowledges individual suffering, while recognizing that not all suffering can be "fixed." Narrative listening also validates that suffering is never purely individual, but is influenced by social contexts, the structural exclusions affecting the patient, the institutional systems that label their patients' experience as unimportant, and the economic pressures that contribute to patient suffering. Narrative listening does not require restitution, transformation or enrichment, but is able to contain stories of pain and suffering without needing to instantly change them.

24. MEDICAL LISTENING VS. NARRATIVE LISTENING SLIDE - 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, omitting everything the physician judges as tangential or unimportant. Although not the intent of medical listening, this approach can distance the physician from patient suffering because suffering is not a diagnosis.

Narrative listening, by contrast, involves listening *with*. This means being fully present with the patient, being willing to accompany the patient in their suffering. It means hearing and respecting the totality of the patient's story, trying to hear what matters to the patient. In a way, it means having the courage to turn toward the patient's suffering, rather than away from it. Finally, it means connecting with the patient on a human level and collaborating with the patient to build a new story, whether of resistance, acceptance, connection or something in between.

25. LISTENING NARRATIVELY II SLIDE - 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. However, these eight sentences, whether articulated explicitly or conveyed through tone and nonverbal behavior can help the physician become a meaningful part of the patient's story.

I see you, I hear your story

I believe, accept, and value your story

I will try to understand how you feel

I care about you and what your story means to you

I can't always fix you, but I want to help you accept this story or help you find a better one

I'm grateful you chose to entrust me with your story

I want us to work together as we think about your story

I stand with you in your story

From a certain perspective, these statements are not dissimilar to the thoughts and reactions of a reader toward a beloved story or novel – not those of a literary critic who dissects and judges, but someone who, even while not always agreeing with every aspect of the story, appreciates and values it.

26. WHY LISTEN NARRATIVELY SLIDE - Both patients and physicians can benefit from narrative listening. 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, whether the patient recovers, accommodates to their illness, or succumbs, they will feel more empowered and healed.

For physicians, narrative listening gives them the opportunity to understand their patients more wholly and more deeply. Using the terms of Martin Buber, a 20th century philosopher, they can encounter their patient in an I-Thou, rather than an I-It relationship – experiencing a person to person connection rather than a person to object relationship. 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.

27. RESTORYING SLIDE - Often it is enough just to listen or to witness another's story – just by sharing their story, people themselves sometimes begin to edit and revise the story in more congruent and healthy directions.

When the physician deeply listens to the patient's story, they can sometimes create a space for the patient to search for a story that is better suited to their circumstances. This is sometimes referred to as restorying, or helping the patient to build a better story.

According to the ethicist Jodi Halpern, the definition of clinical empathy is that, while deeply grasping another's story, the physician also may sometimes glimpse elements of a different story.

A story that…

Makes more sense for the person given their medical and social circumstances; provides more acceptance; or 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 a more accurate and hopeful narrative.

Or this story: "Maybe a Phase One trial will cure my stage 4 metastatic pancreatic cancer." After listening to the person's hopes, fears and longings, the physician can help them find a story that allows for the possibility of dying while also contemplating how the life remaining to them can best be lived.

28. RETINAL DETACHMENT SLIDE - In 1997 I experienced a spontaneous retinal detachment, that brought with it the possibility of losing sight in my right eye. Like many patients, I initially told myself a restitution story about my situation. Have the surgery, recover, return to writing grants and teaching, caring for my three kids, running a household. Life would be normal as soon as I was out of surgery. However, beneath this cheerful exterior, I was frightened and alone, not understanding how this could have happened, and terrified of having my vision compromised. Worse, I was unable to articulate my concerns in a coherent story. Luckily, my surgeon, a perceptive and compassionate individual, picked up on fragments of my broken verbalizations. He said to me, "Take a pause. This is not a one and done. This is an existential blow, an event that reminds you of your mortality." At first I was shocked but he was right. Through a long recovery in which I had to retrain my depth perception, I reevaluated my life, acknowledged dissatisfaction in my work, and moved into the field of medical humanities. This is a story of transformation, but more importantly it is an illustration of how a doctor gave a patient a different and deeper way of understanding her suffering.

29. SUMMARY SLIDE - 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.

30. HEALING THE WOUNDS SLIDE - Narrative listening is by no means a panacea. It is a small drop in the bucket of reimagining and rebuilding a more just, equitable and merciful healthcare system. But narrative listening can help both patients and doctors realize that, even in the worst of circumstances, even when there is no solution immediately apparent to a patient's suffering, patient and doctor can face these misfortunes, these tragedies together. In doing so, they both may move toward healing.