Bad Words

Presentation of a Hasting's Center Report Case Study

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Raul de Velasco, MD
Ethics For Lunch Series
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Bad Words

Ms. H a seventy six year old woman is admitted to the hospital because of frequent falls and weakness in the left leg

She is a widower and her only family is an adult son

An MRI of the brain shows a brain lesion with soft tissue extension into the epidural space consistent with metastatic disease

The ‘clinical team’ informs the patient of the findings

She refused further work up and is discharged home with outpatient rehab.

Bad Words

- She sees no improvement after one month of rehab so she now decides to come back to the hospital for further work up and treatment
- In the hospital and before a biopsy of the lesion is done Ms. H tells her physicians that she does not want to know her diagnosis or prognosis
- An oncologist requests an ethics consult asking:

"How do we discuss the risks, benefits and alternatives associated with chemotherapy and radiation if the patient does not want to know her diagnosis and prognosis?"

Bad Words

- The clinical ethicist finds a note in the chart from a psychiatrist that says:

  “The patient has decision making capacity”

- The oncologist feels that the patient:

  “could have a very good prognosis
  depending on the type of cancer she has”

- A bedside nurse and Ms. H’s attending believe that the patient truly

  “wants to know her prognosis”

- A resident physician writes in the chart:

  “we don’t really know what she wants”

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The clinical ethicist meets with the patient who:

1. "*wants to receive any treatment who prolongs her life regardless of how the treatment interferes with her ability to engage in the activities of daily living*"
2. "wants to be included in the decision making process as long the physicians use "positive" language and avoids *"bad words"* such as *dying, chemotherapy, radiation* and *cancer.*
3. If the use of those words can't be avoided, don't talk to her but her son
4. She would like to know about risks, benefits and alternatives to treatments but only if *"bad words"* are not used.

Should physicians honor her wishes?

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Desire Not to Know Anything

- From the patient her/himself –first person waiver-
- From the surrogate/proxy/close family members when patient is capacitated to make health care decisions and they think he/she will be hurt if she/he is told

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Bad Words

Courtney Bruce Assistant Prof. Med, Baylor College Med.
Martin Smith Director, Clinical Ethics Cleveland Clinic

- In 1993 Benjamin Freedman(1951-1997) wrote an article that dealt with this difficult issue. He proposed a model based on the idea of “offering truth” rather than “forcing truth”
- In this model clinicians ascertain the information patients want and then provide “truth” at the level of detail desired by the patient **rather** than “forcing truth” on the patients
- B&S agreed doing this in Ms. H’s case and recommend to do three things.

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Recommendations:

1. There is no guarantee that the *bad words* will be uttered by some members of the team in spite of all efforts to the contrary
2. The health care team will communicate directly with her to the extent she accepts but if the use of the dreaded words are unavoidable this will be communicated thru the son
3. The root of her fears should be explored by an appropriate member of the team

A team member should explore daily the first person waiver to see if there are any changes

Bad Words

Adam Pena Clinical Research Assoc Baylor College of Medicine
Mary Majumder Associate Professor Baylor College of Medicine

- Basing in an ethics of rights, the right to information and participation is a privilege that can be waived. Thus, respect for autonomy implies that the patient’s own assessment of their ability to deal with the information and ways of delivery should be respected.
- They recommend that Ms. H should be approached in a way that fosters understanding and connection; empathic skills that are the domain of many health care professional but are more in tune with the role of social work/pastoral care professionals. In contrast with the approach of Bruce and Smith they feel that the patient should be the final arbiter of disclosure. This, they understand, will increase the burden of care for the health care team but it does not trump respecting the patient’s wishes.

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- They support an appropriate nuanced commitment to respect the patient’s wishes, but at the same time they are concerned that “a simple endorsement of her waiver would not address the fears and anxieties that may be at the root of refusals.”
- This, they agree, will require a commitment in time that may not always be available.
- Nevertheless, the care givers should work to resolve these kinds of dilemmas in ways that take account of relationships and rights and make relief of patient suffering an important role.

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DISCUSSION:

Are we doing that?