STORIES OF SICKNESS: LISTENING NARRATIVELY TO CO-CONSTRUCT NEW UNDERSTANDINGS OF ILLNESS

INTRO SLIDE: Hi Everybody. Thank you Dr. SJ for inviting me to lead this session. I'm excited to have the opportunity to speak with all of you. I'm going to be talking about something – narrative listening – that I know all of you do already, whether instinctively or as a result of your role models, your training and your own reflective process. My goal in the next 20 or 30 minutes is just to offer a kind of conceptual framework about why this kind of listening is important and hopefully we can discuss in the breakout rooms how it can be integrated with more traditional medical listening.

SLIDE 1: EVERYTHING IS HELD TOGETHER WITH STORIES You have all seen by now that illness pushes us all toward disintegration and despair. It is our stories that can hold us together and bring us back to our lives. If we're lucky, confronted by illness we learn to make new stories on our own. But when we are able to share our stories with physicians who know how to receive them and really hear them, we will be more likely to construct more satisfying, more meaningful stories.

SLIDE 2: BROKEN STORIES Academics often define illness as a biographical disruption. This simply means that your life is going along one way, you have plans, aspirations, dreams; and then suddenly illness intervenes, and your life veers off in a completely different, and usually worse, direction. The story that you knew has become broken.

SLIDE 3: LISTENING TO THE PERSON'S STORY When doctors listen deeply to their people's stories, they are better able to build trust and eventually work with them to craft better, more collaborative, more healing stories.

(And I'd like to mention here that, following the lead of my colleague Dr. Ralph Clayman, whenever possible I'm going to avoid the term "patient" because of its many constraining and sometimes demeaning connotations, and simply refer to people and persons, because after all that is fundamentally what we all are, patients and physicians alike).

SLIDE 4: SHARING YOUR STORY It's not always easy to give someone else your story. Sharing your story makes you vulnerable, and you fear judgment. Maybe the doctor won't get your story. Maybe they will see it as irrelevant, tangential, or unimportant. Maybe they won't see how precious it is or how terrible it is.

SLIDE 5: WHAT HAPPENS WHEN PEOPLE SHARE THEIR STORIES? One of the constants of sociological research on the illness experience is that illness is isolating and alienating. People can feel very alone in their suffering. Tragically, we have seen this again and again in the current pandemic.

Storytelling, by contrast, reconnects the sick person to others – sometimes to family, friends, or fellow sufferers; but also if they're lucky it connects them to their physicians.

SLIDE 6: WHAT HAPPENS WHEN PEOPLE SHARE THEIR STORIES? People sometimes feel their very personal stories of illness have been taken over and translated into something almost unrecognizable by the medical system. Telling their stories in their own words gives people a way of reclaiming their voice.

SLIDE 7: WHAT HAPPENS WHEN PEOPLE SHARE THEIR STORIES? Finally, the connection and agency that arise from storytelling can help people begin to make sense of the new world that illness has ushered them into; to reclaim or rediscover meaning even in their radically altered lives.

SLIDE 8: RECEIVING SOMEONE'S STORY There's plenty of research and clinical experience indicating that people who are sick benefit when they can share their stories. But, as many of us also know, it's not always easy to receive someone's story. This is especially true for stories of illness which *can* be inspiring and triumphal, but are also often dispiriting, tragic, and horrifying.

Who wants to hear such stories? Who has time?

SLIDE 9: WHY DOCTORS HAVE TROUBLE LISTENING TO PEOPLE'S STORIES Doctors often feel they do not have time. Doctors are very busy and in today's healthcare system, more so than ever. They always have another entry to make in the electronic medical record, another lab result to review, another test to order, another person to see. They have very little time to listen to people's stories.

SLIDE 10: TIME ISN'T THE WHOLE STORY But lack of time isn't the whole story. Stories aren't necessarily novels.

Here is an example of a 6 word story attributed, probably apocryphally, to Ernest Hemingway: For sale. Baby shoes. Never worn.

If doctors are really listening, people can tell them stories in a single sentence –

So it's not only a problem of time.

SLIDE 11: SYSTEMIC AND STRUCTURAL ISSUES THAT DISCOURAGE STORIES The healthcare system itself is not set up to value people's stories. In institutional structures that emphasize efficiency and productivity, completing algorithms and checklists, healthcare by a thousand clicks if you will, stories can seem like a detour, a distraction. No one gets reimbursed for listening to someone's story. But as the old Hmong adage warns, "You can miss a lot by sticking to the point," including what is most important to the person telling their story.

SLIDE 12: THE WOUNDED PHYSICIAN But lack of time, institutional and structural deterrents are still only part of the story. Physicians themselves are often wounded, with broken stories of their own, depleted by sometimes insensitive, occasionally merciless training, beset by a multitude of pressures and demands from their institutions on the one hand and the needs and desires of ill persons on the other.

^CLICK We know that at any given time between a third and a half of physicians and medical students report being burned-out, exhausted emotionally and physically, made disillusioned and bitter by problems not of their making. And burnout has only worsened during the current pandemic.

^CLICK When I've asked residents why they didn't ask about someone's story, sometimes they respond, "I don't want to open Pandora's box," implying they cannot contend with all the demons that will pour out. No wonder they are fearful. Their emotional and spiritual containers are already filled to overflowing. They are reluctant to take on anything more, especially stories they perceive as burdensome and distressing without easy solution.

In truth, doctors are *not* always well-prepared to receive such stories. In part, this has to do with how they are trained to listen.

SLIDE 13: LISTENING MEDICALLY Medicine trains doctors to listen medically, which makes sense – to identify signs, symptoms, and information so they can reach a differential diagnosis and form a useful treatment plan.

^CLICK The novelist EM Forster used the following short short story to illustrate a narrative based exclusively on event and chronology: The king died and then the queen died.

Such a story is similar to the basic structure of the HPI: first this one symptom emerged, then another symptom emerged. Unfortunately, this kind of listening makes it difficult to appreciate fully fleshed stories because it ignores plot, character, and emotion.

SLIDE 14: THE RESTITUTION STORY Medical listening is, however, well-suited to a particular kind of story that narratologists, people who study stories for a living, call the restitution story. A restitution story follows a find-the-problem, fix-the-problem structure, in which the physician identifies the problem, applies the solution, and the sick person is restored perfectly to their pre-illness life. A person goes skiing, they break their leg, they get it casted and before you know it are back on the slopes. Everyone love this story, and why wouldn't we, because the biographical disruption of illness is vanquished and we get our old lives back; while the physician gets to bask in the glow of fixing our problem, and therefore us.

SLIDE 15: THE RESTITUTION STORY In the Restitution story, the person is essentially saying, "My body is broken, can you fix it?"

^CLICK When they hears this story, the doctor feels competent, secure, and safe, because this is exactly the story they have been training to hear for 7 or so years, and they are ready to jump in.

But not every story in medicine can be a restitution story.

SLIDE 16: OTHER KINDS OF STORIES There are stories in medicine that are frustrating, confusing, chaotic, terrifying, heartbreaking of course for the people and families who experience them but also, to a lesser extent, for the physicians who must hear them. These other kinds of stories need a different kind of listening.

SLIDE 17: A DIFFERENT QUESTION In these stories, the person is not saying, "My body is broken, can you fix it?" but rather, "My story is broken, can you help me make a new one?" This question requires a different kind of listening that leads to a different kind of answer.

SLIDE 18: NARRATIVE LISTENING This kind of listening is what scholars call Narrative Listening.

Listening narratively means listening to the HPI, for example, as if the person is telling a story that is a drama, a comedy, a tragedy, a story that has characters, a plot, a theme, a beginning, middle, an end. It is listening for the meaning of the story.

^CLICK Returning for a moment to EM Forster's classic short short story about the death of the king and queen, he demonstrates plot, character, and emotion by adding two words: "The king died, and then the queen died…of grief." In medical listening, the queen's grief might not matter much in determining her cause of death. In narrative listening, it is the heart of the story.

SLIDE 19: WHAT IS NARRATIVE LISTENING? In the words of the medical sociologist Arthur Frank, narrative listening is listening *with,* not *to,* the story.

^CLICK Listening *to* is instrumental, driven by the physician's agenda. It relies on extracting relevant information and discarding the rest.

^CLICK Listening *with* suggests mutuality, a kind of collaboration in the process of building relationship

It means being present with the story.

SLIDE 20: NARRATIVE LISTENING: More of an attitude or an approach than a skill; doesn't necessarily require more time, but more presence

SLIDE 21: WHY LISTEN NARRATIVELY? Why is narrative listening an important aspect of the physician's arsenal?

Scholars and clinicians have suggested that:

^CLICK Listening narratively can help physicians understand why the person is telling the story; and why they are telling it in a particular way

^CLICK Narrative listening can help doctors empathize more deeply with that person's experience; AND develop an emotional connection with that person;

^CLICK Narrative listening can help physicians appreciate the person, not just a disease;

^CLICK And finally narrative listening creates the possibility of helping the ill person construct a better story

SLIDE 21: HELPING PEOPLE CONSTRUCT BETTER NARRATIVES Helping people construct new and hopefully better narratives can seem presumptuous: What right do I have to talk to another person about their life story? So it is an idea that must be approached with care and humility.

Sometimes it is enough just to listen to another's story – just by sharing their story, people see how they need to change or what they need to do next. For example, sometimes a patient with diabetes will tell her story, and conclude I need to make some changes. Help me figure out how!

^CLICK But 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 "better" story.

^CLICK What do I mean by "better?" A story that…

Makes more sense for the person given their medical and social circumstances; provides more meaning; gives more hope.

Think about this story: "Insulin will cause me to go blind" – a caring doctor can hear this story, and rather than mock it, respect its logic, but gently offer a more accurate and hopeful narrative.

Or think about 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.

SLIDE 22: WAYS OF HELPING PEOPLE CREATE NEW STORIES Narrative co-construction involves a process of shared imagining, in the words of Dr. Osborn, for those of her who attended her AoD lecture, "dreaming together" – in effect, it is saying to that ill person, "Given where you are, what can we envision for you in the future? What might this look like? How can we make this happen?"

In narrative listening, the physician views themself not as the author of the story (a very physician-centric approach) but as a collaborator or editor (more person-centered), facilitating the ill person's exploration of their own values and priorities; and helping that person choose a story line that best supports those values and priorities.

SLIDE 23: HEALING THE WOUNDS As I mentioned earlier, like the stories of those asking for their help, there can be pain and suffering in physicians' stories as well. It is perhaps paradoxical that, by listening to the stories of others, physicians can sometimes find healing for themselves.

When we listen narratively, we are enlivened and inspirited by a recognition of our common humanity. We feel better able to bear more because we are bearing it together. As the spiritual teacher Ram Dass once said, "We're all just walking each other home." When physicians can glimpse their own human limitations, their human uncertainties and human suffering, as well as their human courage, commitment, and perseverance in the stories of others, they too have the possibility of experiencing a kind of healing.

SLIDE 24: INDIVIDUAL PHYSICIAN VS. SYSTEMIC RESPONSIBILITY Where does responsibility lie for narrative listening? It's easy to just say, physicians should listen narratively more often, but that does an injustice to the good intentions of doctors and the complexities of the systems in which they find themselves working.

Partly of course responsibility for narrative listening *does* lie with physicians themselves. We need to do a better job of training physicians, first by simply giving them permission to listen narratively, and then by giving them practice in developing this approach.

But right now we make it incredibly difficult for even well-intentioned, open-hearted, and narratively skilled physicians to engage in narrative listening. Both doctors and the people they care for are canaries struggling to breathe amidst stifling fumes. So when we look around, and see people suffering and physicians suffering in part as a result of a paucity of narrative listening, we should remember that we can try to save the canaries one bird at a time; but we should also think about CHANGING THE COAL MINE!

In this case, this might mean changing the healthcare delivery system to make it more human, less frustrating; shifting the culture of medicine to a culture that recognizes the centrality of stories in health and wellness…and importantly, a culture that can tolerate, even embrace, stories that may make us uncomfortable, from voices that may make us uncomfortable.

SLIDE 25: FINAL THOUGHTS: Narrative listening is a clinical approach that can benefit both physicians and the person who is seeking their aid:

^CLICK By listening *with* rather than only *to* the story, physicians learn to relate differently to those who are suffering,

^CLICK Narrative listening provides doctors with a way of "being with" ill people for a moment, rather than always simply "doing *to*" them.

^CLICK Narrative listening is a way of sharing suffering, rather than trying to instantly fix suffering, and in the process it results in coming to understand the other more deeply.

^CLICK This kind of listening honors the truths of those seeking help and, when appropriate, opens the door to helping people rebuild their stories in ways that are better matched to their new realities.

^CLICK CLICK Narrative listening and story rebuilding also make doctors feel less alone, partnered with and emotionally connected to those who are sick , and ultimately more human. When physicians listen with the stories of the sick, they take the first step toward healing, if not always curing, both suffering others seeking relief and sometimes themselves as well.