

## Comparison of Diagnostic Disclosure in Japan and the United States: From Communicative Perspective

### 日米における診断開示についての一考察

— コミュニケーションの視点から —

野口 朋香

Tomoka NOGUCHI

#### Abstract

Diagnostic communication between physicians and patients is thought to be one of the most important factors regardless of cultural differences. However, culture influences people's thinking, feeling, and behavior in both obvious and subtle ways. Furthermore, cultural and social factors play a significant role in eating and working patterns, the quality of relationships, attitudes toward life and death, and response to illness.

Although Japan and the United States are both the developed countries and they have the highly developed medical techniques, their attitudes and thoughts toward diagnostic disclosure and the relationship between physicians and patients are different, and one of the possible reasons for that is cultural differences.

The purpose of this paper is to investigate the difference in disclosing information toward patients, taking into account the physician-patient relationship in both Japan and the United States, from communicative perspective.

#### Comparison of Diagnostic Disclosure in Japan and the United States

Generally speaking, Japanese physicians historically have not disclosed diagnoses to patients especially when the diagnosed result is negative, whereas American physicians have disclosed to patients because of a respect for patient autonomy. Regarding informed consent, it has become an essential component in ensuring that patients become knowledgeable participants in choosing health care options in the United States. In Japan, however, the concept of informed consent has not yet been

generally accepted by the medical profession; it implies that the right of the patient to take part in the decision-making process to a large extent remains ignored (Hattori, Salzberg, Kiang, Fujimiya, Tejima, & Furuno, 1991). In the United States, Novak et al. (1979) reported that 95% of cancer patients were told their diagnosis at the time the disease was found. Contrarily, in Japan, giving diagnosis of cancer to patients still remains controversial, though in 1989 the Japanese Ministry of Health and Welfare and the Japan Medical Association suggested that doctors should tell patients with limited life expectancies as well as terminally ill patients of their diagnosis.

The issue of diagnostic disclosure to patients relates to several complicated factors, such as the patient's character, the patient's relatives' wishes, the degree of the illness, religious and cultural background, physicians' attitudes, and hospital policy. The aim of this paper is to examine cultural and social norms and present notions in medical settings by investigating the difference in disclosure of information in Japan and the United States.

## The United States

A generation ago, American physicians seldom told patients the diagnosis of cancer; today, there is virtual unanimity in the United States on the ethical and legal obligation to disclose the diagnosis (Good, Good, Schaffer, & Lind, 1990). In the United States, the practice of nondisclosure was seen well into the 1960's. According to Oken (1961), eighty-eight percent of physicians surveyed in 1961 reported their usual practice was not to tell the patient of the cancer diagnosis. However, during the social upheaval in that country of the 1960's and 1970's, demands by patients for more information and participation in their care became recognized in law and medical ethics (Elwyn, Fetters, Grenflo, & Tsuda, 1998). Trill and Holland (1993) discussed the idea that information regarding disease and treatment option is conveyed to the patients in keeping with the patients' rights movement, and also because of the need for the patients to reach a positive and informed decision regarding treatment choice in the United States. As a result, in a 1979 survey, 98% of respondents reported a usual policy of telling the patients (Novak, Plumer, Smith, Ochitill, Morrow, & Bennett, 1979).

From Americans' viewpoint, providing information has possibility to establish a relationship of openness and trust and increase the patients' autonomy, a value

in itself. This should enhance the patients' motivation to participate in an active, therapeutic partnership. In other words, telling the truth and giving information to patients are defined as a physicians' duty, and knowing the truth and seeking information are defined as a patients' right in the United States.

In terms of disclosure on hope, Good et al. (1990) discussed that "the American disclosure on hope incorporates popular and professional dimensions of our culture of biomedicine" (p.61). They also state that the emphasis of "will" articulates fundamental American notions about personhood, individual autonomy, and the power of thought (good or bad) to shape life course and bodily functioning. Thus, these fundamental American notions about the "will" and the relationship of the will to somatic and psychological manifestations of disease and cure influence how disclosure and hope are expressed in medical disclosure and practice in the American context. In addition to that, it is also important that disclosure is viewed as essential to establishing partnerships with patients and the construction of a partnership is understood as a necessary component of treatments.

## Japan

The Japanese approach to ethical issues in health care has been characterized by the Japanese cultural values of consensus and deference to authority (Hattori et al., 1991). Physicians bear the responsibility to decide the course of patient care, and patients also expect physicians to give them exact advice and diagnoses. In Japan, it is rare that patients challenge physicians' diagnoses. Kim, Holter, and Lorensen (1993) found that the Japanese patients were the least challenging of professional authority compared to the Finnish, the Norwegians, and the U.S.A patients. Concerning giving information to patients, according to Elwyn et al.'s study (1998), the number of physicians usually telling the patients of a cancer diagnosis in the United States was over three times that in Japan in 1991.

Withholding of information is popularly associated with a medical authoritarianism rooted in feudal values, in which the people are expected to simply comply with orders. "The patients leave all decisions to the doctors, follow their advice, and do not question what they are told" (McDonald-Scott, Machizawa, & Satoh, 1992). Information flows from the physician above to the patient below. Persistent questioning by the patients is viewed as an arrogant challenge to authority. The respect for, and perceived authority of, physicians in Japan was very strong before

the Second World War, and patients fully entrusted physicians with total and final decision-making authority with respect to their own medical treatment. This tendency was consonant with the prevailing cultural and historical context in Japan. In these days, however, because universal disclosure promotes the patients' right to know the diagnosis, the traditional relationship between physician and patient, which is closely akin to the teacher-student relationship in Japan and involves great deference to the physician's advice and decisions, has been vanishing. On the other hand, theoretical issues and practical ones are sometimes contradicted. Contrary to the movement of promoting disclosure of information to patients, in terms of emotional aspects, Japanese are more likely to agree that informing would hurt the patients and thereby negatively influence treatment. For example, the late Japanese Emperor Hirohito passed away in early 1989 without ever realizing that he had intestinal cancer (Morioka, 1991). This fact represents the Japanese traditional way of dealing with the terminal patients. Thus, regarding disclosing information to patients, Japan has several complicated issues involved cultural factors with struggling with the question of whether to tell patients their diagnosis or not.

### **The patient as Individual; The patient as Family Member**

According to McDonald-Scott et al. (1992), Japanese physicians are more likely to inform a family member of the diagnosis but not the patient first whereas the Americans also inform the family, but only with the permission of the patients. From American points of view, the family is viewed as a distinct adjunct. To inform only the family is untenable. "In the United States, a long tradition of emphasizing personal autonomy extends naturally to using advance directives in medical decision making" (Sehgal, Weisheil, Miura, Butzlaff, Kielstein, and Taguchi, 1996, p.1655). Atkinson (1989) discusses that it puts the family in the uncomfortable situation of having to inform the patients themselves or to guard against the patients finding out, and it violates the patients' right to autonomy.

In contrast, Japanese tend to see themselves as members of a larger family, rather than viewing the patients solely as an individual. In other word, the family is defined as the primary social unit (Harrison, Al-Saadi, Al-Kaabi, Al-Kaabi, Al-Dedwawi, Al-Kaabi, & Al-Neaimi, 1997). As the patients' family, they have the right to know their members' illness. Seo et al. (2000) stated that one of the reasons why cancer patients were not told the diagnosis was that their family objected.

The study, examining 1918 bereaved family members who had cared for cancer patients, found only 18% of patients were informed of the diagnosis of cancer, while all family members were told about the patient's condition precisely (Uchitomi & Yamawaki, 1997). They also mentioned that it is still a Japanese custom that physicians usually explain about the patient's condition to family members first, and once the family members agree, the patients are informed. "Medical physicians in Japan usually inform the family or close relatives of the existence of the cancer but tell the patient that he has a benign disease" (Hattori et al, 1991, p.1014). In terms of substitute consent, it is only acceptable in the United States when the patient is psychiatrically incompetent or in emergency conditions, whereas in Japan, even in cases where the patients are competent to give their individual consent, substitute consent by the family or close relatives is a common practice in order to avoid disturbing the patient emotionally.

Therefore, the involvement of family members in the decision-making process in Japan is much higher than in the United States.

Regarding the different perspectives toward a "patient" between Japan and the United States, it is worth stating that the notion of "personhood" or "self" in Japanese society is quite different from that of the "individual" in American society. Accordingly, the individual in the United States is conceived to be autonomous, while in Japanese society a person is structurally defined in relation to family and close friends. Furthermore, from human-relational perspective, if a family member or friend is threatened with death, the Japanese feel that they should let the patients die in peace (a concept called "Yasuragi"), without making them go through the agony of knowing their condition. This leads to the practice whereby most of the decisions relating to a patient's medical care are left to the family members and results in the prevalence of substitute consent. These possible reasons why family members and close friends sometimes make major decisions for an individual in Japan.

## Conclusion

This paper investigates the differences in disclosing information while considering the physician-patient relationship between Japan and the United States from communicative perspective. Japanese society places more emphasis on the social relatedness of human beings than on the individualistic notion of the autonomous

self, while American society places emphasis on autonomy and individual responsibility. Under these circumstances, each country has its own problems.

In the United States, respect for patient autonomy works well for the vast majority of patients who want to be told. However, for the minority of patients who do not want wish to be told themselves, blindly following this practice may yield a harmful outcome (Elwyn et al. 1998). In Japan, while physicians appear to be moving toward relationships of greater openness with their patients, with the movement of promoting to disclose information to the patients as human's right on a world scale, the outcry for more disclosure is not a demand for complete disclosure to all patients, since there are still many Japanese who do not wish to be told if diagnosed with a terminal illness.

Since the issue of disclosing information to patients has involved complicated cultural and historical backgrounds, we can not make that kind of sweeping generalization. However, the fundamental goal of both countries in terms of keeping good relationships between physicians and patients is to achieve a balance between autonomy and dependency such that patients' and the family's needs are met in the most satisfactory way.

## References

- Asai, A. (1995). Should physicians tell patients the truth? *Western Journal of Medicine*, 163, 36-39.
- Atkinson, J. M. (1989). To tell or no to tell the diagnosis of schizophrenia. *Journal of Medical Ethics*, 15, 21-24.
- Barnlund, D. C. (1975). *Public and private self in Japan and the United States*. Tokyo: The Simul Press, Inc.
- Beisecker, A. E., & Beisecker, T. D. (1990). Patient information-seeking behaviors when communicating with doctors. *Medical Care*, 28, 19-28.
- Benson, J., & Britten, N. (1996). Respecting the autonomy of cancer patients when talking with their families: Qualitative analysis of semistructured interviews with patients. *British Medical Journal*, 21, 729-31.
- Elwyn, T. S., Fetter, M. D., Gorenflo, D. W., & Tsuda, T. (1998). Cancer disclosure in Japan: Historical comparisons, current practices. *Social Science and Medicine*, 46, 1151-1163.
- Good, M. D., Good, B. J., Schaffer, C., & Lind, S. E. (1990). American oncology and the disclosure on hope. *Culture, Medicine, and Psychiatry*, 14, 59-79.
- Harrison, A., Al-Saadi, A. A. M. H., Al-Kaadi, A. S. O., Al-Kaadi, M. R. S., Al-Dedwawi, S. S. M., Al-Kaabi, S. O. M., & Al-Neaimi, S. B. S. (1997). Should doctors inform terminally ill patient? The options of nationals and doctors in the United Arab Emirates. *Journal of Medical Ethics*, 23, 101-107.

- Hattori, H., Salzberg, S. M., Kiang, W. P., Fujimiya, T., & Furuno, J. (1991). The patient's right to information in Japan—legal rules and doctor's opinions. *Social Science and Medicine*, 32, 1007-1016.
- Irwin, H. (1996). *Communicating with Asia: Understanding people & customs*. Australia: Allen & Unwin.
- Japanese Ministry of Health and Welfare and the Japan Medical Association (1989). The report for terminal care. *Tokyo: Japanese Ministry of Health and Welfare*.
- Kim, H. S., Hostler, I. M., Lorensen, M., Inayoshi, M., Shimaguchi, S., Shimazaki-Ryder, R., Kawaguchi, Y., Hori, R., Takezaki, K., Leino-Kilpi, H., & Munkki-Utunen, M. (1993). Patient-nurse collaboration: A comparison of patients' and nurses' attitudes in Finland, Japan, Norway, and the U.S.A. *International Journal of Nursing Studies*, 30, 387-401.
- McDonald-Scott, P., Machizawa, S., & Satoh, H. (1992). Diagnostic disclosure: A tale in two cultures. *Psychological Medicine*, 22, 147-157.
- Minami, H. (1985). East meet west: Some ethical considerations. *International Journal of nursing studies*, 22, 311-318.
- Morioka, Y. (1991). Informed consent and truth-telling to cancer patients. *Gastroenterologica Japonica*, 26, 789-792.
- Muramatsu, N. & Liang, J. (1999). Hospital length of stay in the United States and Japan: A case study of myocardial infarction patients. *International Journal of Health Services*, 29, 189-209.
- Novack, D. H., Plumer, R., Smith, R. L., Ochitill, H., Morrow, G. R., & Bennett, J. M. (1979). Changes in physicians' attitudes toward telling the cancer patient. *Journal of the American Medical Association*, 241, 897-900.
- Nakata, Y., Goto, T., & Morita, S. (1998). Serving the emperor without asking: critical care ethics in Japan. *Journal of Medical and Philosophy*, 23, 601-615.
- Okamura, H., Uchitomi, Y., Sasako, M., Eguchi, K., & Kakizoe, T. (1998). Guidelines for telling the truth to cancer patients. Japanese National Cancer Center. *Japanese Journal of Clinical oncology*, 28, 1-4.
- Oken, D. (1961). What to tell cancer patients. a study of medical attitudes. *Journal of the American Medical Association*, 175, 1120-1128.
- Sehgal, A. R., Weisheil, C., Mura, Y., Butzlaff, M., Kielstein, R., & Taguchi, Y. (1996). Advance directives and withdrawal of dialysis in the United States, Germany, and Japan. *JAMA*, 27, 1652-1656.
- Seo, M., Tamura, K., Shijo, H., Morioka, E., Ikegame, C., & Hirasako, K. (2000). Telling he diagnosis to cancer patients in Japan: attitude and perception of patients, physicians and nurses. *Palliative Medicine*, 14, 105-110.
- Trill, M. D., & Holland, J. (1993). Cross-cultural differences in the care of patients with cancer. A review. *General Hospital Psychiatry*, 15, 21-30.
- Uchitomi, Y. & Yamawaki, S. (1997). Truth-telling practice in cancer care in Japan. *Annals of the New York Academy of Sciences*, 809, 290-299.