

Scientific Contribution

Cultural Bias in the Medical-Ethical Discussion of Health Care Proxy What Difficulties do Gays and Lesbians Confront in Japan?

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Abstract :

This paper highlights a cultural bias in the medical-ethical discussion in Japan of health care proxy. In particular, the paper looks at a discussion by expert committees that prepared and evaluated the Guidelines for Terminal Care issued by the Ministry of Health, Labour and Welfare in 2007. An absence of institutional guarantees of same-sex partnership and of relationships with gay and lesbian friends causes many difficulties in medical institutions for gays and lesbians in Japan. For example, due to the lack of such legal protections, a gay or lesbian patient and his or her partner are often hindered from seeing each other by social custom. To improve this situation, gays and lesbians campaigned for terminal care guidelines sensitive to their needs. In particular, they discussed whether same-sex partners were covered by the definition of family described in the guidelines and proposed the legal stipulation of a health care proxy. Despite these activities, there was almost no discussion about the two issues in the committees' discussions. This significant omission by the committees reflects a general cultural bias against gays and lesbians. This cultural bias needs to be neutralized by ensuring special representation rights for minorities, including gays and lesbians.

Keywords : cultural bias, definition of family, friendship, gay and lesbian, guidelines for terminal care, health care proxy, multiculturalism, same sex partnership, special representation rights, terminal care

1. Introduction

The aim of this paper is to reveal a cultural bias in the medical-ethical discussion in Japan of health care proxy. In particular, it looks at a series of discussions in 2007-09 by the expert committees that prepared and

evaluated the Guidelines for Terminal Care issued by the Ministry of Health, Labour and Welfare in 2007. The committee members framed the discussions of health care proxy as culturally neutral. In this paper, in order to show the cultural bias against gays and lesbians that the committee members ignored, I illustrate the difficulties gays and lesbians in Japan confront in the terminal phase of care. Then, I describe the concerns expressed by gays and lesbians in their mostly unsuccessful campaigns to convince the Ministry of Health, Labour and Welfare to issue guidelines that reflected their unique needs regarding health care proxy.

The issue of health care proxy in medical institutions touches all of our lives. None of us know if or when we will be injured or fall ill and, thus, require the services of a medical institution. Also, none of us can know if or when we will lose consciousness or mental competence. Moreover, none of us can make every decision in advance in preparation for any such eventuality. Indeed, all of us face the considerable chance that some decisions in medical institutions may need to be made for us by proxy. Thus, owing to the universality of the issue of health care proxy, it is vitally important to maintain fairness in discussing the issue and not let any bias related to one's social category influence the discussion.

In general, issues of health care proxy can be divided into two questions: (1) "what can be decided by proxy" and (2) "who can be a proxy." The latter question can further be divided into (a) "whether or not the closest person to the patient is the right person to make decisions as the proxy" and (b) "how do we measure closeness" or "how do we define 'family'".¹ "What can be decided by proxy" and "whether or not the closest person to the patient is the right person to make decisions as the proxy" have been considered to some extent in the literature about medical ethics². However, so far, the definition of family has been discussed in neither the medical-ethical field nor the current legal system. Due to a lack of public discussion about the legal definition of family, unspoken social convention largely decides who can be a proxy, and, as a result, relationships not recognized by custom are oppressed in medical institutions.

Gays and lesbians in Japan pointed out this unfairness in a campaign over the guidelines in 2006-07. During the campaign, the gays and lesbians keenly discussed the definition of "family" and advocated for the right of a gay or lesbian patient to stipulate one's partner as one's health care proxy.

Despite their efforts, however, there was almost no discussion about these two issues in two committees formally organized by the Ministry of Health, Labour and Welfare. In this paper, I aim to show the cultural bias of the discussions in the committees, a bias which is not limited to the committees but exists in Japanese society at large. In addition, to counter such a bias, I present in the conclusion a considered solution to the marginalization in society of minorities such as gays and lesbians.

2. The Difficulties Gays and Lesbians Face in Japan in the Terminal Phase of Care

In Japan, an absence of institutional guarantees of same-sex partnership and an absence of institutional guarantees of relationships with gay and lesbian friends cause two difficulties that gays and lesbians often confront in the terminal phase of care.

The absence of institutional guarantees of same-sex partnership in Japan means that a gay or lesbian confronts the difficulty that his or her partner has no guaranteed rights when he or she is in the terminal phase of care. This forces Japanese gays and lesbians and their partners to bear unendurable pain, because, in the absence of legal protections, they are often hindered from seeing each other by social custom, which generally only allows blood relatives to have contact with a patient in medical institutions³. This situation in Japan has been caused by: (1) the absence of a legal institution, such as same-sex marriage, civil union or domestic partnership, that protects same-sex partnership, and (2) the absence of a legal institution that establishes and defines health care proxy.

Gays and lesbians in Japan, and in many countries around the world (Chauncey, 2004), have been advocating for a same-sex partnership law to attain a broad institutional guarantee of their partnerships. At the same time, gays and lesbians in Japan also have been campaigning to secure guaranteed rights for their partnerships in the more limited arena of healthcare. Specifically, they seek the rights of seeing and caring for partners who are ill in hospital as well as the rights of getting medical information about and making proxy decisions for these partners⁴. Practically, they are trying to gain these rights through alternative legal methods such as adoption arrangements, authentic deeds, the Japanese

adult guardianship system and the Personal Information Protection Law⁵.

The absence of institutional guarantees of relationships with gay and lesbian friends means that gay and lesbian patients are often cut off from their essential support network, their extended family, if you will, at the time they need support most. Gays and lesbians have built up tight friendship networks similar to kinship, and they share a unique culture of their own (Nardi, 1999; Garner, 2005). However, people with rigid homophobia in the larger society have ignored or are ignorant of gays' and lesbians' friendship networks and this has led to the disconnection of these networks from the larger society. Sadly, this disconnection is painfully manifest in medical institutions, where gay and lesbian patients are kept apart from their indispensable friendship networks, unless they succeed in persuading the medical staffs and their legal relatives into inviting their friends as psychological supporters.

The absence of institutional guarantees of same-sex partnerships and of relationships with gay and lesbian friends results in (1) the absence of psychological supporters for the gay or lesbian patient, (2) the absence of persons who can inform the medical staff of gay and lesbian culture and (3) the disenfranchisement of the grief of the patient's gay or lesbian partner and friends (Smolinski et al., 2006).

3. Campaigns of Gays and Lesbians during the Making of the Guideline for Terminal Care by the Ministry of Health, Labour and Welfare

As a result of the difficulties created by the absence of institutional guarantees for gays' and lesbians' same-sex partnerships and for their relationships with gay and lesbian friends, keen attention was paid by gays and lesbians when the Ministry of Health, Labour and Welfare prepared to issue "Guidelines for Terminal Care" (draft version, September 15, 2006). This was the first set of guidelines the ministry had made by itself; previously, it had merely supported the Japan Medical Association and some research teams in making guidelines. Gays and lesbians hoped that the ministry, in making the guidelines, would consider the needs they have in the terminal phase of care.

Gay and lesbian individuals and groups lobbied the members of the Advisory Commission on Guidelines for Terminal Care, as well as sent

public comments and collected signatures in a campaign directed toward the Ministry of Health, Labour and Welfare. In addition, many websites in the gay and lesbian community encouraged the sending of public comments and published information on the campaign and related issues. A survey of these statements reveals which points of the guidelines attracted the concerns of gays and lesbians⁶. Many of the statements on the websites emphasized “the rights of same-sex partners.” Also, there was much discussion of whether or not same-sex partners were covered by the use of the term “family and the like” in the guidelines⁷.

In other words, the campaign by gays and lesbians over the Guidelines for Terminal Care focused on the definition of family. They claimed that unmerited problems and suffering were caused by recognizing only blood relatives and not a person who might be physically and psychologically much closer to the patient, such as the patient’s same-sex partner. For, in many cases, blood relatives do not know the gay or lesbian patient’s will or best interest as well as the patient’s partner, so they cannot advocate for the patient appropriately. Also, the overly narrow definition of family as one’s immediate biological family, often results in the unreasonable exclusion from medical institutions of the person who the patient wants to be with most. Thus, gays and lesbians insisted that a same-sex partner is much closer to the patient and can advocate for the patient more appropriately than blood relatives, and that, for many gays and lesbians patients, their greatest wish is for their partner to be their advocates. For these reasons, the issues highlighted by the guidelines campaign were the definition of family and the question of who is closer to gay or lesbian patients, blood relatives or same-sex partners⁸.

The guidelines campaign was the first time in which gays and lesbians focused on the issue of terminal care, and it achieved success to some extent. Note 10 of the guidelines slightly widened the definition of family to: “The definition of family members contains not only legally-defined relatives but also other caring persons widely, because the term ‘family members’ means the persons whom the patient relies on and who support him/her in the terminal phase of care. (The definition is the same in other parts of this guideline)” (Commentary on the Guidelines for the Decision Making Process in Terminal Care, final version, May 21, 2007)⁹. Despite this note, however, there was almost no discussion about “the definition of family” in the

proceedings of the Advisory Commission on Guidelines for the Decision Making Process in Terminal Care, the body which made the guidelines, and the Advisory Panel on Terminal Care, the body which succeeded the former after the publication of the guidelines¹⁰.

During the campaign over the guidelines, in addition to the discussion of the definition of family mentioned above, some gays and lesbians proposed attaining the legal right to stipulate one's health care proxy as another way to improve the situation of gays and lesbians in terminal care. An explicit guarantee of the right to a health care proxy would allow a patient to appoint anybody as his or her proxy, no matter how family is defined. However, although a panel member, Naoki Ikegami, professor of medicine at Keio University, briefly raised the issue of health care proxy, there was almost no discussion about the issue by either committee¹¹. Moreover, Norio Higuchi, professor of law at the University of Tokyo, explicitly criticized any discussion of a guarantee of health care proxy.

His criticism referred to a case in Imizu City Hospital in Toyama Prefecture, in which a surgeon removed ventilators from seven patients in the terminal phase with the consent of family members. Criminal charges were subsequently filed with prosecutors against the surgeon on suspicion of murder. In the end, the case against him was dropped. The case's larger significance is that it caused much discussion, both in the public media and among medical workers, that a guarantee of the stipulation of advanced patient directives, such as living wills or health care proxies, was needed. Against this widely held opinion, Higuchi said:

Today in Japan, many people complain that the laws about medical issues are vague and unclear. But I think, in fact, the laws deliver a definite message, saying that everyone is free to choose their way of living or dying, and that nobody wants to be forced into only one way. Current law has supported the ideas that we do not want to be told to die if we fall into a certain condition, or to live even if we enter into a certain condition. This is indicated by the attitudes of the prosecution, the police and the court not to decide the case easily as a legal issue. They mean that these issues are not legal issues and that medical staffs need not fear the law.

(Proceedings of the 4th meeting of the Advisory Panel on Terminal Care)

Higuchi said that people wanted to be free to choose their way of living or dying, and not to be controlled in this choice by any legal stipulations. And he indicated that current law had clearly supported this idea. He further suggested that laws should be indifferent and neutral to issues in the medical arena. Based on this assumption, he attacked the current trend of considering the medical issue of the terminal phase to be a legal issue. Unfortunately, his attitude was shared by many of the members of both the Advisory Commission on Guidelines for the Decision Making Process in Terminal Care and the Advisory Panel on Terminal Care.

4. Cultural Bias and its Correction: Introducing the Idea of Liberal Multiculturalism to the Discussion of Health Care Proxy

The statement of Higuchi that the medical issues of the terminal care should be solved not by legal institutions but by careful discussion among those concerned seems to be conscientious and considered. But the absence of legal institutions regarding living wills or health care proxies does not simply mean that no decision has been made (Lessig, 2000). In fact, it reveals the silent acceptance of the various politics regulating medical decisions in the terminal phase.

As mentioned above, gays and lesbians in Japan confront many difficulties in medical institutions. However, if legal institutions, such as a health care proxy law, were to be guaranteed, the difficulties gays and lesbians in Japan confront in medical institutions would be diminished. Thus, although the medical-ethical discussion of health care proxy seems to be neutral to some observers, such as Higuchi, it contains a cultural bias that brings advantage or disadvantage to certain persons.

Therefore, we must detect, judge and rectify cultural bias, of which we may not even be aware, in legal institutions and related discussions. As one way to fulfill this responsibility, I propose introducing a liberal multicultural approach to the discussion of health care proxy.

Will Kymlicka, who is one of the greatest political philosophers of multiculturalism, says that the traditional idea of an ethnoculturally neutral state is misleading and that it needs to be replaced with a new model of a liberal democratic state, which Kymlicka calls the

nation-building model (Kymlicka, 2001). From the modern era to the present, almost all states have engaged in a process of “nation-building,” which means a process of promoting a common language, and a sense of common membership in, and equal access to, social institutions based on that language throughout its territory. This process integrates all members in its territory culturally to one nation-state, which is usually dominated by a major nation in the state. On the one hand, nation-building serves a number of important goals. For example, standardized public education in a common language has often been seen as essential if all citizens are to have equal opportunity to work in the modern economy. Also, participation in a common societal culture has often been seen as essential for generating the sort of solidarity required by a welfare state, since it promotes a sense of common identity and membership. Moreover, a common language has been seen as essential to democracy—how can the people get together if they cannot understand one another? In short, promoting integration into a common societal culture has been seen as essential to social equality and political cohesion in modern states. On the other hand, however, nation-building often results in a serious injustice to or cultural suppression of internal minorities in the nation-state’s territory.

Kymlicka’s liberal multiculturalism proposes a policy to promote equality by ensuring the competing rights of internal minorities in order to minimize the injustice of state nation-building operated by the dominant nation.

From the perspective of this liberal multicultural approach, let us investigate again the situations of gays and lesbians in Japan discussed above in this paper. (1) The current legal institutions in Japan, such as family laws, are advantageous for heterosexuals and disadvantageous for gays and lesbians. (2) The current legal institutions causing disadvantage to gays and lesbians are unjust, both because gays and lesbians are legitimate social members, and because the sexual orientation of gays or lesbians is not a choice but an inborn nature. (3) It will not cause any disadvantage for others or the erosion of political cohesion by ensuring institutional guarantees of same-sex partnerships and on relationships with gay and lesbian friends in medical institutions. Therefore, the current legal institutions, in which gays and lesbians have no guarantee of same-sex partnership or of relationships with gay and lesbian friends in medical institutions, need to be corrected.

To minimize this current institutional injustice, we need an effective approach which can change the present politics in medical institutions. I propose special representation rights as a practical approach (Kymlicka, 1995). Special representation rights are rights for minorities to occupy some additional seats in the national assembly and other political bodies in order for the minorities to present their opinions and discuss issues of concern to them on equal terms with the majority¹². It is very important to ensure minorities' rights, as the majority is apt to impose its opinion unilaterally and to fail to listen to the minorities' opinions. The absence of discussions of the definition of family or the stipulation of health care proxy law is just such a case.

If special representation rights are guaranteed for gays and lesbians, they will have enough power to discuss and correct current institutional injustices such as the absence of guarantees of same-sex partnership and of relationships with gay and lesbian friends. As a result, the current cultural bias in medical institutions will be neutralized politically. Therefore, special representation rights should be guaranteed for gay and lesbians, as well as other minorities.

Note

- 1 Although Japan does not have a health care proxy law (Arai, 2007), many Western countries have such laws, all of which have some stipulations on the issues of "what can be decided by proxy" and "who can be a proxy," though they vary from country to country. Generally, the stipulations prescribe both "what can be decided by proxy" and "who can be a proxy." For example, *Betreuungsrechts* or the German Guardian Law has the stipulation that, if a patient loses decision-making competence, his or her guardian can act as the patient's agent. In spite of this stipulation, the guardian cannot decide whether or not to make the patient undergo invasive medical treatment unless the written power of attorney contains a statement about it. Even with such power of attorney, no guardian is allowed to make a decision on organ donation or euthanasia. A guardian is nominated by the written designation of the patient before he or she loses decision-making competence or by court decision. Many of the guardians are chosen among family members or citizens who have personal contact with the patient. See Boeum et al. (1999).

2 There has been a large body of literature examining “what can be decided by proxy,” so this paper does not discuss the issue. This note refers to “the issue of closeness,” focusing on whether or not a person physically and psychologically close to the patient should be the right person to be the proxy, for example: (1) “can the person close to the patient make a fair judgment in a situation when his or her interest conflicts with the patient’s interest in matters such as inheritance or the physical, psychological and economic burden of caregiving?” or (2) “is it appropriate to rely on a persons’ words when their burdens can easily distort their thought?” See Tateiwa (2004) and Kawaguchi (2009).

3 A health care proxy law has not been established in Japan yet; therefore, in Japan nobody is legally designated to be a health care proxy. Notwithstanding the lack of a health care proxy law, someone has to make decisions when the patient loses competence. This institutional void has been filled customarily by the patient’s family members, such as the spouse, children or parents (Iida et al., 2008). In the future, however, this void might be gradually replaced with institutional substance. This possibility is suggested by a revision of the Organ Transplant Act (July 13, 2009) that permits the patient’s family members to make decisions regarding donating the patient’s organs if the patient has not made such decisions before losing competence.

4 In 2004, The Association Proposing Policy on Relationship beyond Blood or Marriage conducted a survey on the need for legal guarantees of same-sex partnership among gays and lesbians in Japan. This survey report shows (1) gays and lesbians strongly seek a same-sex partnership law (72.6% of the respondents replied “yes” to the question of whether you would use some same-sex partnership system if it is available) and (2) gays and lesbians especially seek rights in medical institutions (in response to questions of which rights should be guaranteed for same-sex partners, the right of seeing and caring and the right of health care proxy were given greatest priority: responses of “definitely need” were 86.4% and 81.1% respectively, and “want to use” were 87.4% and 83.2% respectively). Gays and lesbians have much more concern about rights for their partnerships in the arena of healthcare than in Western countries, such as the United States, partially because a health care proxy law has not been established in Japan. For example, in the U.S., as in Japan, social custom considers blood relatives more proper than a same-sex partner. Moreover, there is also no legal institution on same-sex partnership in most U.S. states. Gays and lesbians in the U.S., however, can use health care proxy law to secure guaranteed rights for their

partnerships in the arena of healthcare, unlike gays and lesbians in Japan.

5 I'll explain about these briefly. (1) Adoption arrangements: in Japan, it is easier to adopt someone than in Western countries; therefore gays and lesbians couples use adoption arrangements to secure guarantees based on family law, although they are treated as parent and child, not as spouses. (2) Authentic deeds: gays and lesbians have tried to achieve quasi-marriage guarantees by making authentic deeds, which describe the rights and obligations between partners. This attempt has been a failure because authentic deeds can prescribe only bilateral rights and obligations. Thus, authentic deeds are not suitable for health care proxy, because they involve others beyond the partners, such as the medical staff and blood relatives. (3) The Personal Information Protection Law: The Guideline for Appropriate Usage of Personal Information in the Medical and Caring Fields (2004) says "when you give medical information persons other than the patient/customer, you should in advance ask the patient and get his/her consent on to whom to give medical information. According to the patients'/customers' requests, you can give the medical information to their family or other caring persons similar to family, or give it to designated family members only." Gays and lesbians recognize that this guideline enables their same-sex partner to get medical information if they request it, and therefore they urge the making of an "Emergency Contact Address Card," in which they can prescribe an emergency contact, such as their partner's telephone number, in case of an unforeseen accident. There has been an active movement to distribute the cards to members of the gay and lesbian community. See Nagayasu (2009).

6 From January to March 2007, I surveyed many websites in the gay and lesbian community which published information on the campaign to send public comments, and collect and send signatures to the Ministry of Health, Labour and Welfare. Out of these websites, very influential websites were *A Gay's Normal Daily Life* by akaboshi; *NOV'S BLOG* by Akasugi; *Akasugi Nobuyoshi's Lipstick Political News* by Akasugi, *JP news* by Badi jp; *Bose Web* by Bose; *hiropage-blog* by Hiropage; *ROAD OF THE MONKEY* by mameta; *MILK* by Milk; *Japan Gay News* by Stagpass.

7 Specifically, the term, "family and the like," appears in subsection 2, "When the patient's will is unknown," of section 2, "The Decision Making Process in Terminal Care," in the guidelines. The subsection contains the following phrases: "if his/her family and the like can recognize the presumed will of the patient, it should be considered important" and "if his/her family and the like cannot recognize the

presumed will of the patient, the advice of the family and the like should be referred to.”

- 8 Needless to say, the perceptions of the campaigners were perhaps naïve. Although conflict or domestic violence sometimes exist between same-sex partners, the gays and lesbians in the campaign referred only to the good side of same-sex partnerships and not to another side. This shortcoming might have resulted from the facts that there were only a small number of gays and lesbians maintaining long-term partnerships under the absence of institutional guarantees of same-sex partnerships in Japan, and that they thus could not be adequately aware of the dark side of same-sex partnerships. See Note 2 in this paper.
- 9 The Guidelines for Terminal Care issued by the Japan Medical Association (August 22, 2007) has almost the same description about the definition of family as the Guidelines for the Decision Making Process in Terminal Care by the Ministry of Health, Labour and Welfare. On the other hand, the Guidelines for Terminal Care in Emergency Medical Service by the Japanese Association for Acute Medicine (November 16, 2007) has no such description, and it only has the indefinite expression “family member and people concerned.”
- 10 Two members of the Advisory Commission on the Guidelines for the Decision Making Process in Terminal Care raised the issue of the definition of family. (1) The Japanese Nursing Association submitted an opinion paper for the second meeting of the commission that says: “The definition of family should contain the person closest and most important to the patient. If the patient cannot express his/her will, the person who is the closest to the patient and understands the patient best is required to presume his/her will for his/her life to be fulfilled in the terminal phase. Nowadays, there are various forms of ‘family,’ such as marital separation and unmarried couples living together. We propose that the definition of family in the guidelines should clearly include the person closest and most important to the patient regardless of marital relationship and the like.” (2) At the second meeting of the commission, Shyozo Hino, vice-chairperson of the Association of Japanese Healthcare Corporations said “quite many of the public comments mention cases in which a homosexual person had stayed with his/her partner but was cut off the partner by his/her blood relatives at the critical moment. I suggest that the guidelines include such a caring person as well as family members.” Some other members of the commission said that there can be various forms of family and that it is difficult to define family members. In spite of

their comments, however, there was no formal discussion about the issue of “definition of family” in the meetings.

11 The Japanese adult guardianship system covers financial proxy but not health care proxy. The drafter of this law clearly excluded health care proxy: “the issue of health care proxy for invasive medical treatment in the adult guardianship system shares the discussion with the general issues of health care proxy for invasive medical treatment for patients who have lost consciousness temporarily or who are too young to decide for themselves and the like. Moreover, there has never been social consensus about the issues of health care proxy in general; such as who can be proxy and what is to be decided by proxy as well as on what ground with which limitations. Furthermore, the problem of whether the health care proxy system conflicts with the patient's autonomy and fundamental human rights or not has never been solved. Consequently, it is too early to stipulate health care proxy for invasive medical treatment only in the adult guardianship system at the time of this revision of the civil law.” This might be why the members of the panel could not discuss health care proxy or believed it still to be an unfeasible issue.

12 Related to the topic of this paper, for example, gays and lesbians should occupy some additional seats not only in the national assembly but on expert committees, as well. In general, most medical-ethical discussants from the majority are apt to reflect the majority's opinion and to ignore or be ignorant of the minorities' needs. In particular, previous discussions of health care proxy in expert committees revealed a serious cultural bias, as mentioned above, which gays and lesbians would never have approved of if they had had seats in the committees. Therefore, it is important to give gays and lesbians some seats on such committees, so that they can explain their needs and join in the committee discussions in order to rectify any cultural bias. Also, it is important to make additional seats in the national assembly for gays and lesbians, because it is assembly members who chose the members of special committees.

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