

Informed Consent Revisited: Japan and the U.S.

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Informed consent, decision-making styles and the role of patient–physician relationships are imperative aspects of clinical medicine worldwide. We present the case of a 74-year-old woman afflicted with advanced liver cancer whose attending physician, per request of the family, did not inform her of her true diagnosis. In our analysis, we explore the differences in informed-consent styles between patients who hold an “independent” and “interdependent” construal of the self and then highlight the possible implications maintained by this position in the context of international clinical ethics. Finally, we discuss the need to reassess informed-consent styles suitable to the needs of each patient regardless of whether he or she resides in the United States or in Japan.

“DON’T ASK, DON’T TELL”¹

A 74-year-old woman was admitted for increased blood sugar and fever. A CT scan revealed multiple liver masses. A biopsy revealed a squamous cell carcinoma. The patient’s family (a daughter and two sons) was told the diagnosis and insisted, against hospital policy, that the patient not be told. They were afraid that the knowledge would decrease her will to live and thus shorten her life. The patient is very close to her family as she spends most weekdays with her daughter and the weekends at home with her unmarried son. By all accounts, the patient is alert and oriented.

The nursing staff was not willing to tell the patient her diagnosis without the attending physician’s permission (and the patient had never asked, though she was upset about being in the hospital). The attending physician said that he had seen patients for over thirty years and that if the patient didn’t ask what was wrong, he would not tell them. He thought that patients “usually figure out what is wrong anyway and adjust quite well.” The attending physician said that he understood that it was “in fashion” to tell patients what is wrong with them, but that he disagreed with this silly trend.

1. This case, though fictitious, is based on an actual case that occurred in the United States during the 1990’s. It served as a basis for discussion at *Clinical Bioethics: A Starting Point for Dialogue*, Intercultural Exchange Forum, Kyoto University School of Medicine, Kyoto, Japan, July 2003, which was funded by a grant from The Japan Foundation Center for Global Partnership (Mark Aulisio, Case Western Reserve University, PI). This article results from the Intercultural Exchange Forum.

The family became extremely upset when again approached about informing the patient and questioned the justification for the “hospital policy” that patients should be told their diagnosis.

INTRODUCTION

In this article, we examine how the above case would be interpreted from a Japanese perspective. First, following a brief history of informed consent in Japan, we describe the current legal and social significance of informed consent. Second, we examine how this case reflects possible different decision-making styles. In particular, we explore the differences in approaches to informed consent between patients who hold either an “independent” and “interdependent” construal of the self and then highlight the possible implications of maintaining each of these positions in the context of international clinical ethics. Lastly, we discuss the need to reassess informed-consent styles suitable to the needs of each patient regardless of whether he or she resides in the United States or in Japan.

INFORMED CONSENT IN JAPAN: THE PAST AND PRESENT

The term, ‘informed consent’ has been translated into Japanese as either ‘*setsumei to doi*’ or ‘*infomudo konsento*.’ The former term translates back into English as “explanation and consent” while the latter is a phonetic representation of the English term. The Japanese language is unique in that it uses a distinct form of writing, the *katakana* syllabet, for

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phonetic transcriptions of foreign words (i.e., pasta, shower, e-mail). On the one hand, the former term emphasizes the obligation of researchers and clinicians to provide adequate explanation and receive consent from subjects or patients. In so doing, it carries a connotation that informed consent is a duty to be *acted on* the subject or patient, which does not properly purport that informed consent is a patient's right. The katakana term, on the other hand, is neutral.

The concept of informed consent gained a great deal of attention during the 1980s. One translation initially adopted by the Japanese Ministry of Health and Welfare (MHW; currently the Ministry of Health, Labor and Welfare: MHLW) in 1985 was '*shirasareta uedeno doi*',—literally, "consent upon being informed" (MHW 1985, 153). While this translation properly denoted that patients are decision makers, it failed to take hold most likely due to its lengthiness.

In 1990, Japan Medical Association (JMA), the largest medical professional body in Japan, published a committee report that adopted "*setumei to doi*" as a translation of informed consent (JMA 1990). This report emphasized that, although informed consent was an established concept in the United States, professionals need to adapt it to the Japanese context. Likewise, this report may be considered as one of Japan's efforts to implement informed consent in Japan. Soon after this translation was proposed, however, '*setumei to doi*' encountered much criticism due to its lack of emphasis on patient rights.

In 1993, the MHW established a committee on informed consent in Japan. This committee, which explored the implications of various translations, published its final report in 1995 (MHW 1995, 2). The report listed several possible translations and did not specify any one translation. In the end, however, the committee decided on using the katakana form of "*informudo consento*." Thereafter, the mass media, several academic societies and governmental ministries have primarily used the katakana term.

POSITION OF THE JMA

Noteworthy when considering informed consent and the family's role in Japanese clinical medicine is the newly issued Professional Ethics Guideline for Physicians (JMA 2004). This guideline explains in detail the professional code issued by the JMA in 2000. It consists of three sections: obligation of physician, reproductive medicine, and advanced medical technology.

The guideline indicates that physicians have an ethical obligation to inform patients, but it also leaves leeway to physicians not to inform patients directly. The subsection entitled "Physician's Obligation to Patients" describes the need to fully disclose all relevant information to the patient, yet also gives physicians the freedom to withhold information if seen appropriate:

"... physician has a duty to explain in an easy-to-understand manner to the patient his or her disease, prognosis and plan of treatment and testing, and to disclose the patient's diagnosis including name of disease. However, it is permissible to withhold the truth from the patient on exception; when a justified reason exists such that directly disclosing a patient's true diagnosis and symptoms will cause severe psychological shock to the patient and may impact further treatment." (JMA 2004, 3)²

When the truth is withheld from a patient, it is a physician's duty to tell the patient's family. The following section further illustrates the importance of family in the Japanese clinical milieu while also describing the ideal of informing both patient and family.

"Given that the patient–family relationship in Japan is strong and that a mutual dependency is recognized, physicians need to consider the patient and family as *one body* and explain to the family the patient's true diagnosis and symptoms. Physicians also need to act accordingly when the patient wishes not to disclose his or her condition and disease to his or her family. When the family wishes not to tell the patient of his or her condition and disease, it is important for a physician to try to convince the family to tell the patient unless seen inappropriate." (JMA 2004, 3–4)³

Both sections highlight the ethical obligation to inform the patient, yet also leave room for contextual interpretation—freedom to tell only the family and not the patient.

THE LEGAL TREND

Two prominent court cases also highlight to the emphasis on family involvement in the process of informed consent in Japan. In a 1995 Supreme Court case (1983 incident), an attending physician failed to inform a patient (49-year-old female) of her gall bladder cancer at her first visit (Supreme Court Decision. April 25, 1995). He told her, instead, that

2. Author's translation.

3. Author's translation; italics not in original text.

she had a gall stone that required hospitalization. Her physician thought that he would need to tell her family once she was admitted to the hospital. The patient, however, was never admitted to the hospital. The Court ruled in favor of the defendant on the grounds that a physician can overlook a patient's right to self-determination if he or she judges that knowledge of the truth can have an adverse impact on the patient.

More recently, in contrast, is a 2002 Supreme Court decision on a case (1990 incident) in which a physician neglected to inform a patient (77-year-old male) and family of the diagnosis (Supreme Court Decision, April 24, 2002). The Court found the hospital (physician) guilty of informing neither the patient nor the family. In this case, the physician did not inform the patient because he felt that doing so would have an adverse effect. Instead, the physician sought to tell a family member. Before being transferred, the physician tried to meet the family on a few occasions, but ultimately failed to contact them. After the patient's transfer, the physician neither spoke with the family nor asked the subsequent physician to inform the patient of his diagnosis.

The commonality between these two cases is a declared duty to inform *either the patient or the family*. The fact that the Supreme Court found the defendant guilty in the more recent case may reflect a spread of informed consent in Japan.

TWO DIFFERENT STYLES OF INFORMED CONSENT

In our case of the 74-year-old woman, the family withheld the diagnosis of cancer from the patient. Presently in both the United States and Japan, the tradition of nondisclosure is no longer practiced regularly. In a paper published in 1999, we examined a similar case that occurred in Japan (Akabayashi et al. 1999).⁴ Both cases, regardless of whether they

took place in Japan or in the United States, reflect a style of informed consent common among patients who prefer a "family-facilitated" approach to decision making.

A family-facilitated approach to informed consent where the family and the patient function as a single unit differs from the more popular first-person approach. In this paper, we define a family-facilitated approach as a process of informed consent in which a patient's family communicates with the attending physician and medical staff and often makes treatment-related decisions. This differs from acting as a proxy in that the patient does not officially appoint his or her family. *Family-facilitated decision making thus rests on the premise that a patient-family fiduciary relationship exists and that the patient identifies his or her self more as a component of the family unit than as an independent individual.* In the following section, we delineate the psychologies inherent to first-person and family-facilitated approaches to informed consent.

INFORMED CONSENT AND THE SELF

Several scholars in the fields of anthropology, sociology, and psychology propose that self construals are considered to influence, and in many cases determine, the very nature of individual experience (Geertz 1975; Holland et al. 2004; Markus and Kitayama 1991; Sampson 1988; Triandis 1989; van Baaren et al. 2003). Markus and Kitayama (1991) define two different self construals: an independent view and an interdependent view. We use these two self construals as a lens to highlight how a family-facilitated approach to informed consent is suitable to patients who hold an interdependent view while a first-person style is appropriate for patients who hold an independent view.

A person with an independent view identifies oneself as an autonomous individual who holds an individual set of values and a unique perspective.

This view of the self derives from a belief in the wholeness and uniqueness of each person's configuration of internal attributes. . . . The essential aspect of this view involves a conception of the self as an autonomous, independent person. (Markus and Kitayama 1991, 226)

4. Case: A 62-year-old Japanese woman presented to a Tokyo hospital with a fever and severe back pain. Diagnostic work-up revealed advanced gall bladder cancer metastatic to the liver and the back. The diagnosis was first revealed to her family members, namely her husband and her son, away from the patient. The husband and son discussed it with the daughter, and together the family requested that the patient not be told. The family explained that while still healthy the patient had mentioned to them her wish not to be told if she had developed cancer. After initial treatment for pain and fever, the patient stabilized and was competent to participate in decision making, though she was a little withdrawn and dependent. The treating physician and family met with the patient and in the family's presence, the physi-

cian told her: "You don't have any cancer yet, but if we don't treat you, it will progress to a cancer." In response, the patient asked for no further details. An aggressive pain control regimen was continued and though she was intermittently drowsy, she died four months later without apparent suffering from physical pain. The physician never explicitly discussed the diagnosis with her.

Accordingly in the healthcare setting, patients who hold an independent view will prefer a first-person style—one makes their own decisions upon being informed of the risks and benefits of each treatment option.

An individual with an interdependent self construal will identify himself or herself as an amalgamation of his or her interpersonal relationships with family, friends, and other affiliated groups.

This view of the self and the relationship between the self and others features the person not as separate from the social context but as more connected and less differentiated from others. (Markus and Kitayama 1991, 226)

Thus it is considered that patients who hold an interdependent view will feel more comfortable participating in collaborative decision making with their family, friends or medical providers. We further believe that within this collaborative mode, an individual who holds an interdependent construal will tend to entrust decision making to his or her family or medical provider. In effect, patients who entrust their decisions to their family and/or medical provider often do not participate directly in decision making.

In this case, we need to ask whether or not the patient was willing to entrust her decision making to her family. This depends largely, however, on her relationship with her family and her self construal. The patient was “alert and oriented” (competent), “very close with her family,” and she never asked her attending physician about her diagnosis. Judging by these facts, if she had not been willing to entrust her decisions to her family, she more than likely would have asked her family or attending physician directly about her disease. Inductive logic thus intimates that she indeed held an interdependent view. Nevertheless, her attending physician’s ability to decipher her willingness to entrust her decisions depends largely on his or her ability to *contextually understand* the patient’s communication style and relationship with her family.⁵

5. In a previous study (Slingsby 2005), we describe an epistemology—a way of perceiving and understanding—that informs a reflexive style of behavior and communication. This epistemology, “relative subjectivity,” is interdependent on one’s ability to *contextually understand*. Individuals who are relatively subjective take into account, either unconsciously or consciously, the tides of each situation and the nuances of another’s speech. Accordingly, a *relatively subjective* style of behavior and communication is often shaped by what seems most appropriate to one’s relationship with the other and situation.

UNDERSTANDING SELF CONSTRUALS: ATTENDING TO DIFFERENT STYLES OF INFORMED CONSENT

The literature suggests that many Western European cultures maintain an independent construal of the self whereas many Asian, African, and Latin American cultures hold an interdependent construal of the self. While the United States population may be reflective of an independent view, there are numerous Americans who hold an interdependent view (Bellah et al. 1985; Johnson 1985; Markus and Kitayama 1991; Sampson 1988). Likewise, clinical research has shown that many Americans who are not Anglo-Saxon prefer a family-facilitated approach to decision making (Blackhall et al. 1995; Cooper-Patrick et al. 1999; Hsu et al. 1985). The tides in Japan are also diversifying. Although the Japanese mentality has typically been reflective of an interdependent construal (Sampson 1988), an increasing number of Japanese reflect an independent view—separate, autonomous, individualistic, and self-contained. Likewise, clinical research on doctor-patient decision-making models has suggested that an increasing number of Japanese are actively participating in medical decision making (Sekimoto et al. 2004; Slingsby 2004).

Although an independent construal may be more prevalent among Americans while an interdependent construal may be more common in Japan, we believe that this “cultural understanding” is far less important than the need to understand each patient and family. That is, given that patient populations worldwide commonly consist of individuals who either hold an independent view or an interdependent view, medical providers need to attend to the differences prevalent within each patient population.

THE NEED FOR A NEW DECISION-MAKING MODEL: RESPECTING THE FAMILY’S ROLE

Despite the fact that a large number of patients may prefer a family-facilitated approach to informed consent, there persists a dearth of models that function on this premise. In recent years, several models of doctor-patient relationships have been proposed that focus on patient-centered and shared decision making (Emanuel and Emanuel 1992; Lizz et al. 1988; Quill and Brody 1996; Veatch 1972). The majority of these models, however, do not take into account family-facilitated decision making. For instance, Quill and Brody (1996) propose an enhanced autonomy model that “encourages patients and physicians to actively exchange ideas, explicitly

negotiate differences, and share power and influence to serve the patient's best interests." While this model emphasizes intense collaboration between patient and physician, it excludes the patient's family. We agree that patient-centered models and shared decision making should be promoted as they facilitate better communication and a higher respect for patient autonomy (Quill et al. 1996). Nevertheless, these models ignore the characteristics and values of patients who prefer family-facilitated decision making—patients in Japan and from other non-western communities including several subcultures in the United States and Great Britain (Blackhall et al. 1995; Cooper-Patrick et al. 1999; Hsu et al. 1985; Ruhnke et al. 2000; Sekimoto et al. 2004). This empirical evidence that many patients around the world may prefer a family-facilitated approach highlights the need to reassess the process of informed consent.

Moreover, a family-facilitated approach does not necessarily contradict with the general ethical principle of respect for autonomy in the United States. In fact, a family-facilitated approach to informed consent may be respecting a patient's individual choice—that is, if a patient who holds an interdependent view has a propensity to prefer a family-facilitated approach, providing this approach to informed consent may indeed be respecting patient autonomy. However, this argument requires further analysis given the lack of a clear definition for autonomy (or something close to autonomy) in the context of Japanese clinical medicine (Akabayashi et al. 1999).

CONCLUSION

The case discussed herein occurred in the United States and reflects the need to further address interdependent cultural undertones among patients who prefer a family-facilitated informed-consent style. By reassessing diverging styles of informed consent, we will be able to provide a more suitable and just approach to medical decision making to patients who have an aversion to first-person styles. This need for a renewed approach applies to the needs of patients and families not only in Japan but also in several subcultures of the United States and Great Britain. The question that lies before us today is how can we ensure ethical behavior without having to force patients to conform to a particular style of informed consent. The need to reassess varying styles of informed consent is, we argue, universal. ■

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