Informed Consent for Patients with Advanced Cancer

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Introduction

The doctrine of informed consent is intended to regulate primarily the relationship between patients and physicians, and its proper practice should consequently be instrumental in promoting human rights and dignity. In fact, however, many attorneys, hospital administrators and physicians tend to see consent forms primarily as protecting physicians and medical facilities' from liability. The legal requirements and levels of specificity vary substantially from country to country. Although some changes have occurred in doctor-patient interactions in recent years in Japan, the advisory committee to the Minister of Health and Welfare submitted a report in 1995 which opposed indiscriminate legal enforcement of informed consent in daily practice.

There is some evidence that quite a few Japanese physicians are not sufficiently aware of the principles of informed consent, and this paper will discuss some of the problems related to its practice, particularly for patients with advanced cancer.

Telling cancer patients the truth and informed consent

According to a recent public opinion poll, 53% of Japanese people claimed that they were not getting enough medical information. There appears to be a wide gap between the feelings of the two parties, namely patients and physicians. Concerning to the practice of informed consent, 1,284 Japanese physicians were recently surveyed in 1995 by Munekata. 48.4% of responding physicians stated that any medical procedures would not be legally acceptable without a signed consent form, and 97.1% of them claimed that they were practising informed consent. Only about one quarter of them were in favour of full disclosure of information, and 73.0% expressed their conviction that some restriction is necessary in the disclosure of information particularly for patients with cancer.

Although there would be almost no firm rules of always or never telling the cancer patient of his or her diagnosis, informed consent has to be based on the assumption that full and complete disclosure of information is to be given to the patient. The situation as to revealing a cancer diagnosis in the world was reviewed by Koinuma a couple of years ago. A total of 585 physicians from 28 nations responded. In many European countries, the rate of reporting a cancer diagnosis was high, whereas in Japan it was surprisingly low, being 29%. Restriction of information has been practised in Japan and debate about telling the cancer patient the truth has been going on for years.

The Japanese gastroenterological society made a survey four years ago, in which 238 gastroenterologists were involved. It was shown that 14% of them said that they would not tell the diagnosis even with carcinoma in situ in a sigmoid polyp. With advanced sigmoid cancer with stricture, only 20% said that they would report this, and this figure rose to 51% if specifically requested by the patient. Quite surprisingly, 40% of them said they would not tell even if they were specifically requested by the patient.

There is a recent survey conducted on approximately 2,500 outpatients at 7 hospitals including major cancer centres in Tokyo. The study was conducted by Hisata and reported in 1996. 71% of the outpatients at these 7 hospitals expressed the wish to be informed of the diagnosis of cancer even if the possibility of cure was small. The rates ranged from 58.9% to 74.4% depending upon the type of the institution, whether it was a cancer hospital or general hospital, and its location in a metropolitan area or not. The data were analyzed according to educational levels and ages. Percentages of those who specifically requested to be told the truth even with little probability of cure, were 68.4% for junior high-school graduates and 80.4% for college graduates or those with higher education. When categorized according to age, the older, the smaller percentage of patients requested, and the younger, the larger percentage did so; i.e. 51.6% of those who were 70 years or older, and 78.6% of those who were younger than 40.
This gap between carers and caretakers appears to have narrowed since there have been rapid changes in physicians' attitudes concerning reporting a cancer diagnosis during the past several years. At this time it is estimated that approximately 80% of cancer patients in Japan are told about their diagnosis.

Further commentary on informed consent practised in Japan

One aspect of practising informed consent can be reviewed if one looks at who makes a decision when alternative treatment is available. The recent study done by Hisata demonstrated the following results: 65.5% of outpatients stated that they would leave the decision to their physician, 24.3% would make the decision themselves, and 4.9% would have their family members decide. The data were categorized according to educational level, and it was found that the higher the educational level, the less the dependence on their physicians.

What is the response of Japanese physicians when a patient refuses the proposed treatment? When met with refusal, 57.7% of responding physicians thought that the refusal would literally be the informed consent itself, and they did not think much more could be done to overturn the patients' decision by educating them, and they were unwilling to explore the underlying basis for refusal. 52.1% of them felt irritated and frustrated, and only 17.1% felt further effort on the physician's part was required, including assessment of the basis for refusal. We tend to underestimate the amount of information patients would like to have, and it must be realized that well-informed patients are less likely to refuse treatment than those who are poorly informed.

Cultural perspective on medical decision making

A unique study was recently conducted by Hashimoto and reported in 1995. 55 physicians in one medical department of a private medical college in Tokyo filled out questionnaires. When they looked back about their practice in the past, only 23.6% thought that they had been right in revealing a diagnosis of cancer to their patients. 27.3% of them were not sure about the propriety of revealing the truth, and approximately 1/3 of them thought that it had to be on a case-by-case basis. When asked about the likelihood of policy in the future, 83.6% of them responded by stating that revealing the truth to cancer patients would be practised in Japan, but 12.7% thought that this would not happen. In case they themselves got cancer, only 61.8% of these physicians indicated a preference for being told of the diagnosis of cancer. 9.1% did not want to be informed, and 29.1% were not sure about whether or not they would like to know the cancer diagnosis. From this study, it can be stated that even some of Japanese practising physicians may not be willing to promote the idea of autonomy in his/her own medical decision making.

It is thus not surprising to note that many patients in Japan are so reliant on their physicians' advice that regardless of the information they receive they often place the decision in their physician's hands. Japanese consider the importance of balance between organizations and individuals, and the importance of the organization where he or she belongs to is often stressed above the individual. We Japanese tend to avoid pushing our opinion too hard, and do not bother to discuss matters to the end, being noncommittal when we have to say yes or no. These Japanese characteristics often manifest itself in various medical situations.

When we Japanese physicians are to make decisions about our patients, we try hard to figure out what constitutes the total good of the patient by imagining ourselves being in the patient's position. It seems unreasonable that we would be able to compare the medical effect of an action with so many other impacts, including the psychological, spiritual, familial, social, and financial factors, and that we would know better than anyone else.

About 15 years ago I treated a female patient aged 22 with thyroid cancer. She underwent thyroidectomy with neck node dissection, there was no node involved, and she was told that she would probably be cured from her cancer. At this time, 15 years later, she has continued to do well without any evidence of recurrence, her neck wound is barely noticeable, but she looks somewhat depressed, sad and unhappy. She has remained single all these years, probably because she missed chances of an arranged marriage. Marriages in Japan are pretty much dependent on arrangements through relatives.
and friends. I can easily imagine that the diagnosis of cancer has remained not only in her mind, but also in minds of her relatives and friends for all these years. Even a slightest idea of the bad image of cancer, if present, in any member of her relatives or friends would have worked as a major obstacle to marriage arrangements. Few lay persons know that thyroid cancer carries a good prognosis for young ladies, even with multiple lymph node metastases.

I still feel sorry for her for my wrong doing, that is telling her the truth about the cancer diagnosis 15 years ago. The diagnosis of cancer is still perceived as the disease with uniform clinical features and often seen as equivalent to a death sentence by some people. Patients with cancer may easily be stigmatized with the label of having suffered from a dreadful disease, and may be at high risk of losing his or her standing in our society.

**Difficulties with advanced/recurrent cancer**

When dealing with patients with advanced cancer, the difficult parts are how to cope with deep depression, hopelessness, and withdrawal. Some hope needs to be instilled into the patient, and we may be able to offer some last-ditch efforts for a cure or an extended life, if applicable.

In recent years, significant progress has been made in treating patients with advanced cancer. One of the most promising therapeutic strategies is high-dose chemotherapy supported by autologous stem cell support. Over the past 10 years we have engaged in refining this novel therapy, our results have been quite promising with some long-term disease-free survivors among those whom we treated for their disseminated disease. The patients receiving this particular therapy are usually housed in a bioclean room, and the Tokai University Hospital happens to have a well-equipped facility with 11 beds, the largest of its kind in Japan. This treatment is illustrated elsewhere and will not be repeated here at this time. With this novel approach we, patients and physicians, may be able to maintain or even expand some degree of hope for a cure even with advanced cancer.

In Japan, increasing numbers of patients with advanced/recurrent cancer now complain about that bad news having been given in an insensitive and mechanical manner through an one-way conversation without taking into account the wide variation in patients' reactions to the information. A better way of communication must be sought.

**Disclosure of bad news**

It is needless to say that patients should have the right to receive sufficient information to be able to make an informed choice about the treatment recommended. At the same time, however, patients have the right not to receive any bad news. One of the approaches in individualizing the disclosure of information would be to avoid a one-way conversation and to allow patients to ask their physicians as much and as deeply as they wish. The critical point of the art of communication in a medical scenario should be not what we tell to patients, but rather how we let patients ask us. We must have sufficient time to listen to patients and must be willing to comply with their requests to be told the truth. During such communication, we should be careful not to narrow down our answer too hastily. After several exchanges of questions and corresponding answers with a rather wide margin during communication between the patient and the physician, the patient would get to know how much information he or she would like to have. Although we wish to promote better communication, there are the problems of our current system of medical insurance, which limit enough time being spent with our patients. The possibility is that a patient's choice in the future will be overwhelmed by further powerful economic and structural forces.

**Summary**

In order to maintain a desirable patient-physician relationship, we need to continue our efforts to cultivate the idea of informed consent and to promote better communication. This seems to be particularly important for Japanese physicians. Disclosure of information needs to be individualized, and social and cultural background has to be taken into consideration. We also need to refine our efforts to develop and refine therapeutic strategies against cancer, so that we, both patients with advanced cancer and treating physicians, can expand our mutual hopes for cure or extended life.

The benefit which might ensue from the idea of informed consent is the promotion of human rights and dignity, which is the title of this symposium.
References