Exploring Human Stories of Illness:
Health Humanities Portrait Project
PI: Sandy Sufian, PhD, MPH
University of Illinois-Chicago
College of Medicine

Rural Populations: Using Performance Studies to Understand Treatment and Access to Care

Teaching Guide

Creator:
Gretchen Case, PhD
gretchen.case@hsc.utah.edu

Reading List

First Person Narrative:

"IP." Interviewed by "JL," MD. 2013. Unpublished interview transcript [see Interview Transcript as separate document with HHP materials].

Scholarly Readings:

N. Douthit and S. Kiv et al. 2015. "Exposing some important barriers to healthcare access in the rural USA." *Public Health.* 129: 611-20. Exposing some important barriers to health care access in the rural USA.

Gretchen A. Case. 2014. "Performance and the Hidden Curriculum in Medicine." *Performance Research.* 19 (4): 6-13. Performance and the Hidden Curriculum in Medicine: Performance Research: Vol 19, No 4.

Summary: This Health Humanities Portrait includes the transcript of a spoken narrative, performed by two natives and current residents of a rural, remote county in western North Carolina. Although you are reading a transcript, the orality of the story remains important as we talk through the events described here. In telling the story, IP is performing it. She is also describing multiple performances of medical care in an emergency room, where she is alternately participant and observer. The story IP tells addresses the multiple, complex, and often conflicting identities that come with the roles that one takes on in a small community. IP also draws our attention to the way privacy and confidentiality is perceived and performed in a tightly constructed social environment. Finally, the story IP tells allows us to think about the ways in which rural and remote health care is circumscribed by geography and distance.

Session Plan

Discussing Health Humanities Portrait- 75 minutes

- Introduce performance studies as a critical lens and rural health care as an important topic. (10 min.)
- Play selected portions of the audio of this interview and discuss the important differences between listening to a story and reading it. (15 min.)
- Discuss sub-themes in text, referring to scholarly readings for context. (40 min. total)
    - Discuss first three groups of questions, which are intended to establish understanding of the sub-themes. (8-10 min. each)
    - Discuss the fourth group of questions, which require reflecting back on the sub-themes to look at larger structural issues through a lens of performance. (10-16 min.)
    - Concluding thoughts

Objectives

After this session, learners will be able to:

- Recognize the delivery and seeking of health care as kinds of performance.
- Analyze spoken narratives, and written records of such, using language and concepts related to performance.
- Identify challenges and differences related to privacy and geographical access in the delivery of health care in a rural or remote setting.

Background:
The patient story is a transcript of an interview conducted by the patient's primary care provider and friend. In it, she tells a story that lays bare the impossibility of anonymity in a rural, small hospital emergency room, a place where people come in distress. This interview was conducted as part of a decade-long research project conducted by the interviewer and me, focusing on the ways in which privacy is imagined and enacted in a small, tightly knit community. While our research project generally focuses on health care providers in a rural setting, and we had previously sought out interviews, this speaker came to us with her story because she knew of our work. She particularly wanted to share it with her physician friend, who had previously worked at this same ER and subsequently became a high-ranking administrator at this hospital before shifting to outpatient clinical work.

The story told in this interview is particularly revealing to me, as a scholar of performance. The speaker is eloquent in her description of the ways in which she is surrounded by everyday performances and uses theatrical references to describe what she observes without misunderstanding any of it as fakery or artifice. Her clarity on her viewpoint as both audience member and sometime participant, and on the shifts in her role as she observes and is observed, makes it particularly easy to talk about a night in the ER as a performance.

The Douthit, Kiv et al. article offers an overview of the particular challenges facing rural patients and their health providers. Both geographic access and privacy considerations are described as potential barriers to care. This article was published just as the Patient Protection and Affordable Care act was coming into being, and interestingly, comes from authors who list institutional affiliations in Israel, a country with an established interest in population health and accessible health care.

The Case (2014) article offers an introduction to the idea of everyday performance and of performance studies as a discipline and critical lens on medicine. Examples are given of the ways that patients perform, or are compelled to perform, in clinical encounters. Expectations about behavior in a medical setting affect the performances of both provider and patient (as well as others); these expectations are always contingent, depending on individual performers and environmental cues.

HHP Social Issues, Discussion Questions/Activity:

Intersecting, complex identities under scrutiny.

What do you assume about the speaker's race and/or ethnicity? What evidence do you have from the text to support this?

What do you assume about the speaker's class status, which might include financial or other resources, education level, family of origin, or other markers? Again, based on what evidence in the text?

How does language play a role in the scene that the speaker describes?

If attendees (or medical students if using this for final portrait) do not raise the issue on their own, encourage them to think about how often White/Caucasian is the default for when the speaker cannot be seen, as so much of how race and ethnicity is defined is through visual perceptions. You might also prompt them to think about what other elements suggest a particular race/ethnicity, even when the speaker can be seen. In her own words, this speaker identifies as such:

I can give a few short answers:

A. Census Style: Bi-racial/Multi-racial
B. Ethnic Style: African-American and Scottish/English-American
C. Assumption Style: Other, who Appears White (especially to White folks)

Or a longer answer:

From my vantage point, race is a social construction, defined first through the assumptions of the viewer, and highly contextual.

This seems especially true in a medical context. I am usually treated as though I am a White woman coming from an educated class. (I mention this because class issues usually intersect racial ones.) The one exception was when I saw a Latina doctor, who made completely different assumptions. I have found that doctors of all types make assumptions they should have been trained to avoid, and that they rarely have the experience and confidence to ask direct questions. For example: "Where does your name come from?" is usually code for "Please describe your ethnic background." I prefer to be given the chance to self-articulate.

From the language the speaker uses in this explanation and throughout the interview, you might not be surprised to learn that she is a university professor with an advanced formal education. She grew up in the area where this story takes place and still lives there.

The speaker makes a conscious decision to identify several other patients and visitors as Latina/o, which is a preferred term by many people who identify with that ethnicity. Her emphasis is less on their ethnicity than on their language, which is adding to the stressful and chaotic atmosphere in the ER, since no Spanish language interpreter is available and distressed visitors (and someone who might be a patient) are moving between rooms trying to share information as best as possible in an English-speaking environment. Like many rural communities, census data shows significant increases in Latino/Hispanic population percentages in recent years; in Buncombe County there was an almost 150% increase between 2000 and 2010. The speaker does not discuss local attitudes toward that demographic shift in this story, but such a change would not go unnoticed.

Privacy in a small community.

At what points in the text is the speaker's privacy compromised?
At what points in the text is the speaker part of compromising someone else's privacy?

Which health care providers occupy more than one role in this speaker's life?

How do you think HIPAA or other privacy safeguards operate in this setting?

The speaker's privacy is perhaps most obviously compromised by the open curtain in the ER. Everyone she can see can also see her. She also encounters at least two people (the X-ray technician, the person cleaning floors) who know her by name and in other capacities. Even if they abide by HIPAA and do not share private medical information with anyone else, they know that information. Aside from her possible heart conditions is the fact that she might be pregnant, and at a very early stage of pregnancy when many people do not share that news widely.

To a lesser degree, the volunteer firefighters that she recognizes—and at least one nods in recognition of her—know some medical information based on what they can observe: that she is in the ER, hooked up to a heart monitor. She may also have been observed by other staff members, patients, or visitors who know her. Note also that she starts and ends the story by identifying the interviewer as both her doctor and her friend; in turn, the interviewer indicates that she is familiar with the people and the hospital discussed in the story. In a rural area or a small community, people often know each other in more than one role, and interactions become complex and difficult to separate.

The story the speaker tells here is far more concerned with the privacy of others, however. She notes the multiple victims of the car wreck, who she is able to see as she passes by their beds. Their privacy is further and continuously compromised by the need for bilingual speakers to move between patients to share information. The curtains and doors meant to offer privacy are opened frequently. Most notable is the dying patient who has been brought in. While she is unable to see the patient other than his gray foot as his gurney rolls by, she watches the watchers, and by their actions and reactions, witnesses his death. She also witnesses their grief, and the complicated grief of the woman's relative (and possible staff member?), which is the point at which she feels most intrusive.

Geographic access to care.

What evidence in the text tells you something about the choices that the speaker has for health care?

What evidence in the text suggests that this is a rural or remote area?

All rural and remote areas are not the same, even if they share similar challenges regarding health care. What evidence in the text suggests specific challenges in this rural area?

We know from the text that the speaker's doctor is also a friend, but we do not know if that choice was made solely because she wanted to be treated by a friend or if limited

choice of providers was also a factor. Certainly some people in higher-population areas choose to be treated by health care providers who know them in other capacities. This discussion is an interesting one to have with health sciences students: where are your boundaries between your professional and personal roles? What are the pros and cons of being treated by someone who knows you outside of the clinical encounter? Of treating a friend, neighbor, or acquaintance?

The speaker describes the ER as busy, but also offers clues that it is quite small, which suggests a small hospital. She is able to see almost all the other patients as she goes by in the wheelchair upon admissions. The nurse wheeling her past the ambulance bay stops to open the door for a police officer and has what seems to be a casual conversation. From her bed in the ER, she can easily see the central station that holds the "ambulance phone" and is where the doctor and nurses go to read charts. She also notes that she can hear everything and see into all the other rooms. Given the speaker's pregnancy, students might be interested to know that this is the only hospital serving a two-county region, and in 2017, it discontinued all obstetric services.

Staffing levels are clearly at issue: Once it becomes clear that the ambulance is bringing a serious emergency, a second doctor is called in. No Spanish language interpreter appears to be readily available during the hours the speaker is in the ER. Only one uniformed provider arrives on the ambulance, and the rest are volunteer firefighters, which suggests a rural area that cannot support professional firefighters and maintains only minimal ambulance service. The speaker also names a different town (Bakersville) from which the dying patient has been brought to Spruce Pine.

Health care as a site-specific performance.
What specific words or expression does the speaker use to tell us about her experience as an observer in the ER?

This speaker describes the scene as if she were at a theater: "it felt like a stage, except that it was not fake." She further describes herself as an accidental audience member, an observer trying to be unobtrusive: "I'm wallpaper."

Thinking back to the questions about identities, how do others in the ER regard the speaker?

She seems to hold favorable medical and social status in this ER. Medically speaking, she is stable and unlikely to need urgent attention. Socially, she is seen as neutral, at the very least, and perhaps even privileged. Staff inquires about her needs and then asks if she would like the curtain open or closed: she is allowed to decide to keep looking. At least some of the staff know her, and she is likely known by others. She jokes about her doctor being a "bigwig" and getting her preferential treatment, but being the patient a doctor who formerly worked in this ER, and continues to serve the community prominently, truly might confer additional benefits.

In reviewing her telling of this story later, the speaker emphasized that her appearance—her ability to pass as White—felt particularly relevant to how she was regarded during this visit to the ER.

Thinking back to the questions about privacy, what aspects of what the speaker is watching relate to attempts to respect privacy or confidentiality? Or lack of such attempts?

It might be worth discussing the privacy of providers. The doctor, in particular, is given no time or space for grief. He is under observation by the speaker as much as anyone else is, and she participates in what she knows to be a performance for her benefit. She knows he has walked out of the room of a patient who died just moments before and that he speaks to her with calm composure. She also knows that he has not spoken with her doctor, but allows this fib to stand.

Thinking back to geographic access to care, what parts of this story might have played out differently in an urban or suburban area?

- *A larger ER would have not likely have offered the view of so many patient areas; certainly not a view of most of the patients and visitors. More staff would have meant that one doctor was not moving among all the rooms. In a more densely populated place with more options for emergency care, it would be far less likely that our speaker encountered so many people who knew her and were known to her.*

Wrap-up Comments:

- Health care in a rural, remote, small community challenges ideas of privacy that prevail in more densely populated areas.
- Access to health care in rural communities is often limited by options and geographical distance.
- Identities are closely monitored in a rural community, and, at the same time, are complicated by the multiple social roles performed by any one person.
- Performance studies allows us to look at human activity and behavior as performance. To perform does not mean to fake anything; the root meaning of the word perform is "to make something happen." Providing health care is a particular kind of performance that is always affected by the given circumstances.

Student Activity:

- Materials needed:
    - paper/pens/pencils or other sketching media
    - document camera/overhead projector

- Ask each learner to draw the emergency room described by IP in her narrative. Ask for volunteers to draw different perspectives: overhead, from IP's view, from the nurses' station, etc.
- Share some or all of the drawings on the overhead camera and look for what's been included in every rendering, what's been left out, ask individual learners how taking a perspective affected what they included.
- Ask learners to place themselves in the space they've drawn. What is their role? Where do they think they are allowed, and expected, to be?
- Ask learners what happens if they imagine this as a stage for a play, or a set for a movie. How does it change their feelings about their inclusion in this space if they think of it as a *performance space*?
    - Ask them to suspend judgment for the purposes of the ensuing discussion, and let this idea of a performance space help them frame IP's description of the "show" she saw in the ER that night.

-Does faculty have any others to suggest?

Take-Away Points (always worth saying out loud, at conclusion of session):

- Health care in a rural, remote, small community challenges ideas of privacy that prevail in more densely populated areas.
- Access to health care in rural communities is often limited by options and geographical distance.
- Identities are closely monitored in a rural community, and, at the same time, are complicated by the multiple social roles performed by any one person.
- Performance studies allows us to look at human activity and behavior as performance. To perform does not mean to fake anything; the root meaning of the word perform is "to make something happen." Providing health care is a particular kind of performance that is always affected by the given circumstances.

Recommended Readings

Case G and Brauner D. (2010). Perspective: the doctor as performer: a proposal for change based on a performance studies paradigm. *Academic Medicine* 85(1): 159–163. https://doi.org/10.1097/ACM.0b013e3181c427eb

Conquergood D. (2002). Performance Studies: Interventions and Radical Research. *The Drama Review* 46 (2): 145-156. https://doi.org/10.1162/105420402320980550.

Frisch M. (2003). Sharing Authority: Oral History and the Collaborative Process. *The Oral History Review* 30(1), 111–. https://doi.org/10.1525/ohr.2003.30.1.111.

Gish S. (2014). "Me 'n' Suzie." In *Country Doctor: The Story of Claire Louise Caudill*. Louisville: UP of Kentucky.

Pollock D. (1990). Telling the Told: Performing "Like a Family." *The Oral History Review* 18(2), 1–36. https://doi.org/10.1093/ohr/18.2.1

Pollock D. (2015). Performance Trouble in *The SAGE Handbook*, ed J Hamera and DS Madison. Thousand Oaks: SAGE Publishing. https://doi.org/10.1162/dram.2007.51.1.186.

Shapiro J, and Longnecker R (2005). Country Doctors in Literature: Helping Medical Students Understand What Rural Practice is All About. *Academic Medicine* 724-27. https://doi.org/10.1097/00001888-200508000-00003.

Shopes L. (2002). Oral History and the Study of Communities: Problems, Paradoxes, and Possibilities. *The Journal of American History* (Bloomington, Ind.), 89(2), 588–598. https://doi.org/10.2307/3092177

Thaddeus S and Maine D. (1994). Too far to walk: Maternal mortality in context. *Social Science & Medicine* (1982), 38(8), 1091–1110. https://doi.org/10.1016/0277-9536(94)90226-7.

Additional Questions for Discussion: (Case includes some more questions than Section 1 here)

Intersecting, complex identities under scrutiny.

- Do you understand the reaction of the opera-loving student in the Case article, who felt that naming elements of performance (i.e., white coats as costumes) was inappropriate for a medical setting?
    - Why does discussing human behavior as performance seem to imply fakery or insincerity for this student?

    - What benefits can you see to discussing human behavior in a medical setting as performance?
- The Case article discusses the "hidden curriculum," in which information is transmitted to learners without explicit acknowledgement, and perhaps without the teacher realizing what they are teaching.
    - What kind of audience is necessary for a hidden curriculum? Do the performers and the audience need to be aware of what is being taught for it to be learned? Does thinking of this teaching as a performance make you uncomfortable?
    - Usually, the hidden curriculum is written about with medical students and trainees in mind as the learners/audience. What if we consider patients and their family members or loved ones to be the audience? What might they learn? Can you think of an example from your own experience?
- From the narrative, From the narrative, what do you assume about the speaker's race and/or ethnicity? What evidence do you have from the text to support these assumptions?
    - What do you assume about the speaker's class status, which might include financial or other resources, education level, family of origin, or other markers? Again, based on what evidence in the patient narrative?
    - How does language play a role in the scene that IP describes? How does it play a role in your determining her identity, and thus who she is in this performance?
    - How do others in the ER regard IP?
- How do the identities of the various people present in this ER work together, or at odds, with each other? How might those interactions affect access to health care?

Privacy in a small community.

- The Douthit et al. article tells us that patients in rural areas worry about stigma when seeking health care. Cultural perceptions of particular health conditions may prevent someone from seeking care if they think that care will not be private and/or confidential.
    - What is the difference between privacy and confidentiality?
    - What sorts of conditions tend to incur stigma? Are these perceptions different in a rural/tightly knight community?
    - Does the perceived anonymity of an urban/large community change the effect of stigma when seeking access to health care?
- Looking at the narrative again, when and where is privacy compromised?
    - At what narrative points in the text is the speaker's privacy compromised?
    - At what narrative points in the text is the speaker part of compromising someone else's privacy?
- Looking at your drawing again, at what physical points in your drawing of the ER do privacy breaches occur?

- What are the narrative and physical points at which access to *private and/or confidential* care are compromised?
    - Which health care providers occupy more than one role in this speaker's life?
    - How do you think HIPAA or other privacy safeguards operate in this setting?
    - What might stand in the way of correcting these breaches?
- What aspects of what IP describes in her narrative relate to attempts to respect privacy or confidentiality? Or lack of such attempts?

Geographic access to care.

- Go back to your drawing and take a few minutes to extend it outside the ER/hospital to the surrounding area, perhaps going 20 miles out. This new area does not have to be in proportion to your original drawing, and may be more useful if it has only a few important features rather than attempting to be a realistic map.
    - Instructor: Show an example.
    - As possible, please compare to others in the group, as above with original drawing.
- Can you separate the influences of the portrait readings from your own preconceptions about areas like the one described?
    - What evidence in the narrative suggests that this is a rural or remote area?
    - What did you draw outside the ER/hospital that you think makes clear to a viewer that this is a rural or remote area?
- The Douthat et al. article notes that problems of access to health care in rural or remote areas include how far or how hard "getting to the doctor" proves to be.
    - What evidence in the narrative tells you something about the choices that the speaker has for health care?
    - All rural and remote areas are not the same, even if they share similar challenges regarding health care. What evidence in the narrative suggests specific challenges in this rural area?
    - Do you think that online health services, as mentioned in the Douthat et al. article, would have solved any geographic problems of access to care in IP's case? For any other patients she mentions?

Health care as a site-specific performance.

- A site-specific performance is one that depends on the space in which it is performed. A site-specific performance might call for climbing a particular tree, and thus must be performed on that tree, where that tree grows, rather than with any other tree or a replica of a tree. Any changes to the site change the whole meaning of the performance. Political or social protests are often site-specific performances: think of where those are held, and why.
    - How is health care delivery a site-specific performance?

    - What parts of the story IP tells could only have happened at this specific site? At this specific time (of day and in history)?
    - What parts of this story might have played out differently in an urban or suburban area?
- Accepting that health care is site-specific does not preclude the transfer knowledge and experience across sites!
    - What lessons learned in rural/remote/underserved settings can transfer to urban/better served settings?
        - Instructor: If learners need prompting, try discussing :
            - doing more with less, innovation, improvisation,
            - recognizing when rules can't be followed perfectly, addressing challenges directly, accepting limitations,
            - knowledge of patients' wider identities as perhaps a benefit rather than drawback
    - What questions must be asked, or issues addressed, before lessons learned at one site are applied at another?
        - Instructor: If learners need prompting, try discussing :
            - No two sites are the same, so what are the relevant similarities and where do they end?
            - Is the problem/challenge really the same at both sites, or does it just appear the same?