



## PALLIATIVE CARE CASE OF THE MONTH

### “Cultural Implications and Request for Non-Disclosure of Medical Information”

by

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**Case:** Mrs. J. is a 75-year-old Chinese woman who comes into the hospital with fatigue and a worsening cough for the past week and is found to have a pneumonia, along with evidence of metastatic lung cancer. She has just moved from Shanghai several months ago to be closer to her family. You are about to enter her room when her son stops you outside the door and says, “Don’t tell her anything about the cancer! It would kill her faster if she knew, in our culture everything must go through me.”

The medicine resident rotating through palliative care wonders about the cultural implications of sharing information and whether or not such information would in fact affect her prognosis, and you discuss how to approach such a request for non-disclosure of information from a family member.

**Discussion:** While there is no significant evidence supporting an increase in morbidity or mortality with giving prognostic information, there are certainly a number of cultural factors that influence the method, or efficacy, or “truth telling.”

According to many Asian cultures, an older adult should be treated like a child when sick, and therefore requires more “protection” than usual. Many fear that openly acknowledging a bad prognosis or impending death is similar to casting a “death curse” on the person, and may trigger a hastened death.<sup>1</sup> Therefore, a request for non-disclosure of medical information may culturally signify a wish to protect against a worse outcome than death itself.

In addition, Chinese culture is strongly family-centered and often decisions about which doctor to see, when to go, and whether or not to comply with recommendations are made as a family.<sup>2</sup> It is generally assumed that the physicians will speak to the family rather than the patient, especially when the prognosis is poor. Out of deference to social structure, this often falls to the eldest son.

When responding to requests for non-disclosure of medical information, a three-pronged approach is generally recommended.<sup>3</sup>

1. **Explore the family’s perspective.** Asking “what are you most concerned about?” or “what is culturally important for us to keep in mind as we think about the next steps” may provide key insight into the family’s priorities and concerns, and help you better arrive at a recommendation moving forward.
2. **Respond to emotion, and validate.** Recognizing that often a request for non-disclosure of medical information is influenced by emotion is key. Responding with empathy and validating concerns can help with cognitive processing without compromising our own ethical obligations to the patient.
3. **Negotiate information sharing.** Putting in more preparation with the family up front is often helpful. Saying something like “perhaps I can ask her, while keeping in mind your concerns, how much information she wants to know?” If Mrs. J. does not want to know, then legally and ethically we are not obligated to share the information and can communicate directly with her surrogate/HCPOA. Preparing in advance for an answer of “I want to know everything” is recommended and gives an opportunity to role-play with the family what exactly you will say and engage them in the truth telling process.

**Conclusion:** With the assistance of translator services, you are able to negotiate information sharing with her son and ask Mrs. J if she would like to know what the doctors have found. She indicates that she does not want to know and wants her son to make the decisions and she will do what he thinks is best. After careful consideration and discussion as a family, they decide to return to Shanghai so that she can be with her deceased relatives there.

#### References:

1. Muller JH, Desmond B. Ethical dilemmas in a cross-cultural context – A Chinese example. *West J Med.* 1992, Sep; 157:323-327.
2. Louie KB. Providing health care to Chinese clients. *Topics Clin Nurs.* 1985; 7:18-25.
3. Stone D, Patton B, Heen S. *Difficult Conversations: How to Discuss What Matters Most.* New York: Penguin Books. 1999.

*Personal details in the case published have been altered to protect patient privacy.*

For palliative care consultations please contact the Supportive and Palliative Care programs at PUH/MUH, 412-647-7243, pager # 8511, Shadyside, 412-647-7243, pager # 8513, Perioperative/ Trauma Pain, 412-647-7243, pager # 7246, UPCI Cancer Pain Service, pager 412-644-1724, Magee Women’s Hospital, pager 412-647-7243 pager # 8510, VA Palliative Care Program, 412-688-6178, pager # 296. Hillman Outpatient: 412-692-4724. For ethics consultations at UPMC Presbyterian-Montefiore and Children’s pager 412-456-1518  
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