

### IDEAS FOR NAS TALK APRIL 3

Some of us feel, especially in the academic community where the scientific method, evidence, meticulous and painstaking research subject to rigorous interrogation reign supreme, that we live in perilous times. Increasingly, scientists, experts, authorities are looked at with suspicion and disdain as members of an out-of-touch elite. Often, people no longer even attempt to dispute evidence – they simply say, I don't believe it, I am not convinced, or it doesn't matter. In our society as a whole, we hear this message from the highest institutions of power.

What are the implications for clinical medicine, at the bedside and in the clinic? Today I will be speaking to you not as a clinician – I am not one – but as someone who has spent 40 years observing, interpreting, and working with physicians and medical students. In these settings, I function as a kind of anthropologist participant-observer, noting the conflicts, sharing a third perspective. My thoughts here relate primarily to clinical settings, to encounters between patients, families, doctors, and other health professionals.

Let's be clear. We are talking about the nature of truth. As a narratologist, I swim in the sea of multiple truths. An old folk saying asks the question: 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 as opposed to scientific knowledge.

The above quote 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" about erroneous assertions. But it is to suggest that one's person's evidence is another person's gobbledygook. When I examine this issue with medical students, they often say, but our position is *true*. It is based on science, on facts. I have numbers and data. But sometimes the patient and the family see it differently, and rely on other sources of knowledge and evidence.

Contested stories: 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, although not all of them get to be told. Sometimes, once the patient offers her story to her physician, she loses control of it. It is fed through the medical shredder and when reassembled by the clinician, is often unrecognizable. 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.

There are many reasons why patients sometimes look with skepticism on the advice and counsel of their doctors. Sometimes they mistrust physicians because what they're hearing conflicts with their particular information world – the information bubble phenomenon. Simply put, they trust the sources in their world more than those outside. Sometimes medical advice conflicts with deeply held cultural, religious, or familial convictions. Sometimes there are longstanding historical and societal pervasive discrimination, dishonesty and exploitation realities that influence the exchange of information in the doctor-patient encounter. And intrapsychic factors can play a significant role: your hemoglobin A1C may establish that you have diabetes, but you feel fine – your body is telling you are not sick, and every shred of your being resists the idea of chronic illness.

Further, not every dispute around the meaning of evidence is viewed similarly. This is influenced by many specific factors. For example, Morgellons, a condition in which patients experience skin lesions characterized by “fibers” growing out of their bodies as well as a range of other symptoms, has been diagnosed as delusional parasitosis, and research by the CDC and Kaiser Permanente found no infectious or environmental explanations for the lesion. Case closed, right? But many Morgellons sufferers remain unconvinced.

Similarly, the anti-vaxer movement still has widespread support, particularly in certain areas of the country, despite convincing research refuting any link between vaccines and autism.

A different kind of conflict can emerge around end-of-life decisions, in which physicians (who often up till that visit have implied that aggressive treatment is the way to go) suddenly call in the palliative care team. When the family resists, they are regarded as in denial and maintaining false hope.

Problems with disinformation and rejection of accurate information:

- 1) Disinformation may be more appealing – you don’t have to take metformin to manage your diabetes. Our program can cure you!
- 2) Lack of trust in the medical community and science in general – elitism; historical treatment – supported by like-minded social networks and communities
- 3) Differences in power between patients and doctors
- 4) Stigmatizing implications of the evidence (psychiatric diagnosis, AIDS, obesity)
- 5) Differences in culturally-based assumptions, expectations, priorities

So all of this context is operating when that individual encounter between doctor and patient occurs. And it is worth noting that this encounter takes place in a situation of unequal power, with the physician holding most of the cards.

Historically, and often still today, these encounters have gone something like this:

Doctor: Your labwork indicates you have diabetes.

Patient: But I feel fine.

Doctor (eyerolling): Look at your labs (shows labs). You have diabetes. You need to change everything you eat, start exercising, and take this medication (holds out the prescription).

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

Doctor: (more eye-rolling) That’s ridiculous, there is no such tea. Here, take the prescription.

Patient: (takes the prescription, but has no intention of filling it). Okay. I’ll try to cut back on the carbs.

As a narratologist, I know that people’s stories matter. In the medical encounter, a shared story must be co-constructed, a story that makes sense to both doctor and patient. Both doctor and patient must

have some degree of openness to each other's story. The co-construction of a shared story involves listening and respect, a genuine curiosity about the other's story. This is different than mastering rhetorical skills to "persuade" a patient of the rightness of the medical position. Since rhetoric is an inevitable part of the encounter, every clinician must ask herself whether her arguments fall within appropriate moral boundaries.

In the case of Morgellons, dermatologists now often look for a middle ground, negotiating with the patient around topical treatments, antibiotics, as well as antipsychotic medications. Pediatricians try to hear and empathize with the fears of parents, and explore slower vaccination schedules, or maintain respectful communication in the face of continued disagreement. Palliative care doctors find common ground with families seeking to spare their loved one suffering and navigate the various kinds of hope possible at the end of life. In the case of the person with diabetes, her primary care doctor might tell her to try the tea, work with her to modify her eating and exercise habits, share her experiences with other patients, explore the patient's resistance to medication, and negotiate the treatment plan.

Different kinds of knowledge all belong at the clinical table.

Medical students sometimes say in exasperation, "But what I'm telling the patient is right." That may be, but it also may not matter. What will matter is the context of trust, respect, and collaboration.

Misinformation about science – different manifestations

Looking for generalized conclusions

Reaching diverse audience – people impacted by research, scientific, technical information; not just policy makers; emotional aspects of communicating, empathic nature;

Narrative medicine – physician-patient interaction; medical profession itself may be misinformed

Diversity of methods – anthropologist observer-participant

Illumination of what different methods bring

Storytelling piece and narrative medicine – what is the scope; what are major themes

Technical research-based information how is it communicated

How to engage people in a productive way? listening, humility, other perspectives; how to configure one-on-one interactions; extrapolating from one set of experiences to another – so derive broad themes

What makes basic values of respect, listening, trust sometimes so difficult to apply

Video – before and after; might be able to use segment from Empathy videos where son talks about diet to cure cancer

Could also use excerpts from Difficult Encounter essays to show frustration vs. understanding of misinformation

More like a retreat – panel, with 10-15 minute presentation; interaction and discussion

Respect for others' stories, no matter how uncomfortable they make you feel; curiosity not judgment (curious, not furious) ; different beliefs lead to different stories; don't have to be right

Ethical dilemmas – when does persuasion blur into coercion? Softer, gentler coercion

Importance of building relationship vs. being right

Audience and National Academy – critique is they should stick to the science; try to ground remarks in data; how do you know what you know? I know what I know partly from my own research, partly from the research of others, partly from my experience observing many medical students and physicians; and partly from my personal life experience

Contending stories – insulin is the next evidence-based step in your treatment vs insulin will make me go blind

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Each presenter has 8 minutes for own remarks; 20 min moderated Q&A, then audience discussion

On-line audience

Presentation needs to walk the talk

Liz Neely, Story Collider – performance storytelling like the Moth; true personal stories about science; most storytellers are researchers and doctors; how stories work; how performance helps convey story

Michael – research perspective; review - what has been written about narrative and research science; Marty does entertainment education – get science into programming; showing video about vaccines

Valerie – Communicating the Gist; evidence-based research on communicating information; mental representation of information – how people process information; role memory plays – how we use narrative identity; interpretation of the message

Monica – cultural issues in promoting science

\*Medical students' attitudes toward training in empathy – resistance to narrative approaches

Elliott – iBiology; content for general public; documentary on CRISPR; worked at CBS News; responsibility of the storytellers; unfair critique that scientists don't understand stories; and that public are not sophisticated enough to understand science; looking for bridges between scientists and storytellers to help them tell their stories; science is awe and wonder of discovery; spirit of science

**Be very concrete and specific in presentation – explain what you mean by storytelling; information-packed; high idea/unit of time**

**Audience 180 people – people professionally involved in science communication on research side; communication officers at science societies; nonprofits that run science training curricula; researchers that study information communication; many people come from hard science and social science backgrounds; some from arts/humanities**

**Microphones in aisles, and circulating**

**Can use slides and videos; Liz will be editor for talks (send her slides, video)**

**Don't read from notes or slides – know bullet points and speak directly to audience**