Dynamic Axes of Informed Consent in Japan

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Abstract

Scholarship in cross-cultural bioethics routinely frames Japanese informed consent in contrast to informed consent in North America. This contrastive analysis foregrounds cancer diagnosis disclosure and physician paternalism as unique aspects of Japanese informed consent that deviate from American practices. Drawing on in-depth interviews with 15 Japanese medical professionals obtained during fieldwork in Japan from 2013-15, this article complicates the informed consent discourse beyond East-West comparisons premised on Anglo-American ethical frameworks. It expands professional perspectives to include nurses, medical social workers, clinical psychologists, and ethicists and it addresses informed consent for a broad range of conditions in addition to cancer. The results suggest that division of affective labor is an under-theorized dimension of informed consent that is perceived as at odds with principled demands for universal informed consent. These practical tensions are conceptualized as cultural differences, with Japan identified in terms of *omakase* as practical and supportive and the United States identified in terms of *jiko kettei* as principled and self-determining. These results have implications for the methodology of cross-cultural bioethics as well as for theories and practices of informed consent in both Japan and the United States. I

conclude that responsible cross-cultural work in bioethics must begin from the ground up, incorporating all relevant stakeholder perspectives, attitudes, and experiences.

1. Introduction

Japanese informed consent has long been of interest outside Japan (Long and Long, 1982; Higuchi, 1991-92; Elwyn et al., 1998; Long, 1999; Akabayashi et al., 1999; Ruhnke, 2000; Leflar 2001; Elwyn et al., 2002; Akabayashi and Slingsby, 2006). The familiar narrative has focused on physicians' disclosure of cancer diagnoses, identifying universal disclosure of cancer diagnoses in the United States as the norm (Oken, 1961; Novack, 1979) and suggesting that the Japanese Medical Association and Japanese courts' allowance of nondisclosure of cancer diagnoses is a surprising peculiarity (Japanese Medical Association, 2008; Masaki et al., 2014; Kaizaki et al., 2014). Cancer diagnoses and physicians' practices have shaped this cross-cultural discourse on informed consent, yet informed consent is a more variable and diffuse practice than this discourse suggests. Here, I present a grounded analysis that rejects the assumption that "cancer" and "physicians" are the definitive categories by which informed consent in Japan is understood and which highlights the complexity of cross-cultural bioethics.

Informed consent has legal, institutional, and ethical meanings. I consider its standard use in bioethics as consent to a medical procedure or treatment with full knowledge and evaluation of the risks and benefits. Diagnosis disclosure is thus an important piece of informed consent. Influenced by the contrast in cancer diagnosis disclosure trends, cross-cultural accounts of informed consent have maintained a dichotomy between North America and Japan. North America is described as upholding the principle of patient autonomy, while Japan is described as prioritizing family

dynamics over individual patients' needs (Akabayashi et al., 1999; Kakai, 2002; Akabayashi and Slingsby, 2006; Traphagan, 2013; Masaki et al., 2014). This distinction between principlist ethics in the West and particularist ethics in Asia resembles other cross-cultural bioethical discourses in which the West is presented as individualistic and Asia as collectivist (Fan, 1997; Kato and Sleeboom-Faulkner, 2011; Nie and Fitzgerald 2016).

Aspects of Japanese culture, such as perceptions about professional responsibility (Elwyn et al., 1998; Elwyn et al., 2002), indirect communication (Kakai, 2002), and the role of the family (Akabayashi et al., 1999; Akabayashi and Slingsby, 2006) have been used to explain different approaches to disclosure. The symbolic meaning of cancer has played a central role in many explanations (Long and Long, 1982). It is true that cancer has different cultural, social, and epidemiological manifestations in the U.S. and Japan (GfK Roper Public Affairs). Yet studies of cancer diagnosis disclosure in Japan frequently reach beyond cancer, drawing conclusions about how informed consent manifests Japanese ethics and values. While nondisclosures of cancer diagnoses are a meaningful phenomenon, exclusively studying informed consent in the context of cancer biases the understanding of what is significant about Japanese practices towards those practices that challenge American universalist frameworks.

Further, Japanese informed consent is studied in the context of the physician-patient relationship, a fact that has been raised as a limitation of previous studies (Elwyn et al., 2002). This is not unusual for the ethical discussion on informed consent in North America and Europe, which analyzes informed consent through the physician patient relationship and pits patient autonomy against physician paternalism (Katz, 1984; Faden

and Beauchamp, 1986; Charles et al., 1991; Emanuel and Emanuel, 1992; Leflar, 1996; Wear, 1998; Leflar, 2001; Joffe and Truog, 2010). The Japanese discussion on informed consent also foregrounds the physician-patient relationship (Morioka, 1994; Uchiyama, 1994) and, if not defending alternative forms of autonomy (Akabayashi and Slinsby, 2006), then argues that Japan is behind the West in recognizing the ethical necessity of informed consent (Morikiwa, 1994; Seo et al., 2000; Masaki, 2014). However, without a broader understanding of how informed consent takes place in Japan – including how support staff such as nurses and social workers might ameliorate concerns of physician paternalism – these suggestions are premature.

The cross-cultural discourse on informed consent has been dichotomized in two ways: as involving physicians and patients on oncology wards and as a practice that manifests cultural differences between North America and Japan. This persists despite dissatisfaction with theories of informed consent that idealize autonomous patients' rational choice (Faden and Beauchamp, 1986; Beauchamp and Childress, 2013). Informed consent theories are critiqued for presuming rational rather than affective relationships between physicians and patients (Manson and O'Neill, 2007; Kukla, 2009; Olthuis 2013) in the face of the vulnerability and uncertainty that accompanies illness (Nelson and Nelson, 1995; Schneider, 1998). There has also been increased interest in different roles that medical professionals and family can play in shared decision-making (Charles 1997). Yet attempts to re-theorize informed consent in light of these critiques have generally not been successful in unseating dominant theoretical paradigms, especially as they operate across cultures.

I propose that a grounded analysis of informed consent in Japan can have two beneficial effects: it complicates the informed consent discourse beyond East-West dichotomies, and it highlights unrecognized aspects of informed consent in Asian cultures. Focusing on physician-patient relationships and cancer diagnoses inhibits the comparative understanding of informed consent by implicitly adopting Anglo-American assumptions about which relationships are ethically significant and highlighting only those dimensions of Japanese practices that stand out in contrast to North American practices. This presents Japanese informed consent as a foil to North America, a form of analysis that preserves narratives of Japanese—and American—uniqueness.

To my knowledge, little has been examined about practices and conceptions of informed consent in Japan from multiple professional perspectives and outside the narrow focus on cancer diagnosis disclosure. The few previous studies of nurses' perspectives have either focused on cancer diagnoses or on physicians' roles (Long, 1999; Seo et al., 2000; Long, 2005). This study moves beyond these anachronistic comparisons through a qualitative study of informed consent in Japan from the perspectives of nurses, clinical psychologists, social workers, medical ethicists, and physicians and including, but not limited to, the specialization of oncology.

The analysis shows that dynamic axes discursively and practically shape Japanese informed consent in terms of affective goals, professional roles, practical motivations, and conceptual structures. The affective axis highlights the goals of patient and family satisfaction and reduction of anxiety and stress experienced by physicians, patients, and families. The professional axis reveals that support staff, such as nurses and social workers, take on substantial affective labor in informed consent, and that physicians are

largely unaware of this background facilitation. The practical axis suggests that these concrete, affective features of informed consent are perceived as at odds with theoretical explanations of informed consent in principle. The conceptual axis indicates that these affective, professional, and practical tensions play out in cross-cultural terms, with *jiko kettei* being used to allude to foreign influences and societal change in Japan, and *omakase* referring to traditional Japanese practices and preferences.

In addition to the practical consequences of attending to these affective, professional, and conceptual dimensions of informed consent, these results also have implications for the methodology of cross-cultural bioethics, which all too often becomes mired in orientalist or *nihonjinron* characterizations. As I will argue in the conclusion, such cross-cultural work must begin from the ground up, incorporating all relevant stakeholder perspectives, attitudes, and experiences.

2. Theoretical Framework

As described below, data collection and analysis followed an inductive, iterative, and thematic approach in line with the constant comparative analysis stage of grounded theory (Glaser and Strauss 1967; Strauss and Corbin 1990). This approach does not test theoretical hypotheses nor confirm a priori themes, but rather tracks emergent themes and concepts in participants' descriptions of and reflections on informed consent in Japan.

This approach was chosen due to its appropriateness for the cross-cultural nature of this study. As a North American scholar trained in Japanese studies and comparative philosophy and with practical and academic experience in medical ethics, it was important to be cautious not to shape the study results through my own assumptions

about what might be important in Japanese informed consent (Fox and Swazey, 1984). In particular, this study was guided by grounded theory's avoidance of positivism and emphasis on creative, flexible, and holistic interpretation of qualitative data with the goal of conceptually dense, interrelated results (Cho and Lee, 2014). These particular data are part of a broader study that utilized a larger data set to generate both a theoretical explanation and particular recommendations for informed consent practices in Japan.

The fact that I am not Japanese creates opportunities and introduces challenges. Interviewees could not assume that we would share tacit knowledge about Japanese society and practices. Some interviewees may have felt they could confide in me, while others may have avoided more complex reflections on informed consent. As tradeoffs also exist for Japanese interviewers, this is not a limitation of the study but a contributing factor to its particular results.

3. Methods

I conducted in-depth interviews with 15 Japanese medical professionals in the Kansai region of Japan from August 2013 through March 2015, where I was a visiting researcher at the Kokoro Research Center (KRC), Kyoto University. The KRC is an interdisciplinary center that is committed to using diverse approaches to answer conceptual questions about the human mind and to solve practical problems facing human society. While in Japan, I also attended graduate and undergraduate seminars on bioethics at Kyoto University, participated in a bioethics research group, and attended numerous meetings, lectures, and conferences.

This study was approved as exempt by the Human Studies Board of the University of Hawai‘i at Mānoa.

3.1 Recruitment

Subjects were selected through a combination of convenience sampling and intentional sampling. I used my research network based at the KRC to identify subjects from a variety of specialties and at different points in their careers. Inclusion criteria were experience participating in informed consent practices in medicine, or experience studying informed consent in medicine. Exclusion criteria were no experience with informed consent in medicine. In several cases, a Japanese colleague provided an introduction to the interviewee, and in a few cases, this colleague was present for the interview, although their participation in the discussion is excluded from the analysis.

3.2 Data Collection and Analysis

Interviews occurred in medical or academic offices, coffee shops, or restaurants. Interviews ranged from 45 minutes to 2.5 hours. All participants gave informed consent for the interview and the audio recording. Interviews were conducted in Japanese, although some interviews also utilized English, when initiated by the interviewee. I am functionally fluent in Japanese and many interviewees were fluent in English, so interviews occasionally moved between languages for clarification.

The interview guide was created through spring and summer 2013 with linguistic and content-based input from colleagues at the KRC. Initial questions were open ended and follow-up questions encouraged elaboration. Participants were first asked to explain

their specialty and their experience in hospital or clinical practice. Interviewees were not asked to define informed consent but rather to describe their practical experience with informed consent. This avoided influencing explanations of informed consent practices with potentially dichotomous theoretical definitions. Follow-up questions related to the details of their experience with informed consent (transliterated as *infōmudo konsento*), including the situation in which it is practiced, how the interviewee's practice of informed consent differs from the medical professionals with whom they work, whether their informed consent practices had changed, where and how they learned how to practice informed consent, how they felt during informed consent, their experiences of patient decision making following consent, whether informed consent might be improved, and their further thoughts on informed consent.

Each interview was digitally recorded. I individually transcribed or translated the interviews directly into either Japanese or English. Where idiosyncratic Japanese terms or expressions were used, these were noted in the original Japanese; otherwise, passages were translated into English. Early interview transcripts, translations, and notes were analyzed thematically as they were created, and this early assessment of data informed the questions asked in subsequent interviews (Strauss and Corbin, 2008). In some cases, there were large blocks of times between interviews, allowing for deeper analysis and reflection on the emerging themes. Informal discussion with colleagues in Japan and the Unites States enriched the analysis during this time.

While in Japan, I conducted an initial general analysis, building off the informal inductive analysis completed during the interview process. Interview documents were printed, general themes in the interview data were noted, and different methods of

conceptualizing these themes were explored. The interview process concluded once a number of themes characterizing contemporary Japanese informed consent had been identified. Upon returning to the United States, subsequent analysis utilized a qualitative software program, Atlas.ti, to conduct line-by-line thematic coding and to reevaluate the general themes developed in the initial stage based on code frequency. In this subsequent analysis, interview recordings were reevaluated to ensure accuracy and quality of transcriptions, translations, and themes.

4. Results

The final sample consisted of 15 Japanese medical professionals. Participants included six women and nine men, five physicians, five nurses, three medical ethicists, one medical social worker, and one clinical psychologist. In contrast with previous studies of informed consent in Japan, physicians were not all male (Elwyn et al., 2002). Nurses were also not all female (Table 1). Their ages ranged from mid-20s to late-60s and they were from various regions around Kyoto, Tokyo, Osaka, and Kobe. They had experience at medical institutions such as local city hospitals and large university medical centers, and their specialties included oncology, cardiology, obstetrics and gynecology, geriatrics, nephrology, and neurology. To maintain interviewee privacy, I do not note identifying information besides profession and gender.

From these data I identified four themes, described here as dynamic axes of informed consent (Table 2). Each axis discursively and practically shapes how informed consent is conceived and practiced in contemporary Japan. The affective axis highlights how feelings such as satisfaction, anxiety, and stress shape perceptions and practices of

informed consent. The professional axis reveals the critical role played by support staff in managing these affective dimensions of informed consent. The practical axis identifies tensions between theories of informed consent and the considerations that shape actual practices. The conceptual axis suggests how the terms *jiko kettei* and *omakase* are used to refer to foreign and traditional elements of informed consent. In the following section I describe each of the four axes in turn.

4.1 Affective Axis: Anxiety and Satisfaction

Participants' narratives highlight the affective dimension of informed consent. Physicians and support staff all described examples of informed consent going well in terms of patient and family satisfaction, while instances of informed consent going poorly were described in terms of their or their patients' anxiety, worry, and stress.

Some physicians stated that they worried about whether they were doing informed consent well, especially whether patients and family would become angry with them. Others were confident about their abilities to do informed consent well but were not self-aware about their practice (8, physician).

Patients' and families' negative emotional reactions were thought to result from mismanaged expectations. Physicians who reflected on their practice suggested that if patients do not understand their diagnosis or treatment well, this skews their expectations, and they may become angry with the care team later. One physician said that to handle this, he tells patients and families the worst case scenario first (14, physician). That way, if things go well, they are lucky, and if things go poorly, they are not surprised. This same physician recognized that his own communication skills only go so far, so he said

the nurse's follow-up is essential to ensure that expectations match reality. A nurse reinforced this point:

> What are patients anxious about? It's when they don't understand what the doctor said, not because they're anxious about treatment. Not all people can understand what the doctor says. And it can be hard for patients and families to say that they didn't understand. The nurse needs to follow up and figure out what these things are. Doctors have gotten better at explaining, but not all doctors (9, nurse).

Support staff recognized that disclosure is stressful for the physician as well as the patient and family. Many suggested that additional communication training would be helpful for physicians, not just to ensure that informed consent goes well, but to support the physician. In a nurse's words, "Bad news isn't just bad for the patient and family, but for the physician as well. More support is needed for physicians and for cancer patients. This is beginning to take hold, but…"(5, nurse).

On the opposite side of informed consent going poorly was informed consent going well through patient satisfaction. For some physicians, patient satisfaction is important because it makes patients compliant. In response to the question, "what is the purpose of informed consent?" one physician suggested:

> For people to feel satisfied. For them to understand and take their medicine. To adhere to what the doctor says. If they don't understand what's going on, treatment isn't so easy and this isn't good. Ideally, you do informed consent, and the other person thinks, and you have an exchange and decide on treatment (8, physician).

Another physician proposed that informed consent is done well if the patient thinks that the physician is a good person (15, physician). Thinking of a physician as a good person may also produce compliance with the physician's suggestions.

For other physicians, patient satisfaction helps patients deal with an uncertain future (11, physician; 14, physician):

> I can't think of any cases where it would be good not to tell (to tell = *kokuchi*). Basically, the result of a test is something that shapes expectations, and you should tell things that let people anticipate the future (15, physician).

Some professionals described the management of expectations as a relational process between patients, families, and professionals (4, physician; 5, nurse):

> A Japanese way of thinking would be the way patients and families think together in local hospitals. The kind of communication (*taiwa*) (7, social worker).
>
> Decision-making should be *suriawase* – bouncing ideas off each other to find a fine-tuned integrated whole. You want to find points in common. The goal is to both not have stress (9, nurse).

For these professionals, addressing the affective dimension of informed consent involves ongoing management of expectations and negotiation of the future. It is more than a single disclosure; telling a diagnosis opens the door to collaboratively imagining future possibilities.

Some participants expressed anxiety not just about patient reactions, but about legal ramifications:

> In the past 10 years it [informed consent] has changed a lot, there aren't really any things that shouldn't be said. There is the fear of being sued… Now, if you don't

> tell the correct things, if this affects the options, then you might be sued. So more than the patient's feelings, despite the patient's anxiety, you have to tell the correct information early so they can make a good decision. If you don't tell when it's discovered, you can be sued. So whether it's good or bad, you have to tell (11, physician).

Institutional and legal pressures can lead to practices of informed consent that are more oriented towards avoiding lawsuits than reducing patient anxiety.

Some support staff described physicians as primarily concerned with whether or not the information is conveyed and the patient gives consent (6, clinical psychologist). This legalistic approach to consent was often explained as a temporary phase, with affectively engaged informed consent posed as a preexisting tradition in Japan and as a goal for improving informed consent practices. According to one physician:

> For people who thought you ought not to tell, it was quite aesthetic (*bigaku*). Really, the patient noticed, that nobody was telling them but that they really had cancer. So the family, and the nurses, maybe not the patient, but everyone was lying to them, and the patient noticed, but they [the patient] wouldn't say it. If they said it, they would have to talk about how hard everyone was working for the patient, how difficult it was, it would be noisy, it would be difficult, and to know this without saying it is happy (*shiawase*). So for people who weren't told, they probably noticed the truth, but then they could have a stronger trusting relationship, and while it's weird to say that to tell a lie is basis for trust, it showed that everyone was thinking a lot about the patient, and wouldn't touch on the patient's diagnosis, and they would use a different expression (11, physician).

For some participants, managing affective responses is part of nonverbal communication in Japan. This entwines ethics with aesthetics – what ought to be done is what feels good, and what feels good is what is right. Several participants noted, however, that whether informed consent is *right* is defined by law, leaving little room for informed consent to feel good.

Nevertheless, affectivity also seemed to be at the root of changes to informed consent practices in Japan that combine legal responsibility with affective responsiveness. In the words of one physician, informed consent has to do with transferring responsibility from the physician to the patient, but it is also for the good of the patient (15, physician). While assuaging patient anxiety is often aimed at satisfaction, one nurse suggested that anxiety can lead to coercion: "If it seems like patients or families are feeling anxiety, it's best not to proceed but to try to address or reduce their anxiety or doubt before proceeding. Otherwise it seems coercive (*gōin*)" (9, nurse). By exploring the relationships between affective responses and institutional or legal requirements, these professionals may also be creating new ways of theorizing and practicing informed consent.

4.2 Professional Axis: Physicians and Support Staff

Participants frequently drew attention to their professional roles in the informed consent process. This adds an additional layer to the affective dimension of informed consent. As described above, physicians are often not confident that they can avoid patient and family anxiety, and support staff are also critical of physicians' abilities. This results in professional tension between physicians, who are legally responsible for

informed consent and yet least confident about its affective dimensions, and support staff such as nurses and clinical psychologists, who are more capable in managing affect and yet less recognized for this dimension of their work.

Physicians recognize that they have control of the informed consent process. One physician stated that he did not consult with anyone before informed consent, and that, as primary physician, he determined how informed consent would be done (15, physician). All physicians said that they would encourage families to be present for diagnosis disclosure, in some cases scheduling a separate meeting so that families could attend. Physicians and support staff acknowledged that nurses (and sometimes social workers) are also routinely present for informed consent.

While all participants spoke to their unique professional values, nurses and support staff were the quickest to make distinctions between their roles and responsibilities in the informed consent process and the roles and responsibilities of physicians. They described physicians as authority figures who are focused on treatment and the physical and biological metrics of treatment success. In the words of one young nurse, "The physician only speaks about facts, about medicine, so it's the nurse's job to deal with lifestyle and other issues, and to ask patients about them. I learned this by watching, not in school" (10, nurse). Nurses viewed physicians' practiced critically. As one nurse stated,

> In the past, physicians would explain all at once but then just decide [on treatment] themselves. Things have changed a little. Physicians now explain statistics, side effects, merits and demerits, but they still explain everything all at once and then just hand over the informed consent form and don't check to see if

> the patient has really understood. This is the majority. Patients don't really research on their own and then ask physicians questions. Physicians just explain the "menu" of treatment options and ask patients to decide. But when patients receive a diagnosis there is often an emotional shock, and they often don't remember all of the options (10, nurse).

Given this gap between patients and physicians, nurses described their role through three types of facilitation: setting the stage for informed consent (*bamen settei*), coordinating the roles of various medical professionals involved in consent (*kōtsu seiri*, lit. "traffic organization"), and following up with the patient to make sure that they have understood and have shown their "true face" in the decision-making process. As a social worker described,

> The face that the patient shows to different medical professionals might be different, so you have to get together and unify/integrate/synthesize (*tōgō*) these and try to figure out the patient's true feelings. (7, social worker).

Nurses noted that while this system of preparation, coordination, and follow-up is important, in many hospitals it is not well established, and staff shortages can make it difficult (5, nurse). This is compounded by the problem of busy physicians, who often do not have the time to form the relationships with their patients that they would like (13, nurse).

Support staff had a critical perspective on patients as well. They noted that patients want to flatter their physicians, at the risk that any offense will lead to worse treatment. This gives physicians a sense of superiority: "A lot of people want the doctor to do everything, to make them into a God. People are dependent (*tayori*) on them, and

this gives them a sense of superiority (*yūetsukan*)" (7, social worker). Nurses and medical social workers see a different side of patients:

> Patients and families want to be on the good side of physicians, so they don't want to ask them [physicians] a lot. It's hard to talk to them directly – they do it indirectly, through the nurse. Patients really try to flatter the physician. Nurses and physicians quarrel about this a lot. Nurses feel they have to be patients' advocates (10, nurse).

Nurses often described their role as patient advocate, or in the words of a social worker, an "intermediary (*chuukai*)" between the physician and patient (7, social worker).

One nurse explicitly connected this to self-determination*:* "There isn't really a system of support. But the nurse is there to make sure that people aren't alone in these decisions, they get close to the patients (*yorisou*). Especially with mothers. They will massage the mother's feet, talk to them, stay close with them until they can have self-determination (*jiko kettei*) (13, nurse)." Nurses ensure that patients are not alone in decision making.

This professional axis highlights the dynamics between physicians and support staff in navigating the affective dimensions of informed consent. While physicians focus on structuring expectations through their explanation of diagnoses, prognoses, and treatment options, nurses and other support staff work behind the scenes to form relationships with patients and families, ensure adequate understanding, and manage emotional reactions.

4.3 Practical Axis: Principles and Practice

Participants also explained informed consent along an axis from a principled ethical requirement to a particular, situated practice. The ethical justification for informed consent practices is based in *principle* – it is something that must be done lest patients' rights are violated. But it is also experienced as a complicated, interpersonal, affective practice. This had a significant effect on why participants thought that informed consent should be done in the first place. While principled demands for informed consent are acknowledged, they are often cast aside in practice in order to respond to the situational features of medical decision-making unacknowledged by principles: shock, discomfort, fear, and abandonment.

Informed consent as a principled ethical requirement was often introduced with skepticism. As one nurse described it, "To tell (*kokuchi*) is a principle, but people still don't tell" (1, nurse). A medical ethicist suggested that this may be because relationships are paramount in Japanese society, "Physicians want to be better at communication. Of course, principles are important, but the physician-patient relationship has more weight than ethical or legal principles" (3, medical ethicist). Principles are seen as non-relational, exclusive of the particular affective dimensions of consent.

This axis is apparent in physicians' accounts of their informed consent practices. Some physicians described informed consent as, in principle, a transfer of responsibility from physician to patient (4, physician), or "explanation for a [patient's] choice" (8, nurse; 14, physician). In other words, informed consent is a transaction—physicians have to explain the situation so that patients can make a free choice. Yet few physicians left patients to make these decisions completely independently, and instead told patients what they thought the best plan of treatment would be (8, nurse; 11, physician).

Informed consent as a principled transaction was seen as unrealistic in a society in which making choices together is highly valued. A nurse noted that when physicians understand informed consent too literally, this can "forsake/abandon [*misuteru*] patients to the choice" (10, nurse). A physician agreed, suggesting that making choices may be something that Japanese patients are unfamiliar with:

> To be told the truth, to react to it, together, to think together, has a positive meaning, but there are also people who aren't used to it, who passively can't think about this strongly, they are told in a jumble, they can't understand. Originally, maybe, until now most people think that it is best to entrust things to the physician, and they feel thankful if they can do this. If you're told, then to actively choose, to have to decide, to take on responsibility, maybe comparatively people in the U.S. are more used to this (11, physician).

The practical dimension of informed consent is apparent in participants' descriptions of how they learned informed consent. Both physicians and nurses learn through observation. Few reported specific training in informed consent, although one physician had practice with a mock patient and had been instructed to do a *jiko shokai*—a self-introduction—prior to informed consent to reduce physician, patient, and family anxiety (11, physician).

Informed consent practices are diverse. As a result, physicians' informed consent education depends on their senior physician:

> At a small hospital, they'll say something looks suspicious, they need to do a more detailed study. They explain little by little and don't give a full diagnosis until they're sure… When they're sure, they ask the patient to come with a family

> member to explain the diagnosis… But there are also physicians who don't say anything at all while doing the exams to determine if it is cancer, and these patients are really surprised. Young doctors learn how to do this gradual revealing of the diagnosis little by little through practice (5, nurse).

This does not mean that informed consent practices must imitate those of senior physicians. As two physicians noted, trainees follow their senior physicians early on but then develop their own style of performing informed consent over time through trial and error (11, physician; 14, physician). One young physician explained that he knew when his explanations were too blunt, because the patient or family would become angry. However, he said he was not always sure how he could have done better (15, physician).

Nurses also learn informed consent practices experientially. One nurse noted that her first two years observing disclosure practices helped her to reword physicians' explanations (10, nurse). Nurses' role in these meetings is to pay attention to how the physician is explaining the situation so that the nurse can supplement this later and confirm understanding (9, nurse; 10, nurse). As with the previous professional axis, this further highlights professional differences in responsibilities for the informed consent process.

The upshot of this practical, experiential training is that participants' informed consent practices differ depending on the situation:

> The thinking about physicians and medicine, among Japanese people, is very diverse, so one rule, something like a golden rule or decided by a golden procedure, something where if it is done everyone will be happy, this kind of guideline that is done at every hospital and makes everyone happy, maybe there

> aren't any rules like this. Informed consent is more of a personal event, so, while there are parts that are determined by guidelines, these parts are not so great (6, clinical psychologist).

Participants emphasized that, while certain aspects of informed consent may seem significant in principle, these principles break down in practice. There is repeated emphasis on "fitting information to the patient" – not just what information is conveyed, but how it is explained. For example, a social worker said that, "the medical team should get together and discuss how the particular patient will best grasp the relevant medical information" (7, social worker). A nurse stated that, "How much is told is fit to the patient's precise circumstance" (5, nurse). One physician described himself as explaining facts relatively objectively, but case by case: "It's hard to say that 100% something is always done, it's case by case" (8, physician). Given this situational understanding of informed consent, support staff play a critical role in facilitating informed consent done well.

Informed consent as principle was often discussed in the context of law. Many participants saw a conflict between the universal demand to always tell patients their diagnoses – interpreted as a way to avoid a lawsuit – and the need to respond to the particular patient in front of them. In the words of one medical ethicist, "There are few lawsuits in Japan, and lawsuits relating to medicine are very difficult to resolve. Informed consent has become an easy way to determine whether any errors occurred" (2, medical ethicist). While medical professionals in Japan describe informed consent as pragmatically situational, they acknowledge that being able to say "informed consent was done" is important for forestalling messy legal action.

4.4 Conceptual Axis: *Jiko kettei* and *Omakase*

At the broadest level, medical professionals described informed consent on an axis ranging from *jiko kettei*, or self-determination, to the *omakase seido*, or *omakase* system. *Omakase* means to entrust decisions to another person, as is often heard in restaurants in Japan, where to ask for an *omakase* set is to have the chef determine the contents of one's meal. By contrast, *jiko kettei* is usually translated as self-determination.

The meaning of this axis was explained in two distinct ways: as a comparison of the U.S. and Japan, and as a spectrum within Japanese society. The two explanations are not mutually exclusive: the U.S. was often associated with trends of modernization in Japanese society.

In the first type of explanation, the U.S. is presented as a *jiko kettei* society and Japan as an *omakase* society. A physician speculated that this is because the U.S. and Japan have different social structures; self-determination may be important in a diverse, competitive society (4, physician). Another physician explained that the U.S. is a contractual society and suggested that in Japan trusting relationships are more important (8, physician). As American, *jiko kettei* was also often identified with the ideal principle of respect for self-determination underlying informed consent. In the words of one nurse, "the ideal of informed consent is that it is for patients' self-determination [*jiko kettei*] (9)."

Given this association between *jiko kettei* and the United States, descriptions of informed consent in terms of *jiko kettei* imply an ideal of self-determination unattainable in Japan. As in the previous axis, where informed consent in principle is perceived as

inapplicable to the Japanese context, the ideal of *jiko kettei* is described as a foreign concept out of sync with the practical realities of Japanese social life. Many participants wondered how to best fit the ethical idea of *jiko kettei*, and by extension informed consent, with Japanese society:

> Japan is dealing with a lot of ideas about the individual that have been brought from abroad, like advance directives, informed consent, but Japan should take a pause today and think about these things more carefully… So among these issues, the most important ethical issue is Japan's originality. Not just thinking about what people are doing abroad, but what should happen in Japan (7, social worker).

In this context, *omakase* is the traditional Japanese approach to medical decision-making. It is implied that some patients want to leave decisions to their physicians, since the physician has more knowledge and training in medicine than the patient. This may be conceptualized as "Japanese paternalism," or in the words of one physician, as *tsuyome* (strong/paternalistic) doctors who "guide the patient's conclusion based on how they explain the situation. How the information is connected" (15, physician). While for this physician paternalism was undesirable, according to a clinical psychologist, *omakase* is not necessarily bad.

> Up until now, Japan has… there is Japanese paternalism. There is *omakase*. And it seems that this has gone well (*umaku itteitayou*). Quite well. They properly do *omakase*. There are many physicians who think this is good. There are also many patients who think this is good… This *omakase seido* is the opposite of *jiko kettei*. (6, clinical psychologist).

While some participants identified *omakase* with Japanese custom, others introduced a second meaning of *omakase* and *jikokettei*: as a spectrum of Japanese preferences for decision-making. This same clinical psychologist described broad demographic differences, including age and education, in preferences for *omakase* versus *jiko kettei.*

Most participants shared these sentiments – that Japanese society is changing, and that some prefer the *omakase* system while others are more comfortable with *jiko kettei*. One physician suggested that *omakase* patients are older and more rural, while *jiko kettei* patients are younger and more urban (8, physician). However, despite demographic preferences for *omakase* and *jiko kettei*, a nurse emphasized that *jiko kettei* might happen less frequently than it seems:

> In the case of Japanese people, the number of people who decide just by themselves is unusually small. Compared with the past it's increased, but people still give explanations to the family, to the wife/husband. This is Japanese culture, so to decide by one's self, to take responsibility, is not Japanese culture. You decide with your family, you proceed with your family. This is decision-making within the family (*kazoku no naka no ishi kettei*). It's important to take this seriously (5, nurse).

A social worker echoed her perspective: "Patients still entrust almost everything to the doctor (*yudaneru*). Informed consent is just patients following what physicians want. There isn't really a sense of *jiko kettei*. People live for such a short time, so they entrust these things to the physicians… (7, social worker)." There seem to be two types of *omakase*: one in which patients follow physicians recommendations out of anxiety or fear, and one in which patients intentionally choose to entrust medical decisions to their

physicians – not because they do not care about the outcomes, but because they have more important aspects of their lives on which to focus their attention.

The meaning of *jiko kettei* was occasionally aligned with *ishi kettei.* As in the quote above, *ishi kettei* is translated as decision-making, rather than the self-determination of *jiko kettei.* As such, *ishi kettei* makes room for the relational aspects of decision-making. A commonly heard phrase was "*ishi kettei shien,*" or decision-making support. According to one young nurse, it is often said that Japan has lots of policies to support decision-making (*ishi kettei shien*), but she was not sure if this is really the case. In her words, "It's difficult to change this…in the actual situation" (10, nurse). As in the first dynamic axis, there is still work to do in navigating the complicated space between ethical standards and affective interpersonal practices.

5. Discussion

This study identifies four axes along which informed consent in Japan is conceptualized, explained, and justified (Table 2). According to the first axis, informed consent is a process of rational and attitudinal coordination that, when done well, can manage expectations and build a foundation of mutual trust, which is beneficial if conflicts arise. Affect is a strong motivator and shaper of informed consent in Japan, but because affective work is often invisible and informal, it may be difficult to reconcile with informed consent as a legal requirement for transparency. Medical professionals are exploring how affect might help them pick out the connection between what feels good and what is right.

While informed consent is often described as a patient's evaluation of medical information for an autonomous, rational choice (Faden and Beauchamp, 1986; Beauchamp and Childress, 2013), the affective dimension of consent highlighted here suggests that emotions and attitudes play a substantial role in informed consent practices in Japan. Medical professionals provide information to patients and families as data for decision-making, but also as benchmarks to set expectations and to reduce anxiety. It is unlikely that this consideration of affect is limited to Japan. How one describes treatment options will affect an anxious patient and a confident patient very differently, and will have further implications for the level of trust in the medical team (Fujimori et al., 2005). Yet this affective dimension of consent is only occasionally discussed in theoretical or practical accounts of informed consent (Little, 2009).

This may be because much affective labor is informal, with support staff ensuring that poor understanding does not contribute to negative reactions. The second axis thus highlights the different roles performed in informed consent practices in Japan. Physicians guide medical treatment and initiate decision-making procedures; support staff advocate for the patient and facilitating decision-making. This division of labor is significant because both roles are necessary for fluid execution of the disclosure and decision-making components of informed consent.

Attention to supportive roles in medical care is not novel, although it has been little discussed in cross-cultural bioethics. Maureen Coombs' 2004 book, *Power and Conflict Between Doctors and Nurses*, highlighted the invisible role that nurses play in clinical care. Coombs describes nurses as the "organizational glue" that holds the clinic together (Coombs, 2004, p. 93). This suggests that support staff such as nurses possess an

epistemically advantaged standpoint (Longino, 1990; Harding, 1991; Risjord, 2010; Wylie, 2015); their roles require them to observe and respond to physicians in addition to carrying out their own responsibilities. This gives them a window into medical care not possessed by physicians, who are generally not required to respond to nurses as readily. However, this epistemic advantage also creates a burden for nurses, who are often implicitly expected to facilitate other professionals' work. If this facilitation is not an explicit aspect of their professional role, it is too easily unacknowledged and unrewarded. As Mark Risjord notes in reflecting on Coombs' study, "[physicians] do not appreciate the ways in which nursing work makes their treatment possible" (Risjord, 2010, p. 72).

This is born out in my results. While physicians focused primarily on their own informed consent practices, nurses were able to speak to the practices of both support staff and medical staff. This enriches the understanding of how informed consent is practiced—with a three part system of *bamen settei* prior to disclosure, facilitation or *kōtsū seiri* during decision-making, and follow-up confirmation post-informed consent—and undermines the common understanding of informed consent as grounded in the physician-patient relationship. Yet while there are reports in Japanese of the role of nurses in informed consent, they are rarely discussed in the theoretical literature (Kobayashi et al., 2000; Yamada et al., 2012; Mitsuhori et al., 2013).

Underappreciation of the interplay of these roles has both theoretical and practical implications for informed consent. The exclusion of nurses' perspectives from studies of informed consent (in Japan and worldwide) renders nurses' practices invisible by presuming that the ethically significant set of actors in informed consent is some combination of physicians, patients, and family. Yet as this study shows, nurses play an

important role in facilitation of informed consent. Focusing on physicians as the only significant medical professionals in informed consent is both epistemically and ethically unsound if it precludes understanding and improvement of informed consent practices.

This is not just a theoretical point. If support staff play a central role in facilitating decision-making and informed consent by managing physicians', patients', and families' affective responses, then this role needs to be acknowledged and rewarded. Without acknowledgment, it will be difficult to identify why some informed consent practices fail and why others are successful. Without reward, support staff are more likely to experience frustration and burnout. Concrete attempts to improve informed consent require an expanded perspective beyond the physician-patient relationship.

This is easier said than done. The affective dimension of informed consent both takes place and is learned informally and experientially, making it difficult to fit into standard, principled accounts of informed consent. The third axis highlights the relationship between the principled understanding of the purpose of informed consent and the practical need to respond to particular patients' situations. Conceived as a general standard that respects patients' rights or prevents lawsuits, mandatory informed consent is perceived as inflexible. As many participants noted, there are some situations in which it is just better for patients not to know their diagnosis.

Ethics in Asia is often described as particularist, while Western ethics is characterized as principlist (Traphagan, 2013). While many participants in this study questioned the idea of ethical principlism (according to which ethical decisions are determined by making reference to general ethical principles), their responses acknowledged the theoretical significance of principlism while questioning its practical

usefulness. Their emphasis on experiential learning implies not that Asian ethics is uniquely particularist (according to which there are no ethical principles), but that developing ethical informed consent practices requires more than principlism (Specker Sullivan, 2016[1]).

Finally, the fourth axis shows that cross-cultural reflections do play into informed consent, but in more complex ways than commonly thought. Informed consent is conceptualized along a spectrum from *jiko kettei* to *omakase*. Viewed through the lens of traditional theory in medical ethics, the former end of the axis is aligned with respect for patient autonomy while the latter end is aligned with paternalism (Beauchamp and Childress, 2013). However, embracing traditional theory obfuscates the dynamic nature of this conceptual axis. *Omakase* is not necessarily paternalistic, as it is often initiated by patients themselves. A more apt description might be "medical maternalism," where the physician decides for the patient and this is what the patient really wants (Specker Sullivan, 2016[2]). Likewise, *jiko kettei* suggests that the patient wishes to be the locus of decision-making, but not necessarily that they want to make decisions alone. This is evidenced by the use of the phrase "*ishi kettei shien,*" or support for decision-making. Support for decision-making ties together many of these themes in Japanese informed consent, reflecting affective dimensions of decision-making, informal coordination of team decision-making, and pragmatic responses to particular circumstances.

6. Conclusion

Prior studies of informed consent in Japan have focused on nondisclosures of cancer diagnoses and relied on physician narratives and survey responses to characterize

Japanese informed consent (Long and Long, 1982; Elwyn and Fetters, 2002; Long, 2005). The resulting picture has been one of non-disclosure practices rooted in traditional Japanese social norms, with physicians assuming control of decision-making out of paternalistic concern for the patient and the family and in the face of a disease that is greatly feared. This offers a striking contrast with informed consent in the U.S., where diagnosis disclosure is thought to be part of respecting patients' rights to autonomously make choices for themselves.

The results of this study complicate this neat dichotomy. The inclusion of support staff such as nurses, medical social workers, and clinical psychologists highlights the background facilitation and coordination that makes informed consent possible while also revealing the educational and institutional challenges that render it difficult. Understanding Japanese informed consent practices requires recognizing the tension in axes such as anxiety-satisfaction, physicians-support staff, principles-practice, and *jiko kettei-omakase*. These axes reveal the dynamic nature of motivations and reasons underlying participants' conceptualizations and practices of informed consent. Japanese informed consent is not just one practice, but is a set of responses to conceptual, professional, practical, and affective tensions.

The physicians I interviewed want to help their patients, but they are also uncertain about their communication abilities, anxious about negative emotional reactions, and eager to form relationships that patients find satisfying. They recognize that each patient and family is different and that this requires situational sensitivity, yet they acknowledge a principled obligation to always tell the truth. They may be unaware that support staff are working to ease this process. Support staff facilitate and coordinate

patients' and families' understanding, assist in their decision-making, and manage their emotional reactions. None of these characterizations are starkly different from concerns in North America, where patients are just as emotionally vulnerable, physicians are just as uncertain, and support staff are just as underappreciated. Americans are also critical of informed consent in principle, noting that an exclusive focus on autonomy may obscure other issues, such as patient welfare and socialization (Schneider, 1998; Gaylin and Jennings, 2003).

As in North America, Japanese informed consent is dynamic, with complex, interlocking pieces. If patients are not always told their diagnoses, this is not necessarily due to unique Japanese attitudes about cancer or conceptions of physician responsibility; these are just two pieces of the practice. Affective understandings of a process going well, professional roles and value structures, practical tensions with ethical principles, and systems of decision-making and authority contribute to the ethical analysis of the practice. These features do not so much highlight the unique aspects of Japanese informed consent as they identify aspects of informed consent practices that have been underappreciated and under-theorized worldwide.

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Table 1. Interview Participants

Number	Profession	Gender
1	Nurse	Female
2	Medical Ethicist	Female
3	Medical Ethicist	Male
4	Physician	Male
5	Nurse	Female
6	Clinical Psychologist	Male
7	Social Worker	Female
8	Physician	Male
9	Nurse	Male

10	Nurse	Female
11	Physician	Female
12	Medical Ethicist	Male
13	Nurse	Female
14	Physician	Male
15	Physician	Male

Table 2. Dynamic Axes of Japanese Informed Consent

Anxiety ←→ Satisfaction

Physicians ←→ Support Staff

Principles ←→ Practice

Jiko Kettei ←→ *Omakase*