NAS PRESENTATION

SLIDE I: Good afternoon. My name is Johanna Shapiro, and I am a medical educator, which means I spend a lot of time observing and interacting with medical students and residents about their patient encounters; and I am also a narratologist, which means I study people's stories.

SLIDE 2: An old folk riddle asks, What is truer than the truth? The answer is, a good story. The idea, of course, is that a story can sometimes arrive at deeper truths, what has been called narrative knowledge.

This is not meant to suggest that all facts are equal, or that there is no such thing as misinformation so long as someone can craft a "good story". But it is to suggest that one person's evidence is another person's nonsense.

SLIDE 3: In medicine, it is easy to think there is one story – the true, accurate, evidence-based story. In fact, there are many stories in medicine, and these stories are often contested in the sense that they vie for dominance and acceptance. When the patient's story conflicts with the doctor's facts, the patient's story is sometimes disbelieved. Sometimes other stories that may be relevant, such as those of a family member, are never heard. A narrative approach to medicine seeks out these different stories and tries to help physicians and patients listen more carefully to each other.

SLIDE 4: These studies are for your reference only. They are culled from a large literature with which many of you are probably familiar about internet use by patients, the spread of misinformation, and mismatches between doctors' and patients' understanding and expectations.

SLIDE 5: Some of this work shows that practicing clinicians can demonstrate resistance to their patients' stories. A study I conducted a few years ago analyzing over 100 written student reflections on difficult encounters with patients found, among other things, that students were frustrated, angry, even infuriated when patients rejected their explanations and advice, as these quotes from our research illustrate.

SLIDE 6: What most seemed to frustrate students was their lack of control – they could not force the patient to comply with what the student knew was best for them.

SLIDE 7: In these examples, you can hear the student's disbelief and shock. The source of this astonishment stems from the conviction of the "rightness", the correctness of their knowledge over that of their patient.

In these situations, these students were not interested in the patient's story because it was not factually correct. Instead, the students attempted to persuade the patient using the stories that were compelling to the students: evidence-based medicine, double-blind designs, statistics and percentages. But the patients had what were to them more trustworthy sources of information, and these formed the basis of their stories.

SLIDE 8: Students sometimes observed a similar lack of interest in patients' stories from their physician mentors. The following scenario between a doctor and a patient with worsening diabetes is based on a composite of several student narratives:

Doctor: Your labwork indicates your diabetes is still out of control.

Patient: But I feel okay.

Doctor (eye-rolling): Look at your labs. Look at your Hemoglobin A1C. You need to get serious about changing your diet, exercising. And you need to start insulin. Here's a prescription.

Patient: (doesn't take prescription). My cousin told me about a tea that can cure diabetes.

Doctor: (more eye-rolling) There is no such tea. Here, take the prescription.

Patient: (Hesitantly) I don't want to take insulin.

Doctor: (Impatiently) Why not?

Patient: I've seen family, friends start insulin. Then they go blind and their toes are cut off.

Doctor: (patronizing tone) You're confusing association with cause and effect. Insulin didn't cause those complications. Those patients probably started on insulin too late. That could happen to you if you don't take insulin. Here, take the prescription.

Patient: I'll think about it.

SLIDE 9: So medical students AND physicians may be frustrated by or uninterested in patients' stories. Unfortunately, increasingly patients may also evince skepticism regarding the advice and counsel of their doctors.

Sometimes they mistrust physicians because what they're hearing conflicts with sources within their own increasingly narrow and homogeneous information bubble.

Further, in most patient-doctor encounters, there is an unequal power dynamic. If the patient feels out of control, one of the few ways they can rebalance this power equation is by resisting physicians' explanations.

Sometimes medical advice conflicts with deeply held cultural, religious, or familial convictions. Sometimes there are longstanding historical and societal patterns of discrimination and exploitation that influence an apparently objective exchange of information.

Additionally, physicians can convey stigmatizing information that patients don't want to hear, such as diagnoses of mental illness, addiction, AIDS.

Finally, disinformation may simply be more appealing – you don't have to take insulin to manage your diabetes. Our tea can cure you!

SLIDE 10: In the successful medical encounter, a shared story must be co-constructed, yielding a version that makes sense to both doctor and patient. This co-construction is not rocket science, but involves listening and respect, a genuine curiosity about the other's story, and empathy for their perspective.

SLIDE 11: Returning to the case of the person with diabetes, her primary care doctor could take her patient's concerns about insulin causing diabetic complications more seriously and be interested in her thinking: "What you're saying makes sense, a lot of people in the community have a similar fear. Help me understand what you've seen and heard."

The doctor might convey not only curiosity but kindness: "It's scary to consider starting insulin.".

The doctor might even agree that the patient should try that tea, if it is not harmful, while laying the groundwork for further conversations about how insulin actually works to protect the patient from her feared consequences.

Finally, instead of prescribing insulin in that encounter, the doctor might prescribe participation in a group medical visit with other diabetic patients, so the patient could share her worries and listen to their stories about their own experiences with insulin.

Through such dialogue, patient and doctor begin to co-construct a clinical story that both can accept.

SLIDE 11: Different kinds of knowledge, both narrative and scientific, belong at the clinical table. We have to accept that different beliefs and different life experiences lead to different stories. Respect for others' stories is essential no matter how uncomfortable they make the physician feel. It is important for both medical students and physicians to be curious rather than judgmental about their patient's beliefs. In the end, collaboration and teamwork even in the face of difference is the most effective way forward in clinical practice.