Truth-telling, Disclosure, Privacy and Confidentiality

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Objectives

- Explain the ethical rationale for respecting privacy, maintaining confidentiality, and telling the truth in professional practice
- Contrast the durability of the traditional commitment to respect privacy with the checkered history of truth-telling
- Analyze cases where arguments can be made for not telling the truth in professional practice

Opening Reflection

- Is honesty indeed the virtue we often claim it is?
- If so, why is lack of honesty as common as it is?
- Under what circumstances, if any, is deception justified?
- How can we enhance the levels of honesty in others and ourselves?
- How can we strive to enhance cultures of honesty, trust, and integrity in our organizations and society?

Establishing, Cultivating, and Preserving Trust:

The Critical Importance of Respecting Privacy, Maintaining Confidentiality, and Telling the Truth

- The ethical problem: the problem of the professional's power to control communication and patient-related information
- The durability of the traditional commitment to respect privacy and maintain confidentiality
- By contrast: the checkered history of truth telling

Truth-telling

Hippocratic Paternalism: Rationale for **concealment**

- medicine had little to offer but hope and it was believed that "bad news" destroyed hope --->concealment was in the patient's best interests
- since the physician and medicine's reputation was at stake concealment was in the physician and profession's best interests
- Long-standing physician policy of concealment—sometimes motivated by self-interest
- Long-standing institutional policy of concealment—often motivated by self-interest

Truth-telling

Simple Autonomy Model: Rationale for **disclosure:** informed consent grounded in strong notion of autonomy

- duty to tell linked to right to know: rights-based ethic prompted reversal of the prior policy of concealment
- positive and negative aspects of rights language

1) positive: stakes a claim and affords social protection

2) negative: invites adversarialism and minimalism; distorts the moral issue of communication [”dumping” bad news versus communicating the truth..]

Truth-telling

Expanded Autonomy Model Grounded in Rich Notion of Beneficence: Rationale for **compassionate disclosure**

- commitment to authentic autonomy: patients receive the information and support they need to make the decision that is right for them
- corrects the problem of the non-interference model of autonomy which limits the health care professional's responsibilities to the negative duty not to interfere in the choices patient's make; imposes the positive duty to communicate the knowledge patients need and to provide the support they need

Reflection

Do you agree with Subrata Chattopadhyay?

In traditional Hindu teaching, truth has three qualities or attributes -- *satyam*, *shivam, sundaram* -- and thus for something to be regarded as the truth it has to be true in fact (*satyam*), good in nature (*shivam*), and beautiful or aesthetically appealing (*sundaram*). Disclosure of the painful reality of a fatal disease to a suffering patient -- honoring individual autonomy but with total disregard for his or her emotional state of mind or the role of the family -- might be neither good nor appealing. In the art of compassionate medicine, telling the truth might thus demand -- at least in some cases -- disclosure of some of the factual information about a disease, and communication of the limited information that is true, good, and appealing.

Reflection

Nursing has often been guilty of at the very least *deceiving* patients in order to bring them some benefit. Under what conditions—if any—would you find it justified to crush medications and conceal them in applesauce? Do you agree or disagree with Doug Olsen's recommendations?

Olsen, D. P. (March 2012). Putting the meds in the applesauce. *AJN,* 112(3), 67-69.

- Olsen: Two factors must be considered in determining whether hiding medication is justified or not: the nurse–patient relationship and the patient's rights.

Sissela Bok provides a two-pronged test to determine whether deception is justified:

- ***First, would the deceived patient have agreed—prior to her or his mental impairment—that such a deception is warranted?***
- ***Second, could the deception survive public scrutiny, including that of professional peers?***

[Bok, S. 1978. *Lying: moral choice in public and private life*. New York: Vintage Books.]

Focus Questions

Now read the following scenarios focusing on the prudential question:

- What should—or should not—be done for this patient?
- What informs your judgment about how best to respond in each scenario?

Scenario One:

- A woman originally from the Middle East calls you and tells you that her 16-year old son has both HIV-infection and is recovering from chemotherapy for lymphoma at NIH. He is no longer on protocol and needs a new Peds Infectious Disease Specialist to follow him. Her son knows about the cancer but not the HIV infection acquired by transfusion as a newborn in the US.

- **Question: Should you agree to treat this young man without telling him he is HIV infected?**

Scenario Two

- Dr. Jones is admitted to the hospital for tests and is discovered to have end stage cancer of the pancreas. He, his wife, and daughter are all physicians. He is a psychiatrist. His wife and daughter tell you immediately upon his admission to give all diagnostic information to them—not to the patient. They tell you that "If it is bad news he will lose all will to live and will most likely be suicidal." Should you respect the wife's & daughters' preferences?

Scenario Three

- Mr. Pham is a 65-year-old Vietnamese man with end-stage metastatic cancer and a recent bowel perforation. He refused surgery for the bowel, has a DNR order, and stated that he wants to be kept comfortable. Communicating with Mr. Pham and his wife requires the services of a translator. Mr. Pham is now too weak to communicate for himself. His wife is growing more distrustful of the staff as her husband's condition weakens. She has been observed removing her husband's fentanyl patches and says she thinks they aren't helping him. The palliative care nurse practitioner is questioning whether or not its ethically justified to place the patch where the wife can't see it. "The patient is definitely in pain, and this is the best modality to get sustained relief given that we can't give an oral medication to this patient."
- **Question: Should the NP instruct the nurses to place the fentanyl patches where they cannot be seen? If the wife asks, is it ethically justified to deceive her?**

Scenario Four

- A father of a child wants to donate marrow to the child. Analysis of a DNA paternity test reveals that the father is not the father of the child and not a match.

- **Question: Should the genetic counselor inform anyone of these results? Who, if anyone, is entitled to the results?**

Scenario Five

- You are caring for Jean Marc, a six-year-old boy with leukemia who is clearly in end stage disease. Unable to accept that he is dying, his parents continue to insist on aggressive management to the dismay of many members of the team. You realize too late to your horror that you inadvertently drew up and administered a massive overdose of Jean Marc's analgesic. Returning to Jean Marc's room fifteen minutes after administering the med you find him dead. A DNR was in place so there is no need for intervention. Jean Marc's parents are uncharacteristically not in the hospital that morning and there were no witnesses to the death. You find yourself imagining the horrible repercussions that will accompany an admission of this error, especially since you haven't been getting along well with your supervisor.

Scenario Five, cont'd

- It is possible that Jean March could have died of "other causes" and there really is no reason to suspect error. You begin to think that Jean March was going to die anyway and is probably better off dying this way than having his dying painfully prolonged by parents who aren't ready to let him go and an attending who always "caves in" to the parents' demands.
- **Question: Will you admit your error? Why or why not? Would you institutional culture support telling the truth and disclosing medical error? Do you have a policy about this**

Scenario Six

- You are a nurse manager for a large not-for-profit hospice. The medical director informs you that six home patients received improperly prepared capsules of long-acting morphine which are believed to have directly caused the death of two patients and severely compromised four others. The capsules were prepared by a pharmacy with which the hospice has a contract. All six patients were end-stage and it was not immediately apparent that the drug administered was responsible for the death/change in status. The hospice administrator believes in transparency and admitting medical error but, especially for the two patients who died, thinks that it would actually be harmful to rob the families of the closure they have already experienced. Both were profoundly grateful to the hospice for all the support they received from the hospice personnel.

Scenario Six, Cont'd

- What guidance would you offer the medical director about how to respond to this error?
- In the event you recommend disclosure, who should tell the families?
- What content should be communicated? Demonstrate what should be said and how.
- Are there any timing considerations?
- What documentation should be kept (and where)?
- Name the essential elements of an ethical response to medical error.

Establishing, cultivating & preserving trust
A brief recap

- Respecting Privacy
- Maintaining Confidentiality
- Telling the Truth

Respecting privacy & maintaining confidentiality

The history & durability of these commitments

- **Hippocratic Oath, AMA Principles of Medical Ethics, Nightingale Pledge, ANA Code for Nurses**

- *Why?*
  - **Deeply personal, intimate nature of patient information**
  - **Maintaining confidentiality = basic condition of trust**
  - **Clinicians are stewards of patient information**
  - **Expectation of confidentiality encourages patient disclosure**

Clinician justifications for breaching confidentiality

- **Tarasoff Case, 1974**
  - **If you determine that warning to a 3rd party is essential, then warning must be given**
- **Two years later, 1976**
  - **If warning is essential, you must not only give it, you must exercise professional judgment as to what is required under the circumstances to prevent harm**

Clinician justifications for breaching confidentiality

- Infectious diseases
- HIV infection
- Impaired drivers
- Injuries caused by weapons/crimes
- Child or elder abuse
- Domestic violence

Telling the truth

- **The "checkered" history of this commitment**
  - **AMA 1847 Code of Ethics and the doctrine of benevolent deception**
  - **Oliver Wendell Holmes & "spinal irritation"**

Telling the truth

- **Survey data:**
  - **1953: 69% MDs favored NOT telling patient about cancer Dx**
  - **1961: 90% favored NOT telling**
  - **1979: 97% favored telling**

- **May 1989 survey of 409 MDs:**
  - **Majority stated they would misrepresent test results to secure insurance**
  - **Majority stated they would mislead wife of a male patient w/ STD**
  - **One third would mislead family about cause of patient's death if error were implicated in cause**

Telling the truth

- **Rationales for lies, deceptions, misrepresentations or failures to disclose:**
  - **Impossible to tell whole truth**
  - **Patients don't want to be told**
  - **Lying, deceiving, misrepresenting, or not disclosing will prevent serious harm**
  - **Telling the truth is not culturally appropriate**

Telling the truth

- **Ethical justifications**
  - **Most patients want to know & must know in order to participate**
  - **Disclosure, usually, has more beneficial than harmful consequences**
  - **Lying & deception are morally wrong**
  - **Telling the truth, avoiding deception & misrepresentation are all ways of respecting the patient, honoring dignity & are reflective of virtues essential to the ethical practice of medicine & nursing**

Thank you…