

【Original Article】

Factors related to the current situation regarding the protection of patients' personal information in Japan

Mikiko NATSUME

Department of Nursing, College of Life and Health Sciences, CHUBU UNIVERSITY

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Summary

Since the Act on the Protection of Personal Information was enforced in 2005, the awareness of the protection of personal information has enhanced in Japan. However, this has not raised many problems in the field of medical care, and one can say that the current situation regarding personal information is that patients are not strongly aware about the right to protect personal information. This is believed to be due to the strong influence of Confucianism and Buddhism on Japanese culture. The protection of patients' rights in regards to patients being unable to express their own will and information sharing among medical staff against patients' will, with sufficient understanding of the Japanese concept of values and their differences from the US and Europe, are considered future issues of practitioners.

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Key words: information, privacy, nursing, Japanese Culture

Introduction

In 1980 the Organization for Economic Cooperation and Development (OECD) presented the "Guidelines on the Protection of Privacy and Transborder Flows of Personal Data" in the Board of Directors Advice¹⁾. The eight general rules described therein, such as definition of the purpose of information gathering, approval of information gathering, participation on an individual basis, etc. reflected the basic idea that one has the right to control the flow of personal information²⁾.

Also in Japan, the right to privacy was first approved in 1964 in the process of a judgment related to an incident, as "legal guarantee or right that private life is not negligently made public"³⁾.

Then, in April 2005 together with the overall enforcement of the Law on the Protection of Personal Information⁴⁾, in "Present efforts related to the protection of personal information in medical institutions" by the Ministry of Health, Labour and Welfare, it is mentioned that the right to control

personal information must be given consideration also in the field of medical care⁵⁾, and now it is generally said that the patient has the right to decide about the provision and use of information that concerns him- or herself. Just as it is claimed that this concept is strongly influenced by Western culture, which emphasizes self-determination⁶⁾, the development of the Japanese thought of privacy was influenced by Western thought. Even so, despite the continuing advancement of globalization, the Japanese mindset clearly still differs from that of Europeans and Americans. Perceptions of privacy and people's attitude towards it are thought of as non-fixed, relating to the personality traits of the patient, past experience, and attitudes of the nursing staff. With this concern, it is reasonable to assume that within the context of Japanese society, there also exists a specifically Japanese attitude towards privacy.

In this report I will put right the Japanese view of information privacy using data, etc. from research that

I have conducted, and I will give a future outlook on the handling of information in medical care in Japan.

Result

1. Current situation in Japan

1) Prior to the enforcement of the Law on the Protection of Personal Information

In Japan the secrecy obligation of public health nurses and nurses was clearly specified in 2001, with the revision of the Law of Public Health Nurses, Midwives and Nurses⁸⁾. As prior to its enforcement secrecy obligation regulations had not been developed, legal restrictions such as the criminal law were adjusted.

Information privacy is the right to hold information private, and its chief provision is the right to control one's own information or data. This provision is the right to deny any involvement of other parties in one's lifestyle or circumstances in terms of personal information based on personally identifiable information. Here, the "ichushi web service" was used to perform literature search of articles published in the field of medicine in Japan to find "studies related to privacy and information." The literature search and changes in study numbers with time are

shown in figure 1. During the search, keywords "nursing, privacy" were used to retrieve "studies related to privacy," and keywords "nursing, information, privacy" were used to retrieve "studies related to information privacy". Conference minutes were not included in the search. Before enforcement of the Private Information Protection Law, in the year 2000, 64 "studies related to privacy," of which one-third (21) were "studies related to information privacy," existed. After enforcement of the Private Information Protection Law, in the year 2006, 221 "studies related to privacy," of which more than half (125) were "studies related to information privacy" were present. Of the studies related to privacy, studies not related to information privacy were focused on spatial privacy and environmental privacy. Results presented here show that literature relating to privacy, particularly information privacy, increased in Japan after enforcement of the Private Information Protection Law. Therefore, it can be said that such studies have been attracting much attention in Japan since the enforcement of the Private Information Protection Law.

Furthermore, there are reports regarding the current situation in which approximately half of the nurses

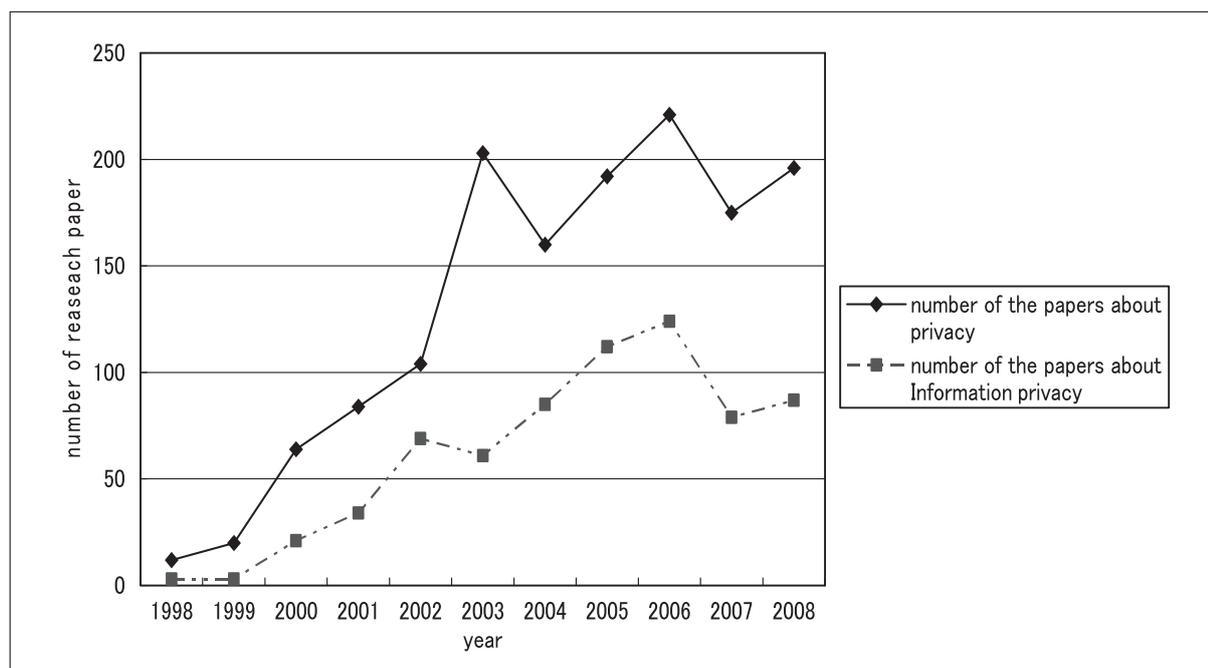


Fig. 1 the number of reseach paper of privacy and information

inquire all their patients as detailed as possible about their medical history and religious belief¹⁰⁾, and reports that the patients not necessarily recognize the necessity of the information that they are asked for by the nurses¹¹⁾ indicating a situation in which both medical care practitioners and patients were not strongly aware about personal information.

2) After the enforcement of the Act on the Protection of Personal Information

After the enforcement of the Act on the Protection of Personal Information in 2005, rules regarding the handling of personal information in medical institutions within the hospitals, the purpose of the actual use of the information, and cases in which the information in question was provided to a third party were laid out within the hospitals by posting, and the opt-out method was used. In short, the patient could come forward if there were matters that were difficult for him or her to agree with.

Prior to the act enforcement, in 2003 the “Code of Ethics for Nurses” of the Japanese Nursing Association, the professional code of nursing attendants, was revised, and along with an increased consciousness of information and data the following 2 items were supplemented¹²⁾.

Nursing attendants should respect the right to know and the right of self-determination, and defend these rights.

Nursing attendants should respect the secrecy obligation, and together with making an effort to protect personal information, share this information with others upon appropriate judgment.

As indicated in the increased number of researches on privacy mentioned above, the awareness of nursing attendants regarding the protection of personal information is definitely growing. This and other factors led to an overreaction regarding the handling of various information. Examples of such overreactions were misunderstandings such as that, patients in the outpatient department may not be called out by their names, and that a patient’s full name may

not be on the patient’s room, and that inquiries by the police or fire-fighters may not be responded to, etc. It is thought that this resulted from still insufficient comprehension by the medical personal, and advanced press coverage, etc., but not from enhanced citizens’ consciousness as in the US and Europe¹³⁾. These misunderstandings also came through the induction of “Q&A regarding the guidelines on the protection of personal information for medical care and caregiving related companies” by the Ministry of Health, Labour and Welfare¹⁴⁾, and the current situation is that these guidelines are in the process of amendment in the direction that the intention of the patient and the level of urgency of the information should be taken into consideration in order to handle personal information. Citizens’ consciousness regarding personal information is growing, and it is now a situation in which it said that in various fields judicial actions and claims are increasing. Regarding the field of medical care, in the “Current situation regarding the protection of personal information, as well as measures and policies” by the Quality-of-life Policy Bureau of the Cabinet Office, Nov. 2005, as far as consultations of complaints regarding personal information are concerned, of 6079 complaints, 2170 complaints were related to in the main 3 fields which have to be dealt with particular care, namely information on medical care and finance, and credit records as well as information and communication, which accounted for one third of all complaints. Out of these complaints, 197 complaints were in the field of medical care and health, thus accounting for only 3% of all complaints, so that one can say that not many problems arise in this field compared to others¹⁵⁾. Specific examples include hospitals specialized in cosmetic surgery, which besides basic identifying information, disclosed customer information belonging to the domain of private life on the internet, and were ordered compensation summons of 35,000 Japanese Yen per person. There are also cases of record high compensations¹⁶⁾, and incidences of the disclosure of electronic media with patients’

information of large scaled hospitals¹⁷⁻¹⁹⁾, which were greatly attracting attention. Even so, investigations have not discovered people of the opinion that details of a confidential conversation with one nurse becoming known to another nurse is a cause of distress. Study reports note that the majority of opinions regarding this issue are to the effect that sharing of information on symptoms and diseases between healthcare professionals is a necessity, and proper communication of such information is agreeable. Although it is impossible to make an overall judgment regarding the numbers of court cases and complaints, it can be considered that there is no major issue related to the sharing of information between healthcare professionals.

I will introduce a part of my research regarding the awareness of the patient's personal information, which I witness in part.

2. Introduction of the author's research

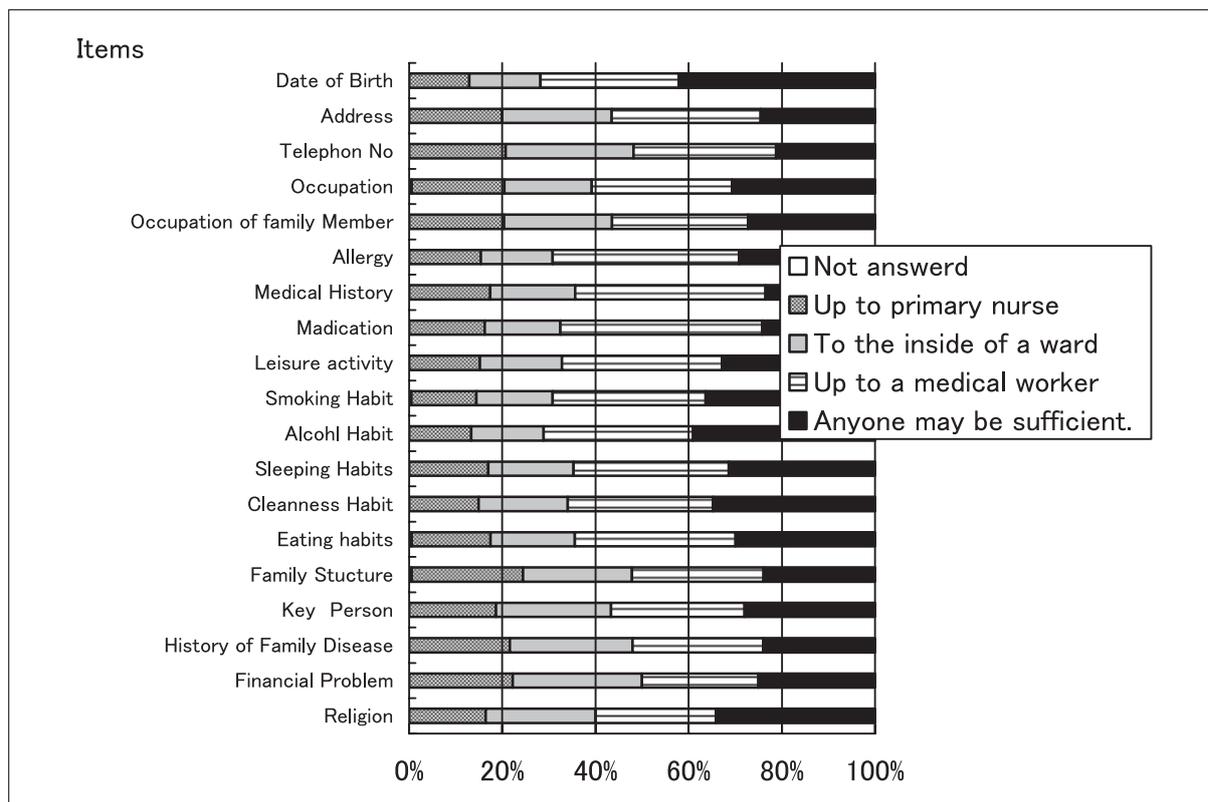
We investigated in 2009 to clarify the consciousness of the patient at the time of providing a nurse with information, and the factor relevant to it.

Ethical considerations such as adding explanations that questionnaires are anonymous, and that responses are voluntary, and the survey was conducted with the approval of the Ethical Review Board of Chubu University. The period of the survey was from Sept. to Nov., 2008. Survey items were related to the 20 question items that nurses generally collect from patients on admission, and included the degree of resistance when providing information to the nurses on admission to hospital this time was examined on a 5-point scale of I felt resistance to I felt no resistance at all, to what extent patients thought that the information they provided may be shared was examined on a 4-point scale of should be restricted only to the person who is taking care of me; should be restricted only to the hospital ward that I am in; I do not care if it is shared with the medical care practitioners that I am involved with; I do not care with whom it is shared, patient attributes such as age, gender and place of residence as factors related

thereto, and an independent - interdependent self-construal scale²¹⁾ (Takada. 2000). This scale measures the balance between the independent construal of self (arbitrariness and assertion of self-consciousness) and the interdependent construal of self (evaluation apprehension and affinity and adaptation with others).

With the consent of 17 hospitals in 3 prefectures 920 questionnaires were distributed, and 275 responses (recovery rate 29.8%) from 162 males, and 108 females, with a mean age of 59.8 ± 14.6 years were obtained. A large number of patients felt little resistance in providing information for all question items. It was found that the current situation is that many did not care about sharing almost all question items with the medical care practitioners in charge of them, and that only few patients desired that information is limited only to medical physicians and nurses in charge of them, and to within their hospital ward (Table 1). There were no differences by patient attributes. "Evaluation apprehension" within an independent - interdependent self-construal scale, more specifically, there was a tendency that those who highly considered and had a high interest in the opinion and position of and relationship with the other had a significantly broader view regarding the scope of sharing information, compared to those who considered these low and had low interest. Regarding the many question items, one can say that many patients thought that the scope of sharing information should be restricted to the "medical care practitioners with whom they are involved", and that few patients wanted the sharing of their information restricted depending on the kind of occupation of the medical care practitioner. Furthermore, as this also indicates that the view regarding the scope of sharing information broadens, and that patients want to build up a good relationship by referring to the opinions of many others, when they highly consider the relationship with and interest in the other, it was speculated that the low resistance to sharing information reflected the relationship with the medical care practitioners who directly aid and support the

Table 1. Range it is considered that may share the information seen according to the item



patients.

3. Factors affecting Japanese information privacy

As mentioned above, it is suggested that currently, after 3 years have passed since the enforcement of the Act on the Protection of Personal information, the awareness of the Japanese regarding information privacy in medical care is not strong. It is believed that this is related to the strong influence of Confucianism and Buddhism on Japanese culture. The following are 3 examples of cultural factors that influence the Japanese view on information privacy.

1) Factors resulting from the relationship with medical physicians

It is a matter of course that for the patient who is no medical care practitioner illness and medical treatment are difficult to understand, and generally in Japan medical physicians, and thus specialists decide on courses of treatment²²⁾. Patients leave their treatment to the medical physicians just as if they were “left to their fate” , and many give up as anyway everything

is decided by the medical physician. According to the Ministry of Health, Labour and Welfare Patient’s Behaviour Survey from 2005, the one who decided the courses of treatment, in case of outpatients was “medical physician in charge” 37.4%, “patient him- or herself” 34.5%, and “family, relatives and friends” 3.8%, in case of hospitalization “medical physician in charge” 45.0%, “patient him- or herself” 22.0%, “family, relatives and friends” 12.9%²³⁾. It is said that in recent years generally the patients themselves decide on courses of treatment, but the structure that the medical physicians decides on courses of treatment and that the patient conforms still remains. Informed consent, a concept that became common in the US from the 1960s, is generally known in Japan since the Japan Medical Association Bioethics Roundtable Conference issued a “Report on Informed Consent” in 1990²⁴⁾, and through the revision of the Medical Service Law in 1997, it was stipulated for the first time that medical staff has the obligation to provide appropriate explanation, and to make an effort to gain the understanding of those who undergo

medical care²⁵⁾. Regarding nursing records, in 2000 the Japanese Nursing Association released, “Guidelines on the Disclosure of Nursing Records”²⁶⁾, but these were not enshrined into law. Also the concept of “second opinion” at last has become known by ordinary citizens in recent years. There are many studies that show that patients do not feel much resistance regarding the collection of information by nurses^{27) 28)}. It is thought that this largely affects the relationship with the medical physicians and medical care practitioners.

The Japanese respect hierarchies in human relationships, and place importance to concept of values that pay their respect to voices of authority. It is thought that to comply with the medical physician, that is to say a person of authority is based on leaving the responsibility of the treatment policy to the medical physician.

Aforementioned research by the author elucidated that if evaluation apprehension is high, in short, if relationships with others are considered high, there is a tendency to consider the scope of information sharing significantly widely with regard to the information provided to the medical care practitioners. Also for this reason, it is speculated that there are also many people who in the process of considering the relationship with the medical care practitioners have the attitude to provide much information to medical care practitioners, and leave all responsibility regarding medical treatment and nursing to them. Furthermore, it has also been reported that regarding information about themselves, patients tend to provide information as detailed as possible²⁸⁾. Also for this reason, there is very little resistance to provide information to medical care practitioners, indicating a strong tendency to think that information may be shared with anyone if he or she is a medical care practitioner.

2) Strong group consciousness, but weak view of privacy

In the first place the Japanese consciousness of the “individual” is weak, and group consciousness is strong. Ethical education at primary and middle schools also attaches importance on explaining the importance of the consciousness of being a group member, family member, community member and a member of the Japanese state²⁹⁾. In particular “family” consciousness is strong, because information about family members information is being shared and kept privately as information inside the group. A survey performed by the Ministry of Health, Labour, and Welfare in 2005 reported that in cases of patients with a life expectancy of less than half a year, only 46% of patients were told the name of their disease by the hospital³⁰⁾. Although cases of patients being told the name of their disease have increased rapidly in recent years, notifying family in cases of poor prognosis still persists in Japan.

For many years, decisions related to family members were left to the head of the household. This is also based on aforementioned Confucian thought, in which importance is attached to “filial piety” namely to pay due respect to one’s ascendants, such as one’s parents. Furthermore, there is a strong tendency to differentiate between relatives and external parties, because information about a relative is being shared as information about one’s group. While in urban areas single-person households have weak relationships with the community, in local regions relationships in the community are still strong. In the “Guidelines for the description of the appropriate handling of personal information for medical care and care giving related companies” which were written down based on the Act on the Protection of Personal information, it is described that without the authorization of the patient, the family should not be provided an explanation about the patient’s medical condition³¹⁾, and this is also regarded as an aspect that diverges from the general custom of informing the patient’s family about the patient’s prognosis.

3) Harmony (wa) is regarded as important, low awareness of rights

Furthermore, group harmony (wa) is being highly esteemed. To assert one's own rights is regarded as self-centred, and as inappropriate behaviour that disrupts peace. Based on the words of "sense of duty", importance is attached to the relationships between people. This requires to make compromises that are based on feelings. Such behaviour is highly evaluated as "flexibility". It stands to reason that the medical staff tries to build up a favourable relationship with the patient, and one might say that also the patient tries to build up a favourable relationship with the medical care practitioners. There is also a study involving a potential group that could use nursing care insurance services, which shows that the main reason why it was thought that information may also be known by others, was "because they would receive a favour (be aided)" by the healthcare practitioners and helpers, etc., and that their judgments were more based on their own advantage and relationship with the healthcare practitioners and helpers, etc, as they might need their help, than on medical care based professionalism³², and it is believed that the presence or absence of one's own advantage and relationships affected these judgments. Furthermore, also because studies conducted by researchers revealed that if one is evaluated by others, more specifically if one's opinion of the other, and one's consideration of and interest in the position of and relationship with the other are high, there is a strong tendency to be concerned about the evaluation, and items with a wide view regarding the scope of sharing information tend to become more frequent. Therefore, it is thought that harmony (wa) with the medical care practitioners who take care of one is important, and that the idea of trying to build up a good relationship is related to the sharing of information.

4. Future prospects and efforts

On the occasion of the proposals of the "Grand Design toward Informatization in the Health Care Field", which was made public by the Ministry of

Health, Labour and Welfare in 2001³³), the trend of electronic medical health records went ahead, and studies directed at standard electric medical health records for coordinating the interoperability among systems and information among medical institutions were conducted. While at the end of fiscal year 2003 the dissemination rate of electric medical health records within the electric medical health records system, was 12% in hospitals with 400 and more beds, 1% in hospitals with less than 400 beds, and 3% at medical clinics, on Oct. 1, 2005 it was 21.1% in hospitals with 400 and more beds, and 6.3% in total at medical clinics, and during the last years its dissemination is further proceeding³⁴). As a result, sharing of information has become remarkably easy.

On the other hand, also in Japan Western ways of thinking are spreading, and awareness of the self-determination and autonomy of patients is growing. Also due to these effects it is estimated that with a focus on the young generation, in the future awareness regarding privacy and rights will further increase. Therefore, it is estimated that this will lead to great differences between those with strong privacy awareness, and those with a traditional way of feeling about this and low privacy awareness.

Based on such a current situation, in order to strike a balance between privacy and medical care with regard to convenience, there are also efforts not to handle all patients uniformly, but to determine the scope of patients' information that is displayed on electric medical health records in a way that it reflects the awareness and needs regarding individual personal information³⁵). Thus, information gathering and utilization corresponding to the awareness of the Japanese regarding medical care, and individual views of privacy are desirable.

Furthermore, different from the US and Europe, and based on a sufficient understanding of the Japanese concept of values, the defence of patients' rights due to the fact that patients cannot express their own will, and to concern themselves that undesirous information sharing among medical staff does not take

place, are considered future issues of nursing attendants. (A Part of this research was founded by Grant-in-Aid for Young Scientists B)

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Correspondence address : Mikiko NATSUME
 Department of Nursing, Collage of Life and Health Sciences, CHUBU UNIVERSITY
 1200 Matsumoto-chou, Kasugai, Aichi, 487-8501, JAPAN
 Tel 0568-51-1111 Fax 0568-51-5370
 E-mail : nmikiko@isc.chubu.ac.jp

日本における患者情報の保護に関する状況とそれに関連する要因

夏目美貴子

中部大学保健看護学科

要 旨

個人情報保護法が 2005 年に施行され、日本人全般に個人情報のプライバシーに関する認識が強くなった。しかしながら、患者は自分自身の情報を提供することや、情報を医療従事者間で共有することに関して抵抗感が少なく、自身の情報プライバシーについて強く意識してはいない状況であることが明らかになっている。そのためか医療の分野では情報プライバシーに関して、他の分野ほど大きな問題生じてはいない状況であるといえる。これは、お任せ医療といわれるような独特の患者-医療者関係や、和を重視する文化があることが影響していると考えられる。日本人には欧米とは異なる、日本人特有のプライバシー観がある。そのことを加味して患者の情報プライバシーに留意した、情報収集・情報共有の方法を探る必要があると考えられる。

キーワード：患者情報、プライバシー、日本文化、看護

連絡先：夏目美貴子
中部大学保健看護学科
〒 587 - 8501 愛知県春日井市松本町 1200
Tel :0568-51-1111 Fax :0568-51-5370
E-mail: nmikiko@isc.chubu.ac.jp