The International Medical Bio-ethics Conference Chungshan Medical College, Taichung, Taiwan, 8th to 10th May 2001 (Program Co-ordinator: Dr. Michael Tai)

Professional Responsibilities Versus Right Of Self-Decision

By Takasu (family name) Toshiaki (given name), MD, DMS Former Professor and Chief and Currently Guest Professor in Neurology, Department of Neurology, Nihon University School of Medicine, Tokyo, Japan (Email address: ttakasu@vesta.ocn.ne.jp

Fax: +81-3-3338-7877

Postal address: 5-9-3 Nogata, Nakano-ku, Tokyo 165-0027, Japan)

I have been a physician and a teacher in clinical neurology. I once served as the chairman of an ethics committee of a medical school and its attached hospitals for the ten years 1989-99. So the matters between physicians and patients have been my concern.

In medical practice all the information about a patient finally must converge on composite judgements by the physicians-in-charge of the patient. They advise to the patient under their care to accept their choice because they view that the choice would be best for the patient at the time of advising. Thus medical practice is fundamentally serial or successive composite judgements on the problems involving an individual case. In this point medical practice is something more than generalized arguments in simplified settings and requires not only logical strictness but also a sense of balance and caring over all actual, inevitable occurrences and accidental happenings. As for the matters emerging in medical practice theoretical bio-ethic expertise is not enough for solving actual problems and experienced medical practical expertise is required to condense discussion so well as to crystallize it into concrete judgements. I will come back to the matters in Section III, what is the medical practice, what is the physician and what is the patient?

I will firstly think about the relationship of two principles, physicians' paternalism versus patients' self-decision, secondly give a brief historical retrospection of the two, and lastly propose a solution to the conflict of the two.

I. PHYSICIANS' PATERNALISM VERSUS PATIENTS' SELF-DECISION

In medical practice physicians and patients are the prime persons concerned. There is a fundamental question which persons should play the leading role in making decisions, physicians as professionals or patients as subjects to the decisions made. In other words the question is whichever ideology should be the prime principle in medical practice, *physicians' paternalism* or *patients' self-decision (or patients' autonomy)*. Different societies of different time and place have different ways of making decisions that may cause different outcomes to the persons concerned.

In societies where professionalism of physicians stands out physicians' paternalism will dominate. If physicians make a decision they have to take full *professional responsibilities* for their decision and its outcome whether good or bad. Patients are subject to their physicians' decisions totally. Patients will not check their physicians. Some physicians inform and other physicians do not. Sometime physicians inform and at another time they do not. If it goes well there will be no problem. If it goes bad physicians can be dogmatic and

patients can suffer losses. Physicians may lose the opportunity to make them reform.

In other societies where rights of patients stand out patients will check physicians' paternalism and there will be much complaint from patients and much suing by patients aided by their proxies (or attorneys or solicitors or lawyers). If patients themselves use full rights of self-decision they must take full responsibilities for their decisions and their outcomes. It would be an uneasy, difficult task for non-professionals to make proper choice. It must be a hard task for sick patients to make proper choice. If it happens to go well there will be no problem. If it happens to go bad a choice can mislead all persons concerned. Patients can suffer bad results. Patients may complain. But finally they have to submit to the results because these came from their self-decisions. The physician-in-charge will become defensive and may escape from preserving true professionalism in order not to be involved in social troubles. Contrarily physicians may shift part of their responsibilities to their patients and be relaxed. Physicians will be exempt from being charged for the outcome and at the same time they will be discharged from their duty. This is because making decision to his best knowledge and all experience to take full responsibilities for its outcome is the fundamental duty of physicians and any other professionals. Habitual exempt from responsibilities and habitual discharge from duties can spoil physician's professionalism. I will come back again to this topic in Section II.

II. A HISTORICAL RETROSPECTION AND SOME ANALYSIS

It is said that the concept of human right was introduced to medical practice first in the 1960's in North American countries and the right of patients' self-decision had been well-established by the mid-70. The achievements of these coincided with the formation of a new bio-ethics in the 1960's and 1970's. Ever since patients' self-decision has been a common knowledge to the medical and paramedical staffs and the patients in these countries as well as a common practice between the physicians and the patients in those countries. There the patients have convinced themselves and have accepted to take full responsibilities for the outcome of their self-decision, and the concept of informed consent found its way into all phases of medical practice and clinical trials. Clinical trials of drugs have acquired a large number of volunteers with a written informed consent. Thus the principle of self-decision has worked well in North American countries for almost three decades.

In East Asian countries physicians' paternalism has been predominant but now the idea of self-decision is being imported from North American countries. People are trying to compromise between the two principles, physicians' paternalism and patients' self-decision. For example the concept of informed consent in medical practice has been imported from North American countries to Japan since the beginning of the 1980's as part of the newly formed bio-ethics and has been settled somewhere. But it is to be seen if the concept can be settled in entire Japan. The informed consent in Japan has so far been often superficial because the awareness of individualism is comparatively immature.

Paternalism is not an exclusive phenomenon in Asian countries. In 1998 a Clinical Reader at Oxford University, stated in Tokyo at a seminar held by Nihon University Research Center saying 'In Britain medicine is still paternalistic, the patients still trust the doctors. The expression, "Whatever you say is best, doctor." is quite common.' Informed consent is perhaps not so common in Britain as in North American countries. There physicians' discretion has been respected

traditionally. Even in North American countries paternalism had been common before the 1960's.

What was the background of the phenomenon seen in North American countries since during the 1960's? My preliminary analysis tells me two possible reasons. The first one is that the ordinary individuals in North American countries in that time had recognized their human rights distinctly, presumably aided by the prosperity, wealth and leisure that the United States had enjoyed after the Second World War. This rise of individualism was a bottom-up phenomenon of the societies sustained by the prosperity. Movements had arisen for the men's right of being exempt from military service, for anti-nuclear weapons, for women's rights, and for consumers' rights. As such patients' right was raised triggering the formation of the new bio-ethics toward the 1970's. Simultaneously medical suits began to increase. The physicians had to protect themselves. The lawyers became busy. The courts in those countries started to give their attention to the ethics guidelines set forth in 1947 at Nürnberg, then to the declaration at Helsinki made in 1964 and then revised in 1975 at Tokyo, and so on. The courts needed a legal principle to settle disputes between physicians and patients. The second reason would be the *high charge* for health care (or medical treatment) by the physicians (paternalism in *fixing fees*) in North American countries in those days. The physician's social status as well as professional standard had been high and basically a free hand had been given the medical profession in fixing medical practice fees. The physicians' attitude had been paternalistic before that time. The medical profession belonged to the privileged social and economic class. The patients who could afford to pay for the medical treatment they received did pay and they were keen on the fitness of their payment and the assurance of their patients' rights. The patients who could not afford went to charity hospitals where their

patients' rights might be restricted. The difference between rich and poor had been enlarged. There was an episode that occurred close to me. An elderly Japanese man who was the father of a technician of my school was hospitalized due to his stroke. He was asked to pay 200,000 (two hundred thousand) U. S. dollars for the medical care he received during his 7 days' stay in a hospital in the west coast of the United States, that took place in the 1980's. His family had to gather that much money quickly in order for the head of the family to be discharged from the hospital. As a consequence of the high cost for health care the patients could not stay long in the hospitals in North American countries. The length of hospitalization has long been generally less than a week. The physicians had enjoyed the high income for their services for a long time. The insurance systems had not covered the people so well that many patients had to pay for themselves. The patients as payers often had to protect themselves by the act of suing. The physicians also had to protect themselves by paying large sums of insurance against medical mistakes and accidents. The people were requiring legal judgements and the courts needed a legal principle. Thus an informed consent was born as a necessity of the civil law. In Japan although a health insurance system was first introduced in 1922 to its society a law enacted in 1961 has since requested every citizen to join any one of the health insurance systems available that actually have covered all citizens for four decades. The insurants and their family have had to pay only less than 30% of the fee for the medical care they received. Naturally the length of hospitalization has been generally much longer than in North American countries. In Britain the National Health Service established in 1948 cared all citizens at no expense until the1980's and after this time at the expense of minor portions of the cost. I do not know the average length of patients' stay in British hospitals. The informed

consent was born where *rise of individualism* and *paternalism in fixing fees* had coexisted, not born where both had not. In Japan the former has existed for half a century increasingly but the latter has not virtually existed since toward 1961. In Britain the former has existed long and the latter never since 1948 at latest. It was after 1965 when two new medical insurance systems started that in U. S. A. the medical care cost in nearly 20 million aged citizens came into control.

The North American physicians and patients in the 1960's who wished to protect themselves thus formulated the informed consent. It was a product of the negotiation and compromise between both sides, that has acted as a legal principle in those countries. The physicians there have obtained the right to shift part of their professional responsibility to their patients and the patients have obtained the right to make choice. But at the same time those physicians have sacrificed the original height of their professionalism to some extent and those patients sometime have missed genuine medical advice and service from their physicians to get exposed to being unguided or misled. I assert myself for the following reason. Indeed the physicians have had to take responsibilities for the outcome of the medical treatment they provided even if their patients had chosen it. But they have been allowed not to propose any medical treatment they do not wish to propose even if they consider it medically best for their patients. The physicians have been allowed to propose only medical treatments that could cause no trouble even if they are not be so efficacious. The patients could have made a choice only from the options their physicians propose, but have not been allowed to request any other options that their physicians did not propose. Accordingly the patients have had to decide if they accept their physicians' proposals or they seek for second opinion. Thus to make best choice have often remained as a patients' task and the patients have had to do it at their own risk. I

once tried to include a condition in the informed consent form that I worked out as the chairman of an ad hoc committee of our hospital to set forth it. The condition was that physicians should propose the best choice for their patients to their patients and declare that they view it was best at the time of informing. This meant that physicians have to take all responsibilities for the outcome of their decisions in their medical practice. The responsibility taken by physicians in this informed consent was grave in comparison to the informed consents in North American countries where part of physicians' responsibilities had been shifted to their patients who act in autonomy, as stated above? However, my attempt failed because young doctors stood against it. Finally I removed the condition from the informed consent form and the committee approved the revised informed consent form. This was an episode demonstrating the immaturity of the young physicians' professionalism. At the same time it lighted up the difficulty in establishing genuine informed consent between physicians and patients.

III. A SOLUTION

Physicians' profession requires firstly knowledge that should be systematic and well oriented but not fragmented. Secondly, it requires trained skill and technique to make full use of his knowledge in practice. Thirdly it requires a sense of balance for appropriate judgement. Fourthly, it requires physicians' physical strength that enables them to perform painstaking work. Also it requires serenity of mind, conscience and ethics. Mind can be closed and view can be narrowed when a man is sick. A sick physician cannot be a good physician for others and himself because his condition is not good enough to make good decision. Can sick patients who are not professional physicians ever accomplish the same task as good

physicians in good condition can do? I do not think so even if aided by proxies. The patients' autonomy is unrealistic when patients are not professional and their condition is not best. Professor Hyakudai Sakamoto allowed me to cite his case. Even he, philosopher of science and bio-ethicist, could not make a choice for him when he was sick two years ago just before he received surgical removal of his stomach. It is said that physicians cannot take charge of their close relatives because they may be often emotional and deprived of serenity of mind. In this situation patients' autonomy may fall in a snare where informed consent is a mere excuse for both sides, physicians and patients.

The following is more realistic. A physician-in-charge of a patient tells what choice will be best for the patient at the time of advising. Then the patient will decide to accept or not to accept the physicians' advice instead of making choice themselves. Now the question is what sort of things patients rely on when they choose hospitals/clinics or physicians? As a matter of fact most Japanese patients have attached importance to the following matters. The matters have been the foundation, affiliation to universities, hardware, organization and location of the hospitals they are going to visit. The matters have been the alma mater and academic degree of the physicians they are going to consult when such information is available. The evaluation and recommendation of those hospitals or physicians by their relatives and friends whether high or low have often been influential. After they have visited a hospital or consulted a physician are included in their judgement the following things. The things are the effect of the treatment they have received, the outcome of their illness they have been subject to, the services, convenience and comfortableness they have had in the hospital, and the personality, performance and appearance of their physicians they have touched. What sorts of thing patients rely on when they choose hospitals or physicians may change

depending upon the seriousness of their illness. The patients have long been apt to evaluate hospitals highly in the decreasing order of national, provincial and private and respect hospitals affiliated to universities. Now they appreciate facilities, equipment and buildings that are big and look new. Now they come to know how far specialized the hospitals are by counting the specialties that hospitals can afford. The patients have long respected physicians who graduated from national universities' faculties of medicine and thought little of physicians who did not acquire the degree of Igaku-hakase (Doctor of Medical Science). Letters of introduction written by patients' reliable, influential acquaintances and addressed to good physicians have been their best cards that have always been longed for enthusiastically. The patients have been favorably disposed toward physicians who showed sincerity, kindness and no haughtiness to them. Sometimes the patients have excused themselves finding reasons that may be ridiculous (hobbies and tastes they have in common to their physicians or look and voice of their physicians they feel pleasing). In recent years there have been so many publications attempting to evaluate, classify or grading hospitals/clinics and specialists, that have provided the patients so much information as can influence upon them deeply. The trend to qualify physicians by academic standards has extended across many fields of medical specialty for the past three decades, but the societies are just starting to appreciate these qualifications. The reality of patients' autonomy has been like these because the real knowledge, skill and humanity of their physicians are hard to assess from the standpoint of patients. No matter what it may be, when the patient can accept the physicians' advice things will be all right but with limitations. With such limitation physicians' true professionalism and self-discipline would be important and essential for good choice. When the patient cannot accept the physicians' advice he may seek second

opinion, and sometimes third opinion. Patients should be assured of their right to seek those opinions and convenience for seeking such opinions. Thus good availability of second or third opinion is important but it is not always there.

In actual circumstances situations may not allow a patient to seek second or third opinion. For instance patients may be bedridden in the evening when a physician-in-charge comes to obtain a patient's sign on an informed consent form and a surgery may be scheduled for next morning. This is too late for seeking second or third opinion and making best choice. This is unavoidable in emergency. Many physicians even good or bad are not always near at hand. Thus patients' autonomy is very often limited in real circumstances. Therefore physicians' true professionalism and self-discipline is finally most important for good choice. Physicians should propose a plan to the best of their scientific knowledge and genuine professionalism. They should refrain themselves from not proposing the best for their social security. Mere citing all options is not enough for good choice. Physicians' decisions should be based on systematically established scientifically good evidence but have to rely on their experiences and discretion that should be utilized fully because at the moment first or even second or third order evidence cannot be available for every medical matter that may arise.

A solution will be that with all knowledge and experience physicians inform their patients and propose them plans, then sensible patients choose a best physician. This solution is based on the admittance that patients' autonomy let holes, gaps and even snares exist in them. We can call this "Informed Proposal". This is not as a legal principle but as an ethical standard. As such physicians can propose the best with no protective attitude or fear of being suited. This solution predisposes physicians' genuine professionalism and self-discipline. Ideally physicians should be so able that their patients would like to follow him and should be satisfied even if the outcome were unhappy, but this is unrealistic. Ultimately all what physicians can do is to make an informed proposal to his best scientific knowledge and genuine professional discretion and discipline. When either second or third opinion is unavailable the original physician takes the responsibility. Ultimately all what patients can do is to sense and choose a physician. Physicians propose, then patients choose a physician. There are so many holes, gaps and snares in patients' autonomy. Physicians' genuine professionalism and self-discipline alone can fill the holes and gaps, clear the snares and find a way.

End.

Reference

- 1. Government medical care. In Encyclopaedia Britanica Volumes 15, William Benton, Chidago and elsewhere, 1970, pp70-72; Social security. ibid, 762-768B; Social welfare. ibid, pp773-782.
- 2. Sakayori Toshio. Shakai-hosho (Social security services). Iwanami-shinsho 309, Iwanami Bookseller's, 1958, p1-221. (In Japanese)
- **3.** Hoshino Kazumasa. Iryo-no rinri (Medical ethics). Iwanami Shinsho 201, Iwanami Bookseller's, 1991, pp1-240. (In Japanese)
- 4. J. Duncan Young. Eikoku ni okeru nokan-shi; rekishi to genkyo (Brainstem death in the United Kingdom, its history and current status). In No-soseichiryo to noshi-hantei no saikento—shin seiki o mukaeta no-teionryoho, zoki-teikyo to zoki-ishoku— (Reappraisal of brain resuscitation and braindeath determination -Brain hypothermia therapy, organ donation and transplantation in the new Century-), ed Takasu Toshiaki, Hayashi Nariyuki, Kindai Shuppan Co., Tokyo, 2001, pp172-180. (Translated into Japanese)

- 5. Takasu Toshiaki. Right of self-decision versus professional responsibilities in informed consent. Read at the First East Asian Conference on Bio-ethics, November 3rd, 1995 in Beijing.
- 6. Takasu Toshiaki. Right of self-decision versus professional responsibilities in informed consent. In: The proceedings of the Asian Bio-ethics Seminar "Global Bio-ethics from Asian Perspectives", November 9-10, 1998, for the Comprehensive Study on East Asian Culture Project. University Research Center, Nihon University, Tokyo, Japan, 1999, pp59-67.

