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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 to 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.

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1. Introduction

Japanese informed consent has long been of interest outside Japan (Long and Long, 1982; Higuchi, 1991–92; Elwyn et al., 1998, 2002; Long, 1999; Akabayashi et al., 1999; Ruhnke et al., 2000; 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 et al., 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 and Teshima, 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, 2002), indirect communication (Kakai, 2002), and the role of the family (Akabayashi et al., 1999; Akabayashi and Slingsby, 2006) have been used to explain

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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 standards.

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; Emanuel and Emanuel, 1992; Leflar, 1996; Wear, 1998; Joffe and Truog, 2010). The Japanese discussion on informed consent also foregrounds the physician-patient relationship (Morioka, 1994; Uchiyama, 1994; Tanida, 1994) and, if not defending alternative forms of autonomy (Akabayashi and Slingsby, 2006), then argues that Japan is behind the West in recognizing the ethical necessity of informed consent (Morikawa, 1994; Seo et al., 2000; Masaki et al., 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; Beachamp 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, 2007; Olthuis et al., 2014) in the face of the vulnerability and uncertainty that accompanies illness (Schneider, 1998). There has also been increased interest in different roles that medical professionals and family can play in shared decision-making (Nelson and Nelson, 1995; Charles et al., 1997, 1999). 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, 2005; Seo et al., 2000). 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

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