

Chapter 3

Informed Consent, Familism, and the Nature of Autonomy



Abstract Informed consent is one of the central themes of medical and research ethics. In this chapter, I would like to introduce the reader to three significant cases in the discussion of informed consent from the 1990s, 2000s, and 2010s. Here, I wish to (1) explore the concept of autonomy and the diversity of this term as influenced by the culture and region, (2) explore further the idea of “something close to autonomy” as described by the American bioethicist Edmund Pellegrino in 1992, and (3) articulate to the extent possible the concept of autonomy in Japan. I propose a “family-facilitated approach” to informed consent, which contrasts with the first-person approach used in many Western countries. This family-facilitated model balances respect for patient autonomy with the cultural importance of the family in decision-making, and more clearly characterizes “something close to autonomy” in the Japanese context. I then extend this discussion to the global context.

In the last part of the chapter, I tackle the topic of prognosis disclosure. Although a modern North American concept of autonomy will dictate that physicians inform patients of their prognosis, regardless of patient preference, I argue that disclosing the prognosis at the terminal stage is situation-dependent, and should be decided on a case-by-case basis with consideration of the specific context, based on physicians’ virtue, and will open this topic to global dialogue.

3.1 Nature of Informed Consent

This chapter is dependent upon “Informed consent revisited: A global perspective” a chapter in the *Future of Bioethics (2014)* in the Appendix of this book [1]. Of particular significance is the pattern of the three cases described therein, and the places where each occurred [2, 3].



Commentaries on this primary article [1] were written by Dr. Carl Becker (Kyoto, Japan, and USA), Dr. Anita Ho (Canada), and Dr. Ruiping Fan (Hong Kong), and face-to-face discussions were held at conferences. Below is a brief summary of the dialogue among the four of us (primarily, my replies to their comments).

Comments to my article can be divided broadly into two categories: First, objections to our appeal to the concept of *autonomy* when supporting the family-facilitated approach. Second, difficulties in practice when implementing the family-facilitated approach.

Let us begin with the first category.

According to Carl Becker, “Dr. Akabayashi’s cases are ethically as well as culturally acceptable, not because they somehow approximate patient autonomy, but *because they have unobjectionable outcomes.*” He also stated that, “We should respect each culture’s way of decision-making even if autonomy is not central to its world view. At the same time, we should seek for ways to avoid *immoral abuse* which cultural systems might permit.”

However, it is not clear on what basis Carl Becker can make such evaluative judgments such as “*unobjectionable outcomes*” or “*immoral abuse.*” Do these judgments really make sense to those who do not share the same cultural background?

Certainly, someone like Carl Becker, who has sympathy for Japanese culture, would probably intuitively know that the family-facilitated approach in Case 2 was unobjectionable. To others, however, is this really self-evident?

One argument frequently used to defend cultural practices is the claim that there are values specific to a culture, namely values that are only accepted within that culture.

But this argument is problematic. It simply insists on one's own viewpoint and is closed off to criticism from other points of view.

Fan only points out the difference between Confucian moral autonomy and Western conventional autonomy (personal autonomy). He seems to be uninterested in the similarities between these two notions. For example, it might be possible to understand that some elements of Confucian moral autonomy explicated by Joseph Chan—voluntary endorsement, reflective engagement, and importance of the will—share some similarities with conventional Western autonomy.

Our purpose in writing this article was to advance this debate while remaining open to criticisms from others. On this basis we sought to explain and critically scrutinize these practices using concepts and terminology that others can understand, rather than basing our arguments on incommensurable values.

Without looking for such common ground, we are skeptical about whether it would be possible to advance the dialogue between people from different cultural backgrounds.

Thus, a concept used in Japanese decision-making was explained as “a form of autonomy,” a notion that is commensurable with other values in other regions of the world. In so doing, I believe that we were able to present a practice specific to Japan in a way that was comprehensible to and open to criticism from those who do not share the same cultural background.

Furthermore, Becker stated that “Dr. Akabayashi's cases provide Western readers a valuable explanation of Japanese decision-making. However, his attempt to defend their similarity to autonomy is questionable.” To the contrary, our attempt to defend its similarity to autonomy is by no means questionable.

The primary article clearly articulated the idea of a form of autonomy, namely (1) rejecting paternalism and (2) complying with patient preferences.

Hayashi and I addressed how, in the context of contemporary biomedical ethics, these two points have the potential to apply broadly beyond the bounds of the Japan-USA binary.

Ho also stated that the family-facilitated approach bypasses the substituted judgment standard. In response to this, I want to emphasize the close relationship between the patient and his/her family in the family-facilitated approach.

As Ho implied in her previous article [4], for patients who hold an interdependent view of the self, the family's best interests are equivalent to or at least part of their interests; in these cases, it is impossible to distinguish the patient's interests from those of the family. Thus controversy between the substituted judgment standard and best interest standard is based on the assumption that the patient's interests and those of the family are distinct and potentially incompatible.

By contrast, in the family-facilitated approach, this basic assumption is nullified by the close relationship between patient and family. Consequently, we will set aside the problem concerning the substituted judgment standards. Further, with respect to our notion of autonomy, Ho commented that, “The notion of ‘something close to autonomy’ or ‘a form of autonomy’ implies that the family-facilitated approach falls short of being ideal.” We do not, however, regard the family-facilitated approach to fall short of being ideal.

Let us recall that “something close to autonomy” or “a form of autonomy” was in fact a quote from the American medical ethicist Pellegrino. From the perspective of the conventional autonomy-centered bioethics approach, the family-facilitated approach may appear non-ideal. Yet, I am not attempting to debate the relative merits of the family-facilitated approach over the first-person approach. That is, we are not saying that the conventional conception of autonomy (personal autonomy by Fan’s definition) is better, or worse, than “something close to autonomy.”

I will move on to second category: difficulties in practice.

According to Becker, we “need to look less at typically easy cases and more at borderline troubling cases.” We believe that each of our three cases represent difficult cases, rather than easy ones.

Perhaps all of the commentators are concerned about the problems that might arise in the application of the idea of tacit consent and the soft proxy approach to actual cases. These concerns are understandable. Nonetheless, our goal in this discussion was to show that, in some cases, the family-facilitated approach is more appropriate than the first-person approach.

We must reaffirm that this argument is constructed based on an ideal situation assuming that two premises have been met *ex hypothesi*, namely that (1) a patient-family fiduciary relationship exists and (2) a patient identifies her/himself more as a component of the family unit than as an independent individual.

Therefore, the question of what the best response is in a non-ideal situation in which these conditions have not been met, or where it is difficult to know whether the conditions have been met, falls outside our framework. Nonetheless, we would like to respond to these concerns to the best of our abilities.

- (a) First, variety of consent as it relates to patient “nodding”: In contrast to Becker’s understanding, we consider the “nod” in Case 3 as expressed consent rather than tacit consent.

Our argument that there is no difference between tacit consent and expressed consent is aimed at Ho, who stated that there is the danger of exploitation in both cases.

If the two premises are not in effect—in other words, in cases where there is no trust between patient and his/her family—then the hard proxy approach or first-person approaches should represent the appropriate options. We understand that the family-facilitated approach is distinguished from the soft proxy approach in that there is no expressed consent but tacit consent.

- (b) Second, a patient’s relational identity and trust in her/his family: How do we know?

The first concern with the soft proxy approach, as Becker and Ho point out, relates to the problem of what the physician should do when s/he does not know if there is trust between the patient and his/her family. In other words, how do we verify or know if a patient adopts an independent or interdependent view of the self?

We might hope that in the future, psychological tests will be created. Physicians could then judge whether or not there is trust, or whether a patient holds an independent or interdependent view using this kind of testing.

Without such tests, it is currently difficult to make such judgments. Yet, because there are in reality patients who have an interdependent view of self, the only option is, as Ho suggests, to ask various questions or know a lot more about the patient's background, in order to make inductive inferences and identify such people.

It is possible that Ho interprets the first-person approach as one in which the patient makes decisions about all matters independently. But even in conventional informed consent, the patient is informed by the physician, meaning that the patient is able to decide with the help of the physician. Thus, even according to the first-person approach, the patient requires the assistance of others.

The third concern, which both Becker and Ho raise, is how to handle situations in which the opinions of family members are divided. Indeed, we did not anticipate the possibility of a disagreement within the family. It would be a problem if opinions were seriously divided among family members. In such cases, one may judge that the family lacks decision-making capacity, and thus is unable to decide on behalf of the patient. If available, a call for a clinical ethics consultation may be in order.

Thus, the point made by Becker is extremely astute, as the family-facilitated approach would not be valid. It may be necessary to add a third premise: that the family as a whole possesses the capacity for decision-making.

In such cases, if the patient still desired to have someone else make decisions, the physician might be permitted to decide. This problem requires further study.

That said, I do want to ask Fan to clarify the kind of action the strong family-oriented approach calls for when there are deep divisions in the opinions of family members.

Finally, a characteristic of contemporary medical treatment is that, as the range of treatment options increases, it becomes no longer possible to proceed solely according to a physician's judgment. This is true irrespective of cultural or regional differences. We believe that in this era, it is valid to have a form of autonomy that (1) rejects paternalism and (2) respects the preference of the patient.

In bioethics today, there is a backlash against some kinds of autonomy-centered approaches, which have been challenged by communitarianism and in particular feminist ethics, which conceptualizes autonomy as relational, through which selfhood must be realized through connectedness. Following these different ways of thinking about personhood, we hope that it will be possible to open up new, global developments in bioethical discussion.

Our purpose in writing the article was to advance the debate. Rather than basing the arguments on incommensurable values, we sought to explain our perspective by introducing concepts and terminology for those unfamiliar with Japanese culture. Without finding such common ground, it is doubtful that further dialogue can be sparked between people from different cultural backgrounds. This is what I wrote in the Introduction to this book.

Accordingly, we labeled our central concept "*a form of autonomy*" to explain the Japanese decision-making model, as this is commensurable with values in the West. We believe that this approach enables us to present a Japanese practice that is easily understood by Westerners, while preserving openness to criticism. We also intended to reopen the discussion on informed consent in order to extract ourselves from the dead-end debate over universalism versus ethnocentrism.

Readers are now aware that there are numerous ways of conceptualizing “autonomy,” but by using the term “autonomy,” researchers from the West can now be cognizant of the fact that there is “a form of autonomy” in Japan, too, and will be able to understand further what this resembles. This, I believe, deepens our mutual understanding. (To obtain a deeper understanding, I recommend those who have access to the *Future of Bioethics* read the commentaries and my replies.)

3.2 Prognosis Disclosure: An Unresolved Issue

In 2003, Japan passed the Private Information Protection Law, which allowed patients to view their own medical charts and learn the name of their disease if they so desired; this demonstrated change around the issue of diagnosis disclosure. However, the next challenge was prognosis disclosure, an issue that remains unresolved worldwide.

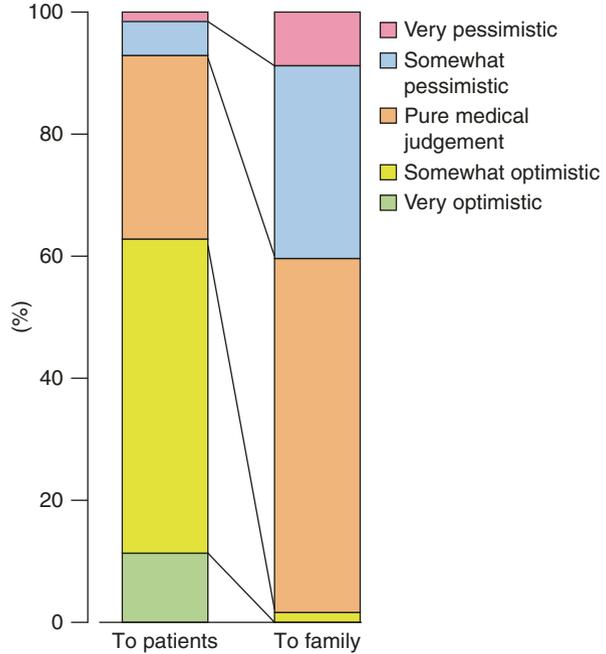
According to a 2002 attitude survey ($n = 404$) [5] targeting citizens from the general population in Japan, 86.1% of citizens desired full diagnosis disclosure, while 11.2% desired partial disclosure, demonstrating that nearly all wished for some disclosure. Notably, with regard to expected length of survival (=prognosis), the majority of respondents did not wish for full disclosure, as revealed in the percentages that reportedly desired non-disclosure (5.7%), partial disclosure (47.5%), full gradual disclosure (16.6%), and full disclosure without delay (30.2%).

In a classic attitude survey around the same time (2008) targeting physicians ($n = 710$) in the USA, 98% of physicians informed their patients if an illness would be fatal to them [6]. However, the content of what was communicated differed by respondent. For example, 42% of physicians felt that it is important for patients to know the prognosis and always communicated the prognosis, while 48% of physicians only communicated the prognosis when the patient asked, demonstrating a division into two nearly equal groups. In response to the question, “In telling, how often do you give your patient a specific *timeframe* or medical estimate of the *amount of time* as to when death is likely to occur?”, roughly 43% responded “always” or “usually,” while 57% responded “sometimes,” “rarely,” or “never.”

What do these numbers indicate? Apparently, even in the USA where respect for first-person oriented autonomy is prioritized so heavily, the practice of prognosis disclosure varies by physician and by patient (Fig. 3.1). Moreover, as predicting a prognosis can be medically ambiguous, the survey results described below are quite thought-provoking.

In a 1999 survey in Japan [7], physicians were asked how a prognosis was conveyed to patients and their families. More than 60% responded that they gave patients a “very” or “somewhat” optimistic prognosis, while more than 40% gave the families a “very” or “somewhat” pessimistic version. Roughly 30% and 60% relayed information solely according to medical judgments to the patients and to the family, respectively.

Fig. 3.1 How physicians convey a poor prognosis [7]



When families are offered pessimism while patients are offered optimism about a prognosis, there may be two explanations. Firstly, from the physician’s perspective, if they were to show optimism to the family, and then the patient died sooner than expected, they may worry about the patient’s family blaming them. Secondly, from the family’s perspective, if they receive a pessimistic prognosis and the patient lives longer than expected, this would be a joyful matter. I would describe this interaction as an unconscious psychological conspiracy between the physician and the patient’s family. Notably, the patient’s own perspective is not included in this.

In an even more recent randomized controlled trial from the USA, physicians delivering the more optimistic message were ranked as more trustworthy. Factors that influence the reluctance of physicians to deliver less optimistic messages to patients with advanced cancer include, among others, fear of being blamed, fear of destroying hope or provoking emotional distress, and fear of confronting their own emotions and death [8].

While the USA also practices a similar type of unconscious psychological conspiracy in disclosing prognosis, a survey from the USA maintains that autonomy is valued, simply because they add the condition, “as long as the patient does not ask.” In this way, the same “do not disclose the prognosis” interaction is based on different forms of moral reasoning that vary by culture and region. I hope the readers can recognize the need for sensitivity to differences in ethical grounds used to justify

this, even though the act/interaction remains the same. In other words, the same end result is not based on the same moral justification.

I should also note that cultural differences are evident in patient wishes regarding prognosis disclosure. For example, an awareness survey stratified by ethnicity in the USA that targeted elderly individuals found that 35% of Korean-Americans, 48% of Mexican-Americans, 63% of African-Americans, and 69% of European-Americans desired prognosis disclosure. Korean-Americans and Mexican-Americans tended to believe that the family should make the decisions about the use of life support [9] (1995). In addition, while European-Americans and African-Americans felt that the prognosis disclosure is empowering, enabling the patient to make choices, Korean-Americans and Mexican-Americans considered this as “cruel,” and “even harmful.” The present text does not make cultural comparisons, because as demonstrated above, prognosis disclosure differs so widely in degree, and seems to be handled in a case-by-case manner by patients and physicians all over the world.

A paper was published recently [10] that directly addresses this problem. The authors state the following:

Does a patient with advanced incurable disease have a right not to hear the bad news? We think not. They should tell the truth, even when the patient would rather not hear it.—
(Underlined by the author)

This article presents a questioning of the North American concept of autonomy. Nonetheless, we mount our own objections to this concept. The paper is under preparation, so whether or not our objections are successful remains to be seen. Overall, prognosis disclosure, theoretically and practically, remains the most difficult problem within the realm of end of life communication between patients and healthcare providers.

References

1. Akabayashi A, Hayashi Y. Informed consent revisited: global perspectives. In: Akabayashi A, editor. *The future of bioethics: international dialogues*. Oxford: Oxford University Press; 2014. p. 735–49.
2. Akabayashi A, Fetters MD, Elwyn TS. Family consent, communication, and advance directive for cancer disclosure: a Japanese case and discussion. *J Med Ethics*. 1999;25:296–301.
3. Akabayashi A, Slingsby BT. Informed consent revisited: Japan and the U.S. *Am J Bioeth*. 2006;6(1):9–14.
4. Ho A. Relational autonomy or undue pressure? Family’s role in medical decision making. *Scand J Caring Sci*. 2008;22:128–35.
5. Miyata H, Takahashi M, Saito T, Tachimori H, Kai I. Disclosure preferences regarding cancer diagnosis and prognosis: to tell or not to tell? *J Med Ethics*. 2005;31(8):447–51.
6. Daugherty CK, Hlubocky FJ. What are terminally ill cancer patients told about their expected deaths? A study of cancer physicians’ self-report of prognosis disclosure. *J Clin Oncol*. 2008;26:5988–93.

7. Akabayashi A, Kai I, Takemura H, Okazaki H. Truth telling in the case of a pessimistic diagnosis in Japan. *Lancet*. 1999;354:1263.
8. Tanco K, Rhondali W, Perez-Cruz P, Tanzi S, Chisholm GB, Baile W, et al. Patient perception of physician compassion after a more optimistic vs a less optimistic message: a randomized clinical trial. *JAMA Oncol*. 2015;1(2):176–83. <https://doi.org/10.1001/jamaoncol.2014.297>.
9. Blackhall LJ, Murphy ST, Frank G, Michel V, Azen S. Ethnicity and attitudes toward patient autonomy. *JAMA*. 1995;274(10):820–5.
10. Stahl D, Tomlinson T. Is there a right not to know? *Nat Rev Clin Oncol*. 2017;14(5):259–60. <https://doi.org/10.1038/nrclinonc.2017.47>.

Open Access This chapter is licensed under the terms of the Creative Commons Attribution 4.0 International License (<http://creativecommons.org/licenses/by/4.0/>), which permits use, sharing, adaptation, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons license and indicate if changes were made.

The images or other third party material in this chapter are included in the chapter's Creative Commons license, unless indicated otherwise in a credit line to the material. If material is not included in the chapter's Creative Commons license and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder.

