Exploring Human Stories of Illness
Health Humanities Portrait Project
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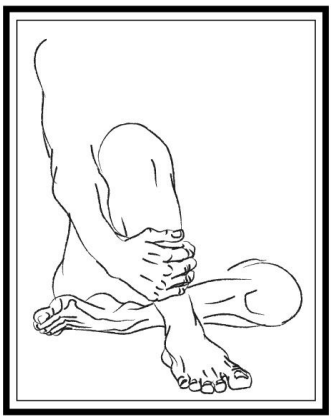

Social Suffering and the Fallacies of Medical Prognosis

Teaching Guide

Creator:
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(Bioethics, Psychoanalysis, Philosophy of Emotions)

Reading List

First-Person Narratives

- Ms. G (read) in Halpern J. *From Detached Concern to Empathy: Humanizing Medical Practice*, Oxford University Press. [see pages below in scholarly reading]

- Michael Hickson: Disabled Man Dies After Texas Hospital Denies Him Coronavirus Treatment

Scholarly Readings

- Halpern J. (2011). *From Detached Concern to Empathy: Humanizing Medical Practice*, Oxford University Press, pp. 1-10 and 111-118. ISBN: 9780195111194, 0195111192

- Gill C. (2004). Depression in the Context of Disability and the 'Right to Die.' *Theoretical Medicine and Bioethics*. 2004: 25, 171-198. Depression in the Context of Disability and the "Right to Die"

- DREDF. Policy Statement on COVID-19: Preventing Discrimination in the Treatment of COVID-19 Patients: The Illegality of Medical Rationing on the Basis of Disability. https://dredf.org/wp-content/uploads/2020/03/DREDF-Policy-Statement-on-COVID-19-and-Medical-Rationing-3-25-2020.pdf
- Cha A. (July 5, 2020) Quadriplegic man's death from covid-19 spotlights questions of disability, race and family. *Washington Post* Disability rights activists rally around wife of quadraplegic man with covid-19 who sought continued treatment

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Session Plan (75 minutes)

5 minutes: Overview of the Learning Objectives anticipating the two distinct patient stories.

5 minutes: A student reads aloud the Ms. G story (which they also will have read in advance).

20 minutes: Discussion of the Ms. G case.

3 minutes: Watch YouTube video/audio of Hickson's wife and physician about ventilator and COVID-19.

22 minutes: Discussion of the Hickson case and wrap up.

Goal:

The overarching goal of this HHP seminar is to bring students to see that:

1) patients' decisions to end their medical treatment and their lives because of suffering are often based on the social and structural barriers that they face.

2) Further, this portrait shows that medical providers' (and the American public's writ large) ideas and decisions about patients' suffering and their future quality of life are deeply subjective; serious errors are often made in these cases when

physicians or other healthcare providers are not conscious of their own emotional responses and biases.

Learning Objectives:

a. To help students identify how serious medical decisions are not based on logic alone and to stimulate their *curiosity* about how the members of the medical team form prognoses about patients' future quality of life based on their own emotional beliefs, which are often unconscious.

b. To use the example of *prognosticating quality of life for patients with disabilities* to identify the basis of the serious medical errors made in these cases, including conflating physical limitations with suffering and using rote medical ethical ideals like "autonomy" as a defense against recognizing when patients are experiencing extreme social and structural barriers in their lives. Use Gill to think through the irony of using autonomy as a reason to withhold or deny treatment.

c. To evoke students' curiosity about their own unconscious feelings of helplessness to address the social and structural barriers patients face. To help them identify steps they can take at the individual and group level: they can cultivate empathic curiosity to become conscious of their own as well as their patients' emotional beliefs to prevent serious errors; they can find the value of their collective voices as medical professionals to advocate for societal change.

Discussion Questions

<u>Key Issues: Ethics, Beliefs, Emotions and Subjectivity in Medical Decision-Making</u>

Portrait Narrative 1: Ms. G:

1. What if any ethical concern or questions do you have about the decision-making in this case?

2. What beliefs did the member of the medical team base their decision on? How did they view her future quality of life? What was the evidence for their view?

3. What emotional processes may have influenced their views? Were they aware of these processes? How might awareness have helped?

4. The team members showed sympathy for Ms. G, did they also show empathic curiosity? What would that involve? What might they have noticed if they were more curious? (e.g. structural factors)

5. How much do you think their views of Ms. G's disability influenced their decision? Is ableism undergirding their views? How or should a patient's disability be considered in thinking about their quality of life?

Portrait Narrative 2: Hickson case

1. What were the contextual factors of COVID-19 in July 2020 that factored into the discussion about ventilator use and disability? (e.g. scarcity, major increase in cases, overwhelmed medical system, medical rationing etc.) [See DREDF legal brief of March 25, 2020] How does the DREDF report address these contextual factors?

2. How did the doctor justify/rationalize the denial of ventilator care to Hickson? How did the physician view his current and future quality of life? How well did he know Mr. Hickson, his family, and his history (typology; the "profile" of people like Hickson)?

3. How did the press report on Mr. Hickson's case?

Wrap up of both portrait narratives:

1. How does discussing these cases affect you? (Prompt can include saying something like: they often make many of us (or me) feel frustrated, angry, sad and at times hopeless).
2. What is ableism? How do definitions of quality of life for people with disabilities undergird ableism? How does it manifest?

Dynamics being Analyzed in this HHP:

-How prognostication about QOL is subjective.
-How people with disabilities are particularly at risk of being a victim of bias.
-How context matters for physicians' views about QOL and for family members.

Activity: Revealing this Portrait Step by Step

The activity below is a step by step discussion that takes the learner through unpacking the role subjectivity plays in clinical care. The questions are structured to motivate students to do their own thinking through a step by step experiential grasp of the narratives and to help question any difficult reactions.

First step: the Ms. G case evokes curiosity about how medical decisions that have life and death import are not strictly logical but influenced by emotional beliefs, beliefs which pose as predictions about patients' futures but are in fact emotionally and socially constructed. This integrates closely with the Halpern readings which draws on social psychology, cognitive theory, psychoanalysis and philosophy.

Second step: the Ms. G case makes the students think about how this is not just the patient's problem, the catastrophic thinking is not just inside Ms. G's head, but in the social communication among the members of the medical team. This wakes students up to two discoveries: the role of doctors own emotions and biases in their prognoses and decision-making; and the way that emotions are projected onto other people when we are unconscious of them through projective identification. All of this is argued for in the Halpern readings.

Third step: still on the Ms. G case. If the students do not raise this themselves, the teacher should stimulate their curiosity about the broader social context here—how much difference did Ms. G's disability or her being a woman (now without a husband) play in the decision of the able-bodied male physicians to end her life? Once the students raise this question, lead into the Hickson case…

Fourth step: view Hickson video prompting students to pay attention to the physician's paternalism and rationalization. How does Mrs. Hickson counter and expose those claims? (uncover his assumptions).

Fifth step: Ask students to name the main reasons Hickson's physician wants to end his life. Ask them to name all the reasons the physician gives to explain the decision to deny treatment. What reasons does Mrs. Hickson give to save his life? How does she try to appeal to emotional connections to illness and mortality? (he doesn't display empathic curiosity). How does he counter that appeal?

Sixth step: have the students address the differences between the physician and the wife. What are the different kinds of questions the two are asking? How does "burden" factor into this dialogue and what questions could the doctor ask to gauge the Hickson's family's situation and view of caregiving?

Remind learners that they can become more curious about their patient's stories and in listening, have a genuinely transformative impact. They can learn from their patients and their patients' families.

Wrap-up Comments:

1. Medical decisions about terminating treatment are not based on facts alone but on judgments that are influenced by emotions, social structures, and biases.

2. Doctors hide behind objectivity and/or rote ethical norms like “autonomy,” or hospital policy and, as such, fail to examine the role of the above factors in their quality of life judgments.

3. By cultivating empathic curiosity and reflectiveness, and considering the social and structural barriers their patients face, learners can become more aware of prejudice and disability discrimination and the ways they work.

4. In doing so, they will learn a great deal about ableism, social and structural barriers to health.