Do We Disclose Everything to Our Patients?

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What is disclosure?

Disclosure is a **process** during which health professionals **communicate** information about treatments or diagnostic techniques to a patient.
What might we disclose?

• risks and benefits of a particular procedure
• medical errors
• things that almost went wrong

Case 1: “Don’t tell mom she has cancer”

Mrs. J was admitted to the emergency department because of severe abdominal pain. After several imaging diagnostics had been done, it was determined that this 76-year old woman has a large abdominal mass, as well as methastatic changes in her liver and lungs. Before talking to the patient, the emergency doctor was approached by the patient's son, who asked the doctor not to tell mom what her disease is.
The son admitted that he knew for a while that mom was seriously ill, since she has been diagnosed with stomach cancer a while ago in another city. At that point, the patient was unconscious and the information about her health had been communicated to her son, who never told mom what was going on with her. The son begs the current doctor not to tell mom how serious her condition is, since the mom would not want to know she has cancer.

Case 2: “I’m not sure he can take it”

Ivan, 34-year old male was diagnosed with polycystic kidney disease at the age of 27. He was on the transplant list waiting for the matching kidney, and successful match was found two weeks ago. The disease interfered significantly with Ivan’s prior lifestyle. He stopped participating in sports, and within three years of the onset of disease, he had to go to dialysis three times a week, so any full-time employment was impossible.

During seven years of his illness, he had 12 urinary infections, which were treated with antibiotics. He had four surgeries to remove enlarged cysts. He was also on medicines to control high blood pressure, a result of his kidney disease.

Ivan’s illness ad unexpectedly rapid progress, so at age of 33 he was already a candidate for kidney transplant. Beside his brother, there are no other relatives who could be a part of Ivan's supportive
Finally, appropriate kidney was found and Ivan was to undergo the surgery. Prior to the surgery, he got detailed explanation of the procedure, including information about the risks, which included increased risk for malignancy due to immunosuppressive therapy he would have to take. Transplantation surgery was successful and Ivan was recovering very fast. His prognosis was very good, and Ivan felt more optimistic than he felt in years.

Two weeks after the surgery, transplant doctor received an autopsy report describing that the deceased donor suffered from beginning stage of colon cancer. This would mean that Ivan has a higher probability to develop the same type of cancer that the donor had. The doctor charted the recent findings, but did not talk to Ivan yet. The transplant surgeon shared the new information with the attending internal medicine specialist, and this conversation was overheard by the nurse who takes

Case 3: “Well…nothing really went wrong at the end”

A young men was brought by an ambulance to the emergency department. When in hospital, the patient breathing worsen and he needed intubation. A nurse, a first-year family medicine resident and an attending emergency doctor were present at the bedside. Both nurse and resident noticed a smell of alcohol on the attending doctor’s breath. The resident never intubated a patient before and felt really uncomfortable even thinking about doing the procedure.
The attending emergency doctor proceeded with the intubation, and successfully completed the procedure. The ICU team came to the emergency, further stabilized the patient and transferred him to the ICU. The nurse approached the resident after the end of the shift asking him what should they together do about what they just witnessed.

How does disclosure occur?

• “reasonable doctor” and “prudent patient” standard
  – Who should know the diagnosis?
  – Where should the disclosure occur?
  – Who should be present at the conversation?
  – Should a doctor withhold some information?
Disclosure connected with…

- capacity
- understanding
- voluntariness
- consent

= informed consent

Empirical Research on Disclosure

- Edwards et al. (2001): most patients value truthfulness about the health condition
- Miyata et al. (2005): the change of attitude toward disclosure in Japan
- Jenkins et al. (2001): patients want more detailed information
- Weiner et al. (2005): the style of disclosure important
- Gallaher et al. (2003): patients wanted disclosure with extent explanation about circumstances and emotional support; doctors agreed about disclosing adverse events…
How to disclose

• individualize message for each patient
  – use of clear language when describing the condition
  – state reasonable treatment options
  – present risks (reversible/irreversible) and benefits
  – invite patient’s participation (questions, concerns, hopes…)
  – summarize pertinent information
  – provide contact information
  – chart the conversation in details

Take home message

• we should tell our patients as much as they want to know about themselves…we must find out how much they want to know about themselves

• showing respect by caring “about the person not solely as a patient but more importantly, as a unique person” (Anderson 2000: 6)
THANK YOU!

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