STORIES OF SICKNESS AOD 2024

SLIDE 1 INTRO: Thank you Martha and Juliet for inviting me to participate in this session to talk about stories of sickness. I hope we'll have plenty of time to talk together about patient and doctor storytelling, and perhaps do a little writing together as well.

SLIDE 2 EVERYTHING IS HELD TOGETHER WITH STORIES: Everyone in this room has cared for someone with a serious illness and perhaps has experienced serious illness personally. I think we can all agree that illness pushes people toward disintegration and dissolution. It is our stories that can hold us together and help us make sense of the new lives that illness has given us. When patients are able to share our stories with physicians who know how to receive them and really hear them, they will be more likely to construct better, more satisfying, and more meaningful stories.

SLIDE 3 THREE FAMILY STORIES: I'd like to share three personal family stories to illustrate the power that stories about doctors and patients can have in our lives, how much they influence our perceptions about what it's like to be sick, and what roles doctors can and should play in our lives. These three stories illustrate themes that were very much a part of my understanding of illness and medical care; first, that Doctors aren't always right; next that Doctors can help us see the big picture; and last, that Doctors can miss what's most important to the patient.

SLIDE 4 DOCTORS AREN'T ALWAYS RIGHT: My mom and dad fell in love playing ping-pong at a ranch in the Santa Monica mountains. But when my father drove from California 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 – my dad - was Jewish, while my mother's people were high church Episcopalians, and he had his arguments ready. 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. 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 5 DOCTORS CAN HELP US SEE THE BIG PICTURE: Another story. When my son was 14 years old, he was diagnosed with ankylosing spondylitis. He was in terrible pain and had to stop doing things he loved like basketball. He became depressed, and rarely left his room. Then one day, he emerged with a brochure and told me, I want to go to Alaska. It was an Outward Bound program for 3 weeks in the Alaskan wilderness. I wasn't so sure. I asked, aren't there bears there? He replied, I'll outrun them. This from a kid who could not jog more than a few yards.

We asked his physical therapist, who recommended yoga instead. We asked his rheumatologist, who recommended PT. Those are for old people, our son said. When we asked our family doc, I think he saw the hope in Josh's eyes. The doc said, Go. You haven't lived till you've seen Alaska. Josh went, and while the experience wasn't without problems, it showed him there was life after this difficult diagnosis.

SLIDE 6 DOCTORS CAN MISS THE MOST IMPORTANT THING: In 2004, I learned I had endometrial stromal sarcoma, a rare sarcoma of the uterus. I had a total hysterectomy and oophorectomy. Little was known about this disease, including how to treat it and what was its prognosis. I'd read studies on-line and they weren't encouraging. Finally, I got up the nerve to ask my gyn-onc directly what my future might look like and what were the chances I might *have a future*.

My gyn-onc was a very good doctor, kind and compassionate. But on that day he was very busy. After waiting more than an hour to see him, during which time I kept rehearsing in my head exactly how I would ask my question, my name was finally called. After waiting for another 30 minutes in the exam room, my doc came in, visibly in a rush. Dr. B, I said, I have something I need to ask you. Sure, he replied, but can you ask me while I'm doing your pelvic. I'm really behind today.

Up in stirrups, I felt too vulnerable to ask my question and he didn't ask me what it was. It was months before I was able to broach the subject with him.

SLIDE 7 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 8 SHARING YOUR STORY: It's not easy to give someone else your very personal story, especially when that story is a broken one. 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 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 frightening.

SLIDE 9 WHAT HAPPENS WHEN PATIENTS SHARE THEIR STORIES?: But, when patients find the courage to tell their stories, some good things can happen. For example, storytelling gives people a way of reclaiming their voice, a voice that may have disappeared through the medicalization of their story. People sometimes feel their story of illness has been taken over and translated into something almost unrecognizable by the medical system. In telling it in their own words and their own way, they can make it their own again.

SLIDE 10 WHAT HAPPENS WHEN PATIENTS SHARE THEIR STORIES?: Storytelling can help patients begin to make sense of their lives within the new world that illness has forced them into; and to rediscover meaning and purpose, even in these radically altered lives.

SLIDE 11 WHAT HAPPENS WHEN PATIENTS SHARE THEIR STORIES?: One of the constants of sociological research about the illness experience is that it is isolating and alienating. Patients can feel very alone in their suffering.

Storytelling, by contrast, reconnects the sick person to others – sometimes to family, friends, or fellow sufferers, as in a support group or through a blog; and also if they're lucky it connects them to their physicians.

SLIDE 12 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 these kinds of stories. Stories of illness can be inspiring and triumphal, but they are also often dispiriting, tragic, horrifying.

Who wants to hear such stories? Who has time?

SLIDE 13 WHY DOCTORS HAVE TROUBLE LISTENING TO y STORIES Doctors often feel they do not have time. Of course, even as medical students you are all very busy and in residency and beyond you will be busier than ever. There is always another entry to make in the electronic medical record, another lab result to review, another patient to see. There is very little time to listen to patients' stories.

SLIDE 14 TIME ISN'T THE WHOLE STORY: But lack of time isn't the whole story. Stories aren't necessarily novels.

Here is a brief but poignant story attributed, probably apocryphally, to Ernest Hemingway: For sale. Baby shoes. Never worn.

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

And you all certainly can think of similar short stories you've heard.

So it's not only a problem of time.

SLIDE 15 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 algorithms and checklists, healthcare by a thousand clicks, stories can seem like a detour, a distraction. No one gets reimbursed for listening to a patient's story. But there's an old Hmong saying that warns, "You can miss a lot by sticking to the point." In the case of clinical medicine, listening only for the information needed to construct a differential diagnosis or assess presenting symptoms can overlook what is most important to the person telling the story.

SLIDE 16 THE WOUNDED PHYSICIAN: But lack of time, institutional and structural deterrents are still only part of the story. Physicians - and medical students - themselves are often wounded, with broken stories of their own, depleted by sometimes gruelling training, caught between the pressures and demands of their institutions on the one hand and the needs and desires of ill persons and their families 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, disillusioned and cynical about problems not of their making.

^CLICK When I used to ask residents why they didn't inquire about a patient's story, sometimes they responded ruefully," I don't want to open Pandora's box," implying they couldn't deal with all the demons that would pour out. Their emotional and spiritual containers were already full. No wonder they were reluctant to take on anything more, especially things they perceived as burdensome and distressing without easy solution.

So it's not always easily to tell your story and it's not always easy to receive someone else's story.

SLIDE 17 OVERCOMING BARRIERS TO WELCOMING PATIENT STORIES: How can we all do a better job of listening to the stories that others want, or need, to tell? First, it's important to just be aware that stories exist. That sounds obvious, but faced with time pressure, institutional demands, and our own burdens, the patient's human story can all too easily disappear.

Second, we can be aware of the things that get in the way for us personally in terms of receptively receiving someone's story, whether it is a sense of too much to do, anxiety triggered by aspects of the patient's situation or something else.

We can make a special effort to listen for hints that the patient has a story; and,

Once we hear that hint, take the time to tease out the full story

We can remember to set aside our own biases, preconceptions about what matters and what doesn't to someone else

And we can intersperse the medical style of listening with a more narrative style

SLIDE 18 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 doing more listening than talking, more appreciating than evaluating, more presence than instrumentality. It is a kind of collaboration in the process of building relationship

SLIDE 19 WHY LISTEN NARRATIVELY?:

Scholars and clinicians have suggested that:

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

^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. We can talk about this more in discussion, but basically it suggests that stories are not fixed, they can evolve and change, and sometimes a caring physician can offer the patient a different and more hopeful or more realistic way of looking at their situation.

SLIDE 20: LET'S WRITE!

Write for 10 minutes in any form you'd like about a patient encounter that was memorable to you for any reason – uplifting, fascinating, demoralizing, insightful, moving

At the end of this time, I'll ask for a couple of brave souls to share their stories if anyone is comfortable doing so. We can talk about what it's like to tell a story and what it's like to receive it.