STORIES OF SICKNESS

Slide 1 Title: Thank you Jim and Doug for such generous introductory remarks. I have had the privilege of working with both Dr. Lee and Vice-Chancellor Haynes for the past 8 years, and their wisdom, insight, and courage has inspired and educated me. Thank you both.

As you can see, tonight I will be talking about stories of sickness. And I want to begin with some stories from my own family of origin.

Slide 2: Mom and Dad 1940: My mom and dad fell in love playing ping-pong at a vacation ranch in the Santa Monica mountains. But when my father drove from California, where they met, to Illinois, where my mom lived, and asked her father for her hand in marriage, as was then the custom, my grandfather fell silent. My father thought it was because he was Jewish, while my mother's people were high church Episcopalians, and he had his arguments marshalled. But although the Episcopalians were not happy about an interfaith union, that was not the main problem. My grandfather, a surgeon, soberly looked at my dad and said, "Nancy won't live more than a year or two." My mom had had rheumatic fever as a teen, and was left with a weak heart that was supposed to fail her momentarily.

My father was unfazed. Four years earlier, when he was only 17, he himself had lost his beloved father to a massive coronary at the impossibly young age of 38. My father had to drop out of college to support his family writing comedy for variety shows and radio. He'd already learned that life was unfair, unpredictable, and sometimes horrifying. But he believed in love. He stared back at my grandfather and said, "I'm going to marry her anyway." Eventually they eloped, married, and spent 70 years together.

Slide 3: Mom and Dad 2008 No text

Slide 4: ME AS A BABY This is only one of many, many stories of illness that run through my family like a bright turbulent river. There is my own origin story – how even though my mom did not die and in fact grew stronger, every reputable physician my parents consulted assured them her heart could not stand the strain of pregnancy, and she would surely die if she had a child.

My parents, dissatisfied with this judgment, sought the advice of my father's younger brother, who had just graduated from medical school and was all of 2 weeks into his cardiology residency. This consultation occurred in the professional setting of Santa Monica beach. My uncle thought. "Can you walk as far as the pier?" he asked my mom, pointing. She proceeded to do so. "You can get pregnant," he pronounced. 10 months later I was born.

SLIDE 5: DOUBLE MASTECTOMY The stories swirled through my family as a child – 6 months after I emerged, my mom was diagnosed with breast cancer and underwent a double mastectomy so that, as her surgeon bluntly informed her, "If you don't die, you can at least bear more children" (which she did). I grew up with a mother who had no breasts, and until I was about 4 and happened to glimpse the naked mother of one of my friends, I thought all women must have long red horizontal scars across their chests.

SLIDE 6: MY PATERNAL GRANDFATHER, DAVID There was the tragic, life-upending story of my grandfather's death from that massive heart attack, surrounded by the background narrative that his father, and his father's father had both died in their early forties of coronary events.

SLIDE 7: MY MATERNAL GRANDMOTHER, BEA There were the stories of my beautiful, unpredictable, dramatic, and seriously alcoholic grandmother, who was only allowed to hold us children under supervision, who occasionally ran about her neighborhood without her clothes, and whose death at 58 from breast cancer shattered my mother for years.

SLIDE 8: FAMILY STORIES OF ILLNESS These and many other stories shaped my family and me as a child. We heard them over and over in various permutations. My parents were both novelists, and knew how to tell a good story. Their narrations were filled with vivid characters, exciting plot twists, moving denouements. These stories made the people in my family who they were.

They also shaped our relationships with physicians. But I doubt any of the many physicians who cared for my mom or the rest of our family ever heard these stories. And that's too bad, because if they had, they might have better understood my parents' complex feelings about their doctors. On the one hand, they were dependent on the physicians who provided the antibiotics that every year pulled my mom through her long bouts of pneumonia…

SLIDE 9 ADDICTION: …they also provided the opiates which helped her cope with the chronic pain of a skull fracture and concussion sustained in a bizarre accident; and the worse pain of her mother's death. Eventually my mom became addicted; and eventually, without any sort of intervention from her doctors, she quit cold turkey. On the other hand, my parents were highly skeptical and mistrustful about doctors who either told them repeatedly that my mom would die, when she didn't; or who couldn't save the people they loved the most, like their parents, my grandparents.

SLIDE 10: EVERYTHING IS HELD TOGETHER WITH STORIES Illness pushes us all toward disintegration and dissolution. 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 better, more satisfying, and meaningful stories.

SLIDE 11: 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.

At a young age, both my parents' life stories were disrupted by illness. As a child I never thought about what it was like at 16 to be so weak from heart disease that you could not climb stairs, and were told you would die before you were 25; or what it was like at 17 to one day have a happy boisterous home filled with laughter and arguments about philosophy and politics and the next to have no father and somehow have to support your bereft mother and 3 younger siblings. My parents' stories were unceremoniously broken, and they struggled on their own the best they could to fix them.

SLIDE 12: LISTENING TO THE PERSON'S STORY If their doctors had heard their stories, they might have been able to build trust with my parents, and eventually work with them to craft better, more

collaborative stories that saw physicians less as pill dispensers and more as partners in the project of keeping my mom alive and my dad healthy.

(And I'd like to note here that, following the lead of my colleague Dr. Ralph Clayman, whenever possible I'm going to avoid the term "patient" in this talk, and simply refer to the person, because that is fundamentally what we all are, patients and physicians).

SLIDE 13: SHARING YOUR STORY Although everyone is full of stories, including stories of illness, those of us who have shared our stories know it is not always easy to give someone else your story. In my family, stories were always for INSIDE the family, never to be shared OUTSIDE, and that included our doctors. Sharing your story makes you have to own it, face it in all its scariness, uncertainty, aloneness. It makes you vulnerable, and you fear others' reactions. You fear judgment. Maybe they 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 dreadful it is.

SLIDE 14: WHAT HAPPENS WHEN PEOPLE SHARE THEIR STORIES? One of the constants of sociological research on the illness experience is that it is isolating and alienating. People can feel very alone in their suffering.

Storytelling reconnects the sick person to others – sometimes family, friends, or fellow sufferers, as in a support group; but also if they're lucky it connects them to their physicians, who have seen the suffering of others and may be expected to understand it better than many laypeople.

SLIDE 15: WHAT HAPPENS WHEN PEOPLE SHARE THEIR STORIES? Storytelling also gives people a way of reclaiming their voice that may have disappeared as a result of their illness, diagnosis, and treatment

SLIDE 16: WHAT HAPPENS WHEN PEOPLE SHARE THEIR STORIES? The connection and agency that arise from storytelling can help people begin to make sense of their lives within the new world that illness has ushered them into; to reclaim or rediscover meaning even in their radically altered lives.

SLIDE 17: RECEIVING SOMEONE'S STORY So 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. Stories of illness can be inspiring and triumphal, but honestly they are also often dispiriting, tragic, horrifying, and filled with suffering.

Who wants to hear such stories? Who has time?

SLIDE 18: WHY DOCTORS HAVE TROUBLE LISTENING TO PEOPLE'S STORIES Doctors are very busy and in today's healthcare system, more so than ever. They have very little time to listen to people's stories.

SLIDE 19: TIME ISN'T THE WHOLE STORY But lack of time isn't the whole story. Stories aren't necessarily novels.

Here is a oft-cited example of what's known as a 6 word story attributed, probably erroneously, 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 20: 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, sticking to the algorithms and checklists, healthcare by a thousand clicks, stories seem like a detour, a distraction. No one gets reimbursed for listening to someone's story. But as the Hmong knew, You can miss a lot by sticking to the point. In the case of clinical medicine, listening only to the information needed to construct a differential diagnosis or assess presenting symptoms can overlook what is most important to the patient.

SLIDE 21: 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. They are the tip of the spear for a broken healthcare system, only with no back-up forces behind them, so they must carry on every day trying their best as caring, dedicated individuals to remedy problems that often require major societal reforms.

^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.

^CLICK When I query residents why they didn't ask about someone's story, sometimes they respond ruefully," 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. No wonder they are reluctant to take on anything more, especially things they perceive as burdensome and distressing without easy solution.

In truth, doctors often have little idea how to receive such stories. In part, this has to do with how they are trained to listen.

SLIDE 22: LISTENING MEDICALLY Medicine trains doctors to listen medically – to identify signs, symptoms, and information so they can reach a differential diagnosis.

^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, the history of present illness: first this one symptom emerged, then at some later point in time another symptom emerged. This kind of listening is antithetical to appreciation of fully fleshed stories because it ignores plot, character, and emotion.

SLIDE 23: THE RESTITUTION STORY Medical listening is, however, well-suited to a particular kind of story that narratologists call the restitution story. A restitution story follows a find-the-problem and 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. Person goes skiing, breaks their leg, gets it casted and before you know it is 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 24: THE RESTITUTION STORY In the Restitution story, the person is essentially saying, "My body is broken, can you fix it?"

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

The physician is center stage in this story, the patient a passive but grateful recipient.

But not every story in medicine can be a restitution story. And when this is the case, from the doctor's perspective, receiving these different kinds of stories can seem messy, ambiguous, onerous.

SLIDE 25: OTHER KINDS OF STORIES These other kinds of stories need a different kind of listening. There are stories in medicine that are frustrating, confusing, chaotic, terrifying, heartbreaking both for the people and families who experience them and, to a lesser extent, for the physicians who must hear them. How can doctors receive these stories in ways that support the sick people who seek their care and themselves as well, in ways that are compassionate and healing?

SLIDE 26: 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 27: NARRATIVE LISTENING We might call this kind of listening Narrative Listening.

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

^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 in determining her cause of death. In narrative listening, it is the heart of the story.

SLIDE 28: 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

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

It means being present with the story.

SLIDE 29: CONTEXTUAL ATTITUDES IN NARRATIVE LISTENING Contextually, it's important that the physician cultivate an attitude of humility to just accompany that ill person for a few moments in their story, as a reader might become engrossed in the twists and turns of a character's journey

^CLICK The physician who listens narratively learns not to block out the suffering of the person, but rather to hold and

witness that suffering

^CLICK In most narratives, even very flawed characters have something likable or relatable about them. Although physicians can find some ill persons challenging, it is important for them to acknowledge the courage, resilience, persistence, and other positive qualities that have enabled the person in front of them to deal with their often very difficult lives.

SLIDE 30: WHAT DOES NARRATIVE LISTENING LOOK LIKE? When a physician is listening narratively, she figures out who is important in the story; who is the protagonist; is there an antagonist?; who are the supporting characters?; what are their dynamics and relationships?

The physician who is listening narratively is able to identify the plot – the *interrelationship* between the main events of the story. This includes the climax of the story, and its resolution, which is often what the person who is ill is seeking.

For example, the plot might be how the person started to feel ill, how this led to a climax of worsening symptoms and going to her family doctor, and the denouement of receiving a diagnosis that helps the person understand what is happening to her.

And the narrative physician also knows how to tease out the theme – the main idea or point, which in a medical context may be something like, I am sick and I am afraid; or I'm here, but not because I want to be – I don't like doctors.

When listening narratively, the physician avoids the tendency to instantly "fix,"; rather she spends a little time understanding the parameters and significance of the story.

SLIDE 31: WHY LISTEN NARRATIVELY? Why is narrative listening an important skill in the arsenal of the physician?

Scholars and clinicians have suggested that:

^CLICK Listening narratively can help physicians understand why the person is telling the story;

^CLICK Help them empathize more deeply with that person's experience; AND**develop an emotional connection with that person;**

^CLICK Help them appreciate the person, not just a disease;

^CLICK And finally create the possibility of helping the person construct a better story

SLIDE 32: HELPING PEOPLE CONSTRUCT BETTER NARRATIVES Helping people construct new and hopefully better narratives might sound presumptuous, and it 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, people themselves sometimes begin to edit and revise the story in more congruent and healthy directions.

^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, 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 33: WAYS OF HELPING PEOPLE CREATE NEW STORIES Narrative co-construction involves a process of shared imagining, dreaming together – 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?

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

The physician must also recognize their own story and how it intersects with that of the person seeking care. Do the characters, plot, or theme trigger responses in the physician that might limit co-construction? For example, if the person behaves in ways that make the physician feel "this person does not care about their health," then the physician's frustration or judgment may get in the way of assisting that person develop a new story.

SLIDE 34: HEALING THE WOUNDS 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 discover that we are less burdened by stories, although they may contain distressing, frustrating, or even heartbreaking elements.

Rather, 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," and when physicians can glimpse their own human limitations as well as their expertise, their human uncertainties as well as their undisputed competence in the stories of others, they too will begin to experience a kind of healing.

SLIDE 35: INDIVIDUAL PHYSICIAN VS. SYSTEMIC RESPONSIBILITY And as a brief but important aside, which could be an entire talk in itself: 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.

We are all familiar with the analogy of the canary in the coal mine. When the canary is placed in a toxic environment, it begins to suffocate and die. We can try to save it by giving it antidotes to carbon monoxide poisoning. But we can also try to change the coal mine.

Partly of course responsibility for narrative listening lies 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 skill.

But right now we make it incredibly difficult for even well-intentioned, open-hearted, and skilled physicians to engage in narrative listening. They are canaries struggling to breathe amidst stifling fumes. So when we look around, and see people suffering and physicians suffering as a result in part 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. For example,

Changing metrics that prioritize efficiency and productivity over compassionate care: people not paperwork

And changing physicians' workload distribution to prioritize what physicians are uniquely trained to do

It might also mean shifting the culture of medicine to a culture that recognizes the centrality of stories in health and wellness…

As well as populating our healthcare institutions with leaders who view narrative medicine as a professional core competency.

As I said, this is another conversation, but one well worth having.

SLIDE 36: FINAL THOUGHTS: Narrative listening is an essential clinical skill that can benefit both physicians and the people who seek their care. It enables physicians to relate differently to those who are suffering, providing a way of "being" with them for a moment, rather than always "doing" to them.

It is a way of sharing suffering, rather than trying to instantly fix suffering, and in the process coming to understand the other more deeply.

This kind of listening, when appropriate, opens the door to helping people rebuild their stories in ways that are better matched to their new realities.

Engaging in these processes with people who are ill helps them simultaneously accommodate and feel more in control of their illnesses.

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 cure, for both suffering others searching for relief and sometimes for themselves as well.

SLIDE 36: VAN GOGH'S PIETA:

I suspect that with a more generous use of narrative listening, the many doctors who cared for our family could have really and truly heard my parents' illness stories; and through hearing these stories might have helped them to co-construct more satisfying, less stressful narratives about our family's

many illnesses. In my imagination, I have the idea that such physicians might have helped to sustain and heal my family in a way that mere medicine could not.

However, there is no doubt in my mind that my parents, while relishing the creativity afforded through this process of narrative listening and story co-construction, would have insisted on retaining authorial control! And with genuine person-centered medicine, that is exactly as it should be.

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