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Healthful, Heartful, and Hopeful Narrative in Medicine: An Autoethnographic Performance Text

Jay Baglia, Nicole Defenbaugh, and Elissa Foster

Healthful, Heartful, and Hopeful Narrative in Medicine is a script derived from the personal experiences of the authors and has been performed twice: first at the inaugural meeting of the International Association of Autoethnography and Narrative Inquiry and later at the International Conference on Communication in Healthcare.[1] Whenever we undergo a "routine" test, learn of disease trajectories, or begin a treatment regimen, we enter what Victor Turner (1994) identified as a particular state of being betwixt and between—a liminal space. The cases that comprise the material for this script center on conditions, illnesses, and treatments occupying—for the patient and the clinician—liminal spaces as they play out in the context of medical care. Driving our inquiry-through-performance is the observation that the greatest liminality in healthcare exists in the time between diagnosis and resolution; and, of course, chronic diseases are, by nature, experienced in the liminal space opened up by their incurability.

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Cast of Characters

PERFORMER 1: (written with masculine pronouns but could be played in any gender) Pancreatic Surgeon 1, Voice of Medicine, Patient.

PERFORMER 2: (written with feminine pronouns but could be played in any gender) Patient, Gastroenterologist, Voice of Medicine

PERFORMER 3: (written with feminine pronouns but could be played in any gender) Pancreatic Surgeon 2, Friend, Patient, Nurse, Audience Member

Setting

The stage is set upstage with three chairs in a row, about two feet apart and turned to face the audience. The PERFORMERS will move these chairs at various times to indicate a change of scene and then return the chairs to these set positions. The two outer chairs have physicians' lab coats draped across the back. There is a projection screen hung at the back as a cyclorama. The three PERFORMERS begin by standing in front of the chairs. They move downstage in turn as they address the audience.

Prelude

PERFORMER 3

We share a unique relationship as colleagues, educators, patients and researchers. Although not at the same time, we worked in the same hospital network as medical educators and researchers, training physicians in skills of clinical communication and collaboration. Speaking today from our experiences as patients and teachers, we share a common vision of "humanizing" medicine by promoting the ethos and epistemology of narrative methods.

PERFORMER 2

Ellis and Bochner published an article in 1999, in the interdisciplinary journal *Health,* arguing for the recognition that emotion and personal narrative could and should have in medical social science.

PERFORMER 1

Of course, narrative is often front-and-center in medical reasoning in the form of the "case." Arthur Kleinman in 1989 identified the case presentation as one type of several meaning-making applications in medicine, but emphasized the prevalence of other narratives as well.

PERFORMER 2

What follows are personal narratives during which we play multiple roles. As medical educators and patients, we ponder what may be gained from integrating vulnerability, reflexivity, uncertainty, and dialogue into the discursive practices of medicine.

PERFORMER 3 walks downstage right to begin the first scene as the VOICE OF MEDICINE. PERFORMER 1 retrieves a lab coat ready to play PANCREATIC SURGEON 1. PERFORMER 2 walks to downstage center, ready to play PATIENT.

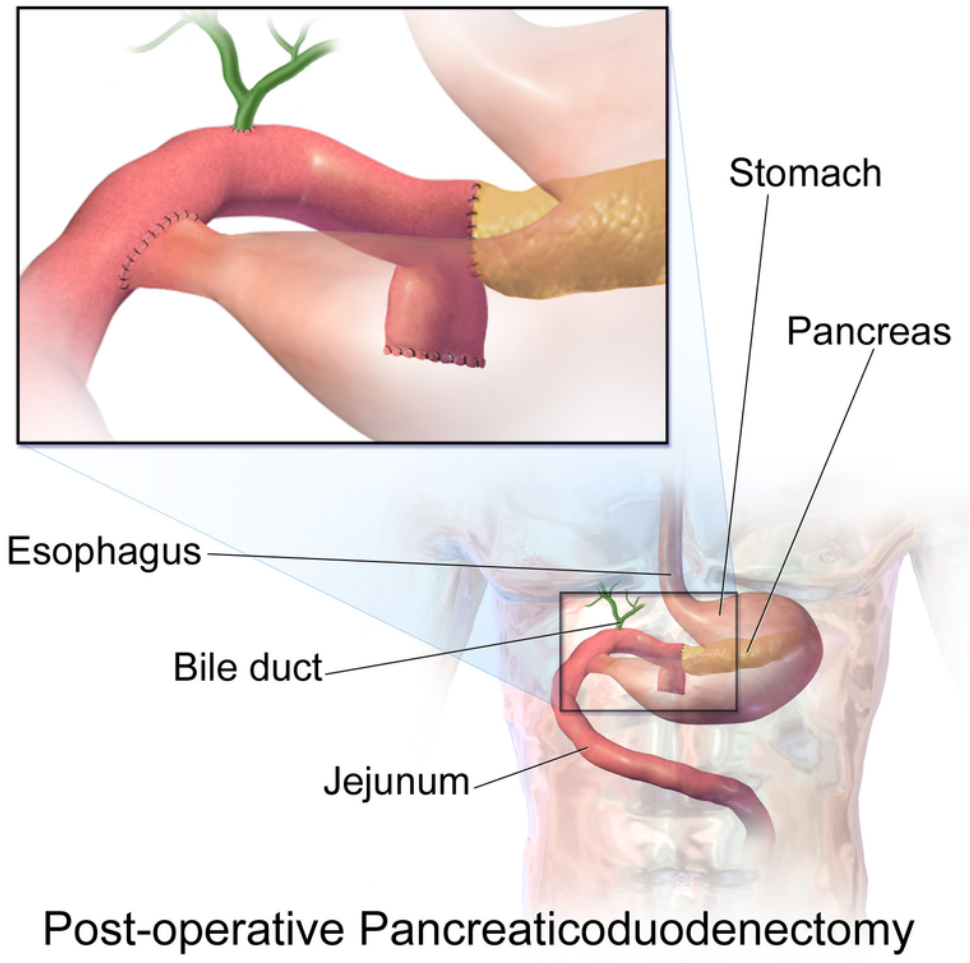
Scene 1.

PERFORMER 3 (VOICE OF MEDICINE)

Case. A 47-year-old female presenting with a non-functional neuroendocrine tumor on the head of the pancreas. Diameter 1.7 centimeters. Incidental finding following abdominal ultrasound to monitor a benign hepatic hemangioma. Diagnosis of neuroendocrine tumor confirmed with endoscopic biopsy. Cell cytology is "bland." Patient is asymptomatic. How do you advise the patient?

PERFORMER 3 walks upstage to retrieve the remaining lab coat, ready to play PANCREATIC SURGEON 2. PERFORMER 1 walks downstage left and addresses PATIENT.

The projection screen at the back of the stage displays a diagram of the Whipple surgery.



PERFORMER 1 (PANCREATIC SURGEON 1)

[*Addressing the PATIENT, who still stands downstage center*] The tumor falls into a "grey area" of clinical determination. If it were one centimeter in size I would say, "Forget about it for now. See me in a year." If it were two centimeters, I would advise surgery— "Get it out of there."

[*Gesturing instructively to the PATIENT*] Consider the position of the tumor: the head of the pancreas. It's tucked in there behind several organs and quite close to major arteries. There's no way to know in advance how many organs may be involved. The patient will have to consent to a full Whipple procedure—removal of the head of the pancreas, duodenum, gallbladder, and part of the small intestine—even though that may not be necessary. The Whipple is a big surgery; a "magnum opus" or Mount Everest, if you will.

[*Smugly*] I've done over 700 of them myself. It's what I do. The bottom line is, the patient needs to be prepared.

PERFORMER 3 (PANCREATIC SURGEON 2)

[*Addresses PATIENT from downstage right, causing her to turn*] After reviewing the case, I concur with the initial diagnosis of a neuroendocrine tumor. The pathology slides show that the tumor cells are not dividing, or not quickly enough to detect. The tumor is benign and non-functioning—not causing any symptoms.

[*Leaning and projecting her voice over to PANCREATIC SURGEON* 1] I can understand the patient's reluctance to undergo major abdominal surgery; there are risks, of course.

[*Slight pause for dramatic effect*] But there are also risks to waiting. So, my question is… what are we waiting for? [*Now incredulous and increasingly emphatic*] For the tumor to grow? To become symptomatic? Why not just get it out of there? I would advise for surgery.

PERFORMER 2 (PATIENT)

[*Still center stage, addresses both PANCREATIC SURGEONS in turn.*] May I tell you something? Please? I have a young child. She needs me. My husband, he needs me. I want every possible moment…..

A short beat, then both PERFORMERS 1 and 3 speak together.

PERFORMER 1

Then I would definitely wait.

PERFORMER 3

Then I would definitely opt for the surgery.

PERFORMERS 1 and 3 remove lab coats as PERFORMER 2 speaks. They move two chairs to center stage immediately behind PERFORMER 2 and place them facing each other, restaurant-style. PERFORMER 3 sits in one chair. PERFORMER 1 returns upstage to watch the exchange. Projection screen goes dark.

PERFORMER 2 (PATIENT)

[*Speaking from downstage center*] So… I went to lunch with a friend. Her husband died of pancreatic cancer four years ago and, although I know I don't have cancer, she knows these doctors. Here's what she pointed out, and it made all the difference:

Turns and joins PERFORMER 3, sitting in the vacant chair.

PERFORMER 3 (FRIEND)

Of course she's recommending surgery. Every day she diagnoses patients like my husband in Stage 3 or 4. There's really not much she can do for them. Then you come along and you *don't* have cancer and she can just take out that tumor. She's probably thinking, "Here's someone I can help. Here's someone who will live."

PERFORMER 2 listens intently, gently nodding.

Now, your other doctor does these surgeries all day, every day. He's older. He's probably seen some bad outcomes—people who didn't make it out of the operating room. He's thinking, "Why take the risk? Why go there before it's absolutely necessary?"

PERFORMER 2 (PATIENT)

Stands and walks back to downstage center. PERFORMERS 1 and 3 return chairs to their upstage position during the following speech.

In other words, these doctors' biographies play an integral role in their clinical reasoning. Their stories inform their thinking… of course! When I told my first doctor that I wanted to wait, I shared this insight about biographical reasoning with him. He shrugged it off. He was happy that I followed his advice, but he didn't want to talk about why the two stories were so different.

Interlude 1

PERFORMERS 1 and 3 join PERFORMER 2 downstage. The following lines are delivered seamlessly—as if with one continuous voice.

PERFORMER 1

Each of us –

PERFORMER 3

Communication PhDs

PERFORMER 2

– worked as medical educators…

PERFORMER 3

…for a large hospital system.

PERFORMER 3

While there, we became familiar…

PERFORMER 1

(intimately familiar)

PERFORMER 2

…with a Family Medicine Residency and their desire to change how physicians were trained.

PERFORMER 1

It was called the P4 initiative, and was described by Carney and colleagues in 2018.

PERFORMER 3

P4. It stands for "Preparing the Personal Physician for Practice."

PERFORMER 2

Preparing the Personal Physician for Practice was a national project to improve family medicine training in the United States.

PERFORMER 1

Fourteen residency programs participated in the project.

PERFORMER 3

We were medical educators employed by one of the fourteen P4 programs.

PERFORMER 2

They wanted us…

PERFORMER 3

…to help with non-clinical elements of physician training.

ALL

Like teamwork.

PERFORMER 1

Curriculum and assessment.

PERFORMER 2

And relational communication in clinical settings.

PERFORMER 3

[*With genuine enthusiasm*] It sounded fantastic.

All three PERFORMERS move upstage. PERFORMER 2 puts on lab coat to play the GASTROENTEROLOGIST. PERFORMERS 2 and 3 move two chairs

downstage right and sit, positioned with both chairs facing but turned slightly toward the audience; the setting is a clinician's office. PERFORMER 3 plays the PATIENT. PERFORMER 1 walks downstage left to begin the scene as the VOICE OF MEDICINE.

Scene 2

PERFORMER 1 (VOICE OF MEDICINE)

Case. A 42-year-old female with undifferentiated Inflammatory Bowel Disease. A colonoscopy in 2002 revealed ulcerative colitis. Patient placed on 750 milligrams of Colozal 3 times a day for 15 years. Patient's 2017 colonoscopy revealed inflammation near the ileum. Upper GI test recommended to identify possible stricture.

PERFORMER 2 (GASTROENTEROLOGIST)

So what brings you in today?

PERFORMER 3 (PATIENT)

I'm here for a follow-up.

PERFORMER 2 (GASTROENTEROLOGIST)

I see that you're no longer taking your Colozal

PERFORMER 3 (PATIENT)

That's correct. I'm concerned by my elevated creatinine levels...

PERFORMER 1 (VOICE OF MEDICINE)

[*Translates for the audience*] …which can signify impaired kidney function or increase the risk of kidney disease

PERFORMER 3 (PATIENT)

...and hematuria.

PERFORMER 1 (VOICE OF MEDICINE)

Blood in the urine.

PERFORMER 3 (PATIENT)

I replaced my meds with four tablespoons of distilled Aloe Vera every day, and that seems to be helping.

PERFORMER 2 (GASTROENTEROLOGIST)

I agree with getting off the Colozal. I'd like to put you on a biologic instead, such as Imuran.

PERFORMER 1 (VOICE OF MEDICINE)

Biologics are used to treat many different types of autoimmune diseases, like Rheumatoid Arthritis, as well as to prevent transplant rejection.

PERFORMER 3 (PATIENT)

I was on Imuran in the past and stopped taking it.

PERFORMER 2 (GASTROENTEROLOGIST)

[*Obviously perturbed*] Why?

PERFORMER 3 (PATIENT)

[*Patiently but* pointedly] I have a lot of cancer in my family, and I'm aware of the link between biologics and tumors. I'm not interested in going on a biologic again.

PERFORMER 2 (GASTROENTEROLOGIST)

Well, I'd like to suggest you get an upper GI so we can check out the inflammation in your ileum and see if it's a stricture. If it is, you'll need to start a biologic.

PERFORMER 3 (PATIENT)

[*Looks to the audience with an expression of confusion and dismay*] For years I didn't understand why my gastroenterologists pushed for tests and medications I explicitly rejected. It felt like we were talking a different language. And, in fact, we were. I was speaking from my Voice of Life World experiences from having witnessed my twin sister live with thyroid cancer and numerous family members diagnosed with other types of cancer. Here's the thing… I deeply dread and fear biologics because they suppress the immune system: good for ulcerative colitis, bad for fighting off *any* disease, including cancer. My gastroenterologist's advice

was spoken from *her* Voice of Medicine, based on what *she* clinically knew and saw as a physician. Mishler's (1984) Voice of Medicine (rather than the Voice of Lifeworld) reflects a technical, logical interest and controlled compassion. From her perspective, there may be an increased risk of tumors from biologics but they *control* active UC and can prevent other complications that are clinically "as bad as" cancer. My request *not* to start a biologic probably seemed… well… *illogical* to my Gastro. A request that she assumed came not from a voice of reason but from a place of fear.

PATIENT turns back to listen to the GASTROENTEROLOGIST.

PERFORMER 2 (GASTROENTEROLOGIST)

I had a patient who wasn't doing any better on Imuran when I eventually suggested turmeric. She takes it three times a day and that did the trick.

PERFORMER 3 (PATIENT)

[*Addresses the audience again*] No way! Did she just suggest TURMERIC?

The projection screen displays a photograph of a turmeric root and dried turmeric powder as the VOICE OF MEDICINE interjects.

PERFORMER 1 (VOICE OF MEDICINE)

[*Enthusiastically*] Turmeric! A bright yellow *plant* used for cooking, primarily in Indian dishes, albeit with scientifically-proven anti-inflammatory and antioxidant health benefits (Brown, N.D.).

PERFORMER 3 (PATIENT)

[*Continues to address the audience*] She's validating my desire to try something other than biologics, like aloe vera, sharing a story of another patient's experience AND supporting my non-traditional approach. *This* communication scholar is speechless ... for the moment.

[*Turns back to GASTROENTEROLOGIST*] OK. I'll give that a try. And perhaps we can talk more about the upper GI test. I'm not against it, but I'm concerned about the radiation and what the results mean for future treatment.

[*To the audience*] A patient-clinician relationship is born.

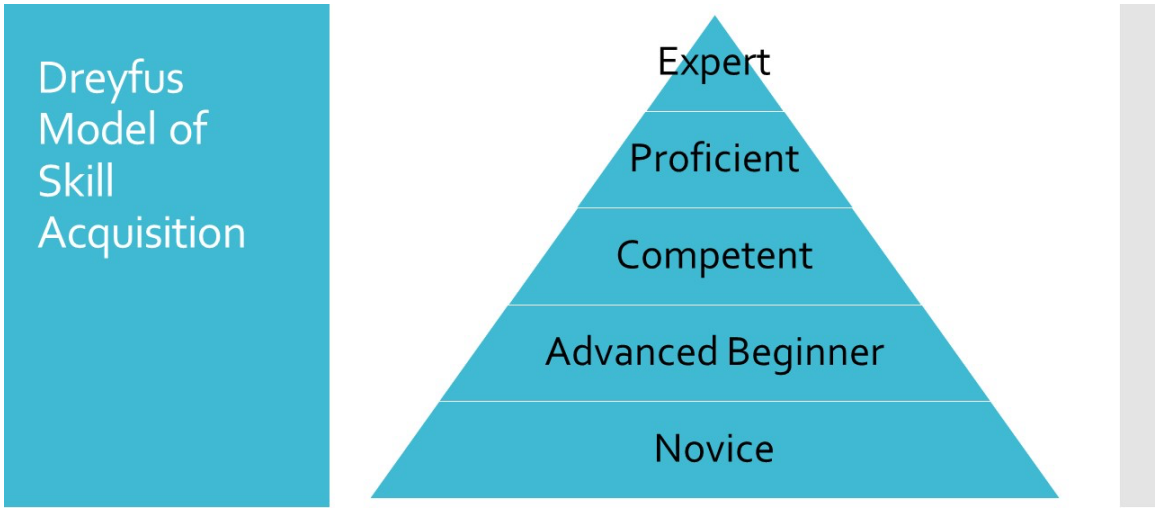
Interlude 2

The projection screen goes dark. PERFORMERS 2 and 3 reset chairs upstage. PERFORMER 2 removes lab coat and places it on the back of a chair. All three PERFORMERS walk downstage to deliver the following lines to the audience.

PERFORMER 1

We were teaching future doctors how to be change agents in their clinical care. Using the Dreyfus Model of Skill Acquisition, we based the curriculum on a vision of what we hoped the future of medicine might look like. The anchor to this residency were its core learning objectives:

The projection screen displays a visual representation of the Dreyfus Model with learning objectives.



PERFORMER 2

At the Novice Level, "the learner participates in self-reflection exercises to enhance comprehension of the professional care provider's emotional life."

PERFORMER 3

At the Advanced Beginner Level, "the learner recognizes biases and works to overcome them and practices from a model of shared decision-making."

PERFORMER 1

Learners at the Competent Level, "Incorporate context, family systems, and culture into clinical interaction and treatment options."

PERFORMER 2

When the learner reaches the Proficient Level, she "integrates the patient's story into long-term care and teaches relationship-centered care to others."

PERFORMER 1

It's one thing to know the definitions; it's another thing to recognize these levels of proficiency in action…

The projection screen goes dark. PERFORMER 3 retrieves and puts on one of the lab coats to play NURSE. PERFORMER 1 walks offstage to sit in the audience, preparing to play the PATIENT. PERFORMER 2 places one of the chairs downstage right for use during the clinical scene and moves downstage left to begin the scene as VOICE OF MEDICINE.

Scene 3

PERFORMER 2 (VOICE OF MEDICINE)

Case. Patient is a 55-year-old male with Stage 4 Non-Hodgkin's lymphoma, large cell B variety. Patient has completed three of six cycles of R-EPOCH chemotherapy. CT & PT scan following third cycle reveals lymphoma is all but resolved. Completion of all six cycles is the protocol.

PERFORMER 3 (NURSE)

Hi! How are you?

PERFORMER 1 (PATIENT)

[*PATIENT delivers lines to audience as he moves to sit in chair at stage right*] My oncology nurse retrieves me from a small waiting area and we enter a clinical exam room where she notes my weight and takes my temperature, and blood pressure. Then she asks me a series of questions about nausea, appetite, and sleep patterns.

PERFORMER 2 (VOICE OF MEDICINE)

The nurse enters this data into the patient's EMR. The Electronic Medical Record.

PERFORMER 1 (PATIENT)

PATIENT continues to address the audience. NURSE stands to one side and puts on surgical mask.

My nurse knows my history.

PERFORMER 2 (VOICE OF MEDICINE)

Today is a Thursday during a recovery week, so the patient has no chemo bag attached to his implanted port. Instead, the oncology nurse dons a mask and surgical gloves …

PERFORMER 3 (NURSE)

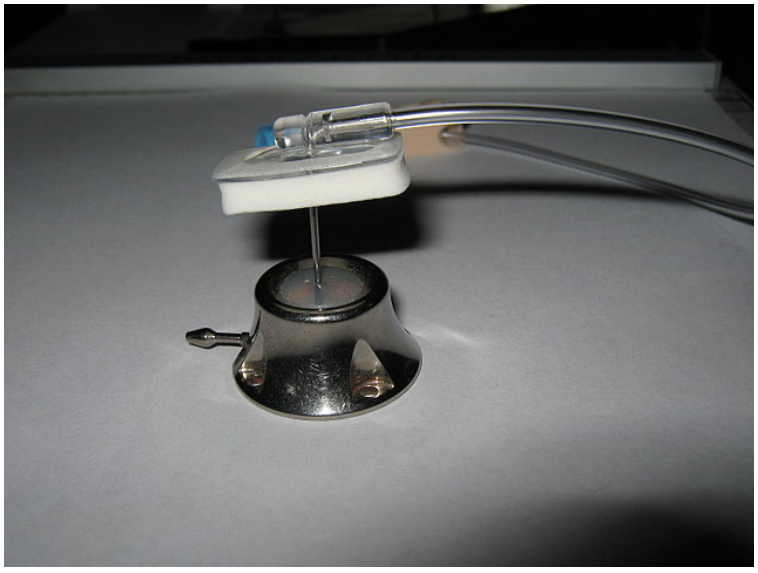
Can you pull your shirt up over your clavicle?

PATIENT complies with NURSE'S instructions and speaks to the audience.

PERFORMER 1

She swabs my port with an alcohol pad. She will be drawing several vials of blood so my oncologist can assess my Complete Blood Count. Now she wields the Huber needle.

The projection screen shows a close-up image of the Huber needle.



PERFORMER 3 (NURSE)

[*Addresses the audience*] The Huber needle has a long, vicious-looking, beveled tip that must go through his skin as well as into the septum of his port. I know that stabbing that needle through his skin and into the port is really uncomfortable for him.

PERFORMER 2 (VOICE OF MEDICINE)

Some of the nurses give a countdown: 3, 2, 1 … This nurse always asks,

PERFORMER 3 (NURSE)

[*Addressing the PATIENT, gently but firmly*] "Are you ready?"

PATIENT nods as NURSE leans in.

PERFORMER 2 (VOICE OF MEDICINE)

And then plunges the needle in. Then, she always says…

PERFORMER 3 (NURSE)

"Sorry."

PERFORMER 1 (PATIENT)

[*To the audience*] She says this whether or not I nonverbally indicate that I've felt this … penetration.

PERFORMER 2 (VOICE OF MEDICINE)

PATIENT speaks to NURSE sotto voce over the following.

Her face is inches away from his face and he chatters away while she concentrates on filling the vials.

PERFORMER 1 (PATIENT)

[*To the audience*] Lately, my oncology nurse keeps me abreast of her wedding plans that are a year away. There is a rhythm to these visits. Along with several other of my "regular" nurses, I mine her for information about oncology, nursing, and perception-check about my many side effects.

NURSE stands upright and backs away as PATIENT lowers shirt. Projection screen goes dark.

And then I read her body language. Her work with me today is done and—as a very busy nurse—she's got to move on to her next responsibility.

NURSE moves toward center stage.

PERFORMER 2 (VOICE OF MEDICINE)

Halfway out the door, the nurse turns, smiles, and tells him…

PERFORMER 3 (NURSE)

You're "doing great."

PERFORMER 1 (PATIENT)

At the Cancer Center, I revel in being an exceptional patient. One who is considered interesting, funny…

PERFORMER 3 (NURSE)

"You're so funny."

PERFORMER 1 (PATIENT)

…and likely to survive.

PERFORMER 3 (NURSE)

[*To the audience*] Oncology nurses need survivors. Do you think we could do this day in and day out if it wasn't for patients like him?

Finale

NURSE takes off lab coat and carries it into the audience and sits, to briefly play the AUDIENCE MEMBER.

PERFORMER 2

Remains standing at stage right, but drops the VOICE OF MEDICINE persona.

While employed as a medical educator at the hospital system, I worked with a group of physicians to write and present their narratives at a conference. Theirs

were not easy stories to tell, and, as one audience member expressed it, the stories were also not easy to hear. As the audience member put it…

PERFORMER 3 (AUDIENCE MEMBER)

We want our doctors to be more human and connect with us, but I don't know that we're all ready to witness and accept their truths.

PERFORMER 1

[*Rises from chair at stage left and moving to center stage*] But we all need to survive…clinicians and patients alike.

PERFORMER 3

[*Rises from audience and joins others center stage*] The practice of medicine is about survival.

PERFORMER 2

The culture of medicine is about survival.

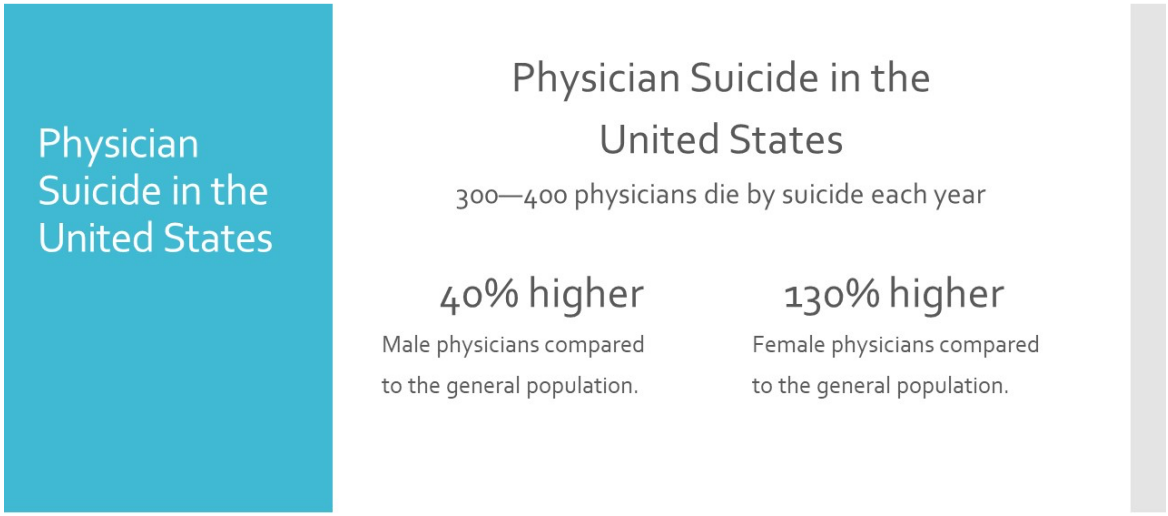
PERFORMER 1

Sometimes keeping patients alive at *any* cost.

PERFORMER 2

Doctors trying to survive.

The projection screen displays statistics about physician suicide.



One-fifth of residents experience a major depressive episode during training. The suicide rate among male physicians is 40% higher than the general population and 130% higher than the general population for female physicians (Eckleberry-Hunt & Lick, 2015).

PERFORMER 1

We're all trying to make it, to treat, to cure, to care. But the caring sometimes gets lost. We forget we're human. We forget to connect.

PERFORMER 3

Reflecting through narrative, we support healthful, heartful, and hopeful relationships between practitioners and patients….

PERFORMER 2

...and practitioners who are patients.

The projection screen goes dark.

PERFORMER 1

So we taught future doctors about the importance of understanding the whole person.

PERFORMER 2

Exploring each other's experiences.

ALL

Our humanness.

PERFORMER 3

The space between.

PERFORMER 1

We share our stories, individually and collectively.

PERFORMER 3

In the doctor's office…

PERFORMER 2

In our classrooms…

ALL

Anywhere and anytime the spirit moves us.

PERFORMER 3

Narrative offers a way for patients and practitioners to derive meaning from their experiences, to connect with others, and to realize the potential for healing and care that transcends treatment and cure.

PERFORMER 2

We teach narrative to encourage physicians to share their stories and reflect on their practice of medicine.

PERFORMER 1

We write our own stories to critique the culture of medicine and raise awareness about the organization of medicine.

PERFORMER 3

We share our personal experiences to make a difference in the world of healthcare...one story at a time.

End

Endnote

1. The first performance was for a panel titled "Vulnerability, Healing, and Hope: The Existential Calling of Autoethnography," presented at the inaugural meeting of the International Association of Autoethnography and Narrative Inquiry in St. Petersburg, Florida, January 2019 by Jay Baglia, Nicole Defenbaugh, and Elissa Foster. The second presentation was at the International Conference on Communication in Healthcare in San Diego, October 2019; Jay Baglia, Nicole Defenbaugh, and Krista Hirschmann performed.

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Image Data

Slide 1: Whipple Surgery

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Slide 2: Turmeric

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Slide 3: Dreyfus Model
Author provided image

Slide 4: Huber Needle

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Slide 5: Physician Suicide in the United States
Author provided image