

BIOETHICS OF INFORMATION DISCLOSURE ACROSS CULTURES: “DON’T TALK WITH HER ABOUT HER CONDITION”

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ABSTRACT

Healthcare providers are routinely faced with the bioethical challenges of information disclosure across cultures. This paper analyzes the case study “Don’t Talk with Her about Her Condition” (Center for Ethics in Health Care at OHSU; See Appendix A). The impact of full, partial, or non-disclosure of information to a patient greatly varies in different cultural contexts. While information disclosure emphasizes patient autonomy and informed decision-making, it also can be controversial to improving patient safety. In some cultures, the disclosure of a negative diagnosis or prognosis can pose significant risk to the patient’s health, so the patient family takes responsibility of the treatment decision-making process. American values are adopted by people of other cultures to various degrees, so it is crucial to appropriately communicate and administer care services without violating the values and cultural norms of patients and their families. Providers must remember that patients have the ultimate right to decide how their individual autonomy is exercised, which may mean non-disclosure and the assignment of a surrogate. Therefore, it is equally important to uphold beneficence and the role of the family and community in patient care. The recommended approach for information disclosure is asking patients for their desired level of participation and how much information they want to know with respect to their own illness. This approach takes into account the perspectives of the patient, the patient’s family, and the provider care team across cultural contexts. In patient-provider communication, it is imperative that cultural and individual sensitivities in information disclosure are respected and understood.

KEYWORDS

bioethics, information disclosure,
cultures, patient autonomy,
beneficence

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Introduction

The norms for information disclosure in healthcare are not universal and cultural differences vary widely. Questions about the moral rightness of full, partial, or non-disclosure to patients have a long history in biomedical ethics (Potter, 2008). Under the influence of cultural variables, the differences and challenges of information disclosure arise from the interrelationship between autonomy and beneficence. This is because patients can only draw from their personal and cultural experiences, but providers can rely on the principles of non-maleficence and justice in addition to autonomy and beneficence to guide them. Hence, ethical dilemmas surrounding whether the disclosure of diagnosis and prognosis is in the best interest of the patient are complex. This paper reviews ethical issues on information disclosure in clinical practice and explores a systematic framework for clinical decision making.

Sharing adverse information, access to appropriate information by family members, and cultural resistance to informing terminally-ill patients of their diagnosis are examples of dilemmas providers face daily with information disclosure. Any illness has an objective and a relational aspect: (1) The objective truth from the provider of the patient's disease and (2) the relational interactions between the provider helping the patient and the family to make sense of having and living with the illness (Surbone, 2006). Cultural and individual differences persist in information disclosure in healthcare, so partial and non-disclosure happen in many contexts. For relevance and to better address the topic of this paper, an in-depth evaluation is conducted on a case developed by the Oregon Health & Science University (OHSU) Center for Ethics. Please refer to the Appendix of this paper for full-text of the case, "Don't Talk with Her about Her Condition" (Center for Ethics in Health Care at OHSU, n.d.).

Case Facts

Mrs. Soon Chai is a 63-year-old Korean woman with cervical carcinoma. The cancer is widespread and inoperable. Art, her son, requests the provider to not disclose the diagnosis and prognosis or "anything bad" to Mrs. Chai, because it is against

their family and cultural traditions. Erin, her daughter disagrees and believes Mrs. Chai should be made aware of her condition. Mrs. Chai was admitted to the hospital for pain control and evaluation of lower extremity edema; her diagnostic test results came back and the provider is faced with the ethical dilemma of how to deal with the situation regarding information disclosure.

Stakeholders and their Perspectives

The provider has a duty to do good by facilitating the patient's adaptation to the illness. This means the provider needs to offer Mrs. Chai the chance to participate fully in her treatment plan. The determination of what news is bad news constitutes a subjective judgment in the mind of the receiver. Thus, if the provider assumes he is delivering bad news, he may inadvertently influence the patient's response. Situations that make information disclosure challenging for providers include the fear of hurting or distressing the receiver, anxieties over how they may respond, and feeling inadequately prepared for handling such sensitive human interactions (Mystakidou, Parpa, Tsilika, Katsouda, & Vlahos, 2004).

In any culture, the family is almost always involved in the progress of a terminally ill patient's disease. The family bears the final burden of taking care of the physical and emotional needs of the cancer patient as well as other pressures that accompanies a cancer diagnosis (Mittal, Dean, Mittal, & Saks, 2015). Thus, the family cannot be excluded from participating in the information disclosure of Mrs. Chai's test results and treatment plan, unless it is against her expressed wishes. Even though Art and Erin have different views on the sharing of information with their mother, the provider cannot share anything with them without permission from Mrs. Chai.

The role of trust in the patient-provider relationship is asymmetric, involving unequal knowledge and power from the vulnerability induced by illness in the patient. Hence, the asymmetry inherent in the patient-provider relationship shapes Mrs. Chai's capacity to choose and implement choices. The provider needs to respect Mrs. Chai and her

children while at the same time working for the patient's good, which includes involving Mrs. Chai as much as she desires in her care and respecting her cultural identity.

Values in Conflict

In the United States, patients have the right to full disclosure of information regarding their health condition (U.S. Department of Health and Human Services Office for Civil Rights [HHS], 2013). The information empowers competent individuals to make decisions about their treatment options and their life plans. In some cultures, withholding information from the patient, such as Mrs. Chai with cancer, is seen as an act of beneficence to protect her and as a way to respect her wish to exercise her autonomy to delegate the treatment decision-making process to others (Sharif & Bugo, 2015). Therefore, the conflicting values are patient autonomy and self-determination versus the value of decision-making by the family in some cultures.

While the intrinsic good of truth-telling as a moral duty and recognition of the patient's autonomy have been used to validate disclosure, beneficence has been invoked to justify non-disclosure. Even when the patient has been fully informed about their treatment options and the risks and possible benefits associated with them, many cultural factors affect the patient's freedom of choice. Age, race, ethnicity in addition to culture can influence patient attitudes toward autonomy. Thus, a patient's autonomy lies within specific relational and cultural contexts.

Literature and Historical Precedents

In a study on the attitudes of different ethnic groups toward information disclosure of diagnosis and prognosis in the terminally ill, approximately 35 percent of Korean-Americans and 48 percent of Mexican-Americans held a family-centered model of decision making rather than a patient autonomy model favored by 63 percent of African-American and 69 percent of European-American patients (Backhall, Murphy, Frank, Mishel, & Azen, 1995). These findings suggest that providers should ask their patients if they would like to be informed, or if they prefer their families handle such matters.

Mrs. Chai's case is similar to the case, "Going Home to China" in the Lapine, Wang-Cheng, Goldstein, Nooney, Lamb, and Derse article (2001). The hospital ethics committee found the family of a 71-year-old gentleman from China who had renal cell carcinoma with brain metastases was not being unreasonable in their request for the patient to not be informed. The family upheld the value of community and prioritized beneficence above autonomy (Lapine et al., 2001). In many Asian cultures, it is perceived as unnecessarily cruel to inform and burden the patient with a cancer diagnosis (Blank, 2011).

Furthermore, some ethnic groups hold onto traditional beliefs about the value of truth-telling that are in conflict with bioethics in the United States. For example, the Navajo Native Americans believe that being told negative health news will adversely affect their health, so they wish to only be told positive information (Potter, 2008). Their view is that a person's beliefs have influence over one's physical condition (Sharif & Bugo, 2015; Turner, 2005). In order to respect differing value and belief systems among various ethnic groups, it may require providers to take a stance of cultural relativism regarding information disclosure.

HIPAA

Ethically, informed consent and respect for autonomy requires the additional effort of assessing the patient's desire regarding the amount of information she wants to know in order for the provider to make decisions. The Health Insurance Portability and Accountability Act (HIPAA) permits the sharing of information with family members identified by a patient. For example, HIPAA permits OHSU to share information that is directly relevant to the involvement of a spouse, family members, friends, or other persons identified by a patient, in the patient's care or payment for health care (Center for Ethics in Health Care at OHSU, n.d.).

As shown in literature, requests for non-disclosure of information by patients are not rare, especially among Asians. HIPAA has no specific guidelines on withholding information from the patient if she makes this her desire. However, HIPAA Privacy Rule at 45 CFR 164.510(b) allows a patient to give

full authorization to any protected medical information to a designated surrogate (HHS, 2013). Additionally, in Section 164.502(g), a competent person who is 18 and older like Mrs. Chai has the right to formulate advanced directives such as a living will and powers of attorney for healthcare, appointing a surrogate such as Art or Erin to make decisions on her behalf. In some states, individuals can make their advanced directives effective immediately, even if she is not in an end-stage medical condition or incompetent to express decisions. When effective the surrogate can step in at any time, but the patient has the ultimate authority in terms of treatment decisions.

The surrogate must follow any healthcare wishes and always act in the best interests of the patient. Likewise, the provider has an obligation to respect the patient's decision-making rights and privacy, which does not exclude non-disclosure. Furthermore, the provider should routinely assess the patient's wishes regarding surrogate participation and strive to provide the patient's desired level of privacy, which may mean to not be informed (Kuczewski & McCruden, 2001).

Recommendation

Providers can best inform patients like Mrs. Chai by asking how much information they want to know, especially since people of other cultures have adopted American values to various degrees such as Erin. Mrs. Chai may refuse to be told information about her illness even though she is mentally capable of making her own decisions through a medical interpreter. In refusing to be told information directly, she needs to assign someone like Art or Erin to receive information from the provider so he or she can make decisions for her. This approach is similar to appointing a surrogate.

In honoring the wish of a capable patient for non-disclosure, the provider is respecting the patient's autonomy to delegate and determine what she wants to be told. This approach is not only culturally sensitive, but also legally sound as long as the patient's wishes and chosen surrogates are documented in the health record (Glass & Cluxton, 2004). As healthcare providers become more

sensitive and knowledgeable about other cultures, improvements on this framework can be made.

Sensitive and compassionate handling of information disclosure can be achieved with careful attention to cultural variations. A provider who is empathetic to moral differences and attempts to understand dilemmas from the points of view of culturally different patients is more likely to be trusted by the patient and family. This is a reminder that it is the patient, not the provider nor the family, who ultimately owns the right to decide how she wants to exercise autonomy with regard to her own illness (McCabe, Wood, & Goldberg, 2010).

Conclusion

The question about whether the disclosure of healthcare information is in the best interest of the patient is centuries old (McCabe et al., 2010). Between the extremes of full disclosure and non-disclosure, there needs to be room for understanding and respect of both scientific knowledge and different individual values and cultural practices (Surbone, 2006). By adding this awareness to traditional understandings of autonomy and self-determination, providers can find new ways to address dilemmas and respect the wishes of patients and their families. Furthermore, the rate of disclosure of terminal illness diagnoses is progressively increasing throughout the world (Zahedi, 2011). It is becoming ever more important, beyond legal reasons, to facilitate patient-provider trust so that the patient's desired level of participation in her own care is appropriately carried out while respecting her and her family's culture and values.

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Appendix A

Case Study “Don’t Talk with Her about Her Condition”

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Mrs. Soon Chai is a 63-year-old Korean woman who does not speak English. When her husband died six years ago, her son Art took her into his home.

A year ago, Mrs. Chai was seen for pelvic pain. Pelvic exam revealed an abnormal-appearing cervix and adjacent abdominal mass. A workup confirmed cervical carcinoma, widespread and inoperable. At that time, Art insisted that she not be told “anything bad” about the diagnosis or prognosis. He told her that she would receive radiation for her condition, and she completed a full course. The patient’s daughter (Erin) was away at graduate school at the time and was concerned about not sharing information with her mother, but was at a distance and decided to not intervene.

Last night, Mrs. Chai was admitted to the hospital for pain control and evaluation of lower extremity edema, which have limited her self care. As you enter her room, Art quickly introduces himself and asks to talk with you in the hall. He again requests that his mother not be told her diagnosis and prognosis. He says it is against their family and cultural traditions, and that she would want him, as her eldest (and only) son, to receive information and make decisions about her care. He says he will tell her only positive things, so she won’t lose hope and courage. He then asks you for the results of diagnostic tests, as well as your treatment plan and prognosis. Just then, the daughter who has now moved to town also would like information about her mother’s condition. However, she disagrees with her brother and feels her mother should be made aware of her condition. If you don’t tell the patient about her condition then the daughter will. An argument ensues in the hallway between the son and daughter prompting the patient to call from the room about what is wrong.

In addition, you have just come from a noon conference on privacy, confidentiality, and HIPAA (Health Insurance Portability and Accountability Act of 1996). You have concerns about sharing Mrs. Chai’s test results with her children without her permission. You call for a Korean interpreter and step into the room with the two children.