

# Globethics Repository

The logo for Globethics, featuring the word "Globethics" in white, sans-serif font centered within a solid blue rectangular background.

## Medical uncertainties and patients# decision making

This page was generated automatically upon download from the Globethics Repository. More information on Globethics see <https://www.globethics.net>. Data and content policy of Globethics Repository see <https://repository.globethics.net/pages/policy>.

Item Type	Article
Authors	Nagaoka, Shigeo
Publisher	EUBIOS ETHICS INSTITUTE
Rights	With permission of the license/copyright holder
Download date	2026-07-05 01:08:31
Link to Item	<a href="http://hdl.handle.net/20.500.12424/176440">http://hdl.handle.net/20.500.12424/176440</a>

given away in the same manner that seeds must be buried to the ground in order to grow and bear fruits (PBE, 62). The products of human intelligence, like medical knowledge, must be applied and shared if wisdom is to be attained by its practitioner. Such acts of self-giving is a dictum of nature that can be characterized by nothing else but an ontological love, the diffusiveness of the inherent goodness of being for the sake of others.

It is perhaps appropriate that we momentarily pause at this point of our reflections and open the floor for discussion on this session which is aptly entitled "The spirit of medicine and love."

## References

- KH: Jürgen Habermas, *Knowledge and Human Interests* (Boston: The Beacon Press, 1971).  
 LR: Karol Wojtyła, *Love and Responsibility*, Trans. by H.T. Willetts (New York: Farrar, Straus, Giroux, 1981).  
 MMC: *Making Life Beautiful: A Bioethics Manual of the Makati Medical Center* (Makati: Salesiana Books, 2008).  
 PBE: Norris Clarke, *Person, Being and Ecology* (Quezon City: Ateneo Office of Research and Publications, 1996).  
 ST: Thomas Aquinas, *Summa Theologica*  
 TTC: *Tao Te Ching*, Trans. by Man-ho Kwok et.al. (New York: Barnes and Nobles Book, 1993).

---

# Medical Uncertainties and Patients' Decision Making

- Shigeo Nagaoka, M.D.,  
 Niigata University, Japan  
 Email: shigeo@ed.niigata-u.ac.jp

## 1. Introduction

It is often reported that despite various efforts on the part of medical providers to inform patients of their medical conditions and to encourage them to make their own decisions about treatments, patients tend to have difficulties in understanding the information disclosed to them and, further, in making decisions about which options to choose. Patients often blindly follow whatever is recommended to them by medical providers, and due to this, many physicians come to feel that all the efforts to make the technical information accessible to lay people are more or less in vain, and to doubt what informed consent is for, e.g. whether it is simply a legalistic ritual or not.

This paper tries to explore patients' attitudes in the informed consent situation. Quite often the step from understanding to decision (consent) is conceived in intellectualistic terms: the decision follows naturally, once the necessary information has become available and the patients make clear their values to themselves. In reality, the patients

have to struggle to find an answer in a world full of medical uncertainties. Whatever decision they finally reach, there may be a dynamic process of receiving input and transforming it so it suits their own individual needs. This aspect will be called the gambling phase. First the standard version of informed consent will be briefly reviewed. Next, risks will be identified as the biggest stumbling block when the patients try to make medical decisions. A reported case is brought in, to illustrate that not intellectual problem solving but rather gambling, or taking a chance, plays a central role in the process of decision making. Then some comparisons with other theories are made. This will be followed by some implications from the gambling thesis will be considered. Lastly a modest proposal is submitted.

## 2. The standard version of informed consent

It is widely agreed that informed consent consists of the following five elements: (1) disclosure, (2) comprehension or understanding, (3) voluntariness, (4) competence, and finally (5) consent (or decision).

With the background conditions that the patients can understand various situations (as in 2) and can make judgments about them when necessary (as in 4), and that there is no coercion from the physicians and/or others (as in 3), the patients receive information about her medical conditions from physicians and also are offered some treatment options, together with information of the benefits and risks of each (as in 1). After considering each option's merits and demerits, using their own values, the patients are supposed to make a decision about what treatment to receive. In the course of the decision making processes, they may consult with physicians, friends or other patients, and even seek advice from them, but the final decision is supposed to be the patients' own. It is expected that they make rational enough choices and that the final decision is reasonable to themselves as well as to others.

## 3. Risks: perhaps the greatest difficulty for the patient

In our everyday lives, we are surrounded by various risks. Even in routine parts of our lives, like commuting from home to office, there could be devastating accidents which may greatly affect our ways of living thereafter, as is sometimes reported in the media. How do we cope with those possible risks? We are unable to guard ourselves against all possibilities, since for one thing we cannot enumerate all of the remote possibilities and for another what few risks known to us are still too many for us to be prepared for. We may want to take precautions against the kinds of events which have received a lot of media coverage, or which

affected our personal acquaintances. Yet, considering the whole range of risks awaiting us, we only randomly select some to guard against. Probably from a self-defense instinct, we try to ignore or look away from the myriad of possible risks, and continue with the ordinary course of our actions, assuming things will go on as before. When reminded of any of the possible risks, some people may be embarrassed and uneasily turn away their eyes from those possibilities. Some may even laugh at those who mention them, as too cowardly, thinking that those risks will never materialize in their own lives.

Informed consent in clinical settings does not allow this kind of attitude. Typically the patients receive information about the diagnosis of their condition, and then about treatment options to alleviate or cure the problem. If they are unwilling to face various risks, the second component of the doctrine, i.e. understanding, is compromised to a great extent, and the whole process of informed consent is undermined. The more faithful the medical providers are to the ideal of patients' self-determination, the more explicitly they are bound to emphasize the risk factors inherent in each option. The patients do not have recourse to the self defense mechanism they employ in everyday life, but instead they are forced to face those risks directly and squarely.

The problem for the patients is not simply that they are scared of the possibility that some risks disclosed in the course of informed consent might materialize in their own case and consequently they have to endure some serious adversities. More importantly, they may be unable to navigate the world of uncertainties and compare the positive values from the benefits with the negative values from the risks. Typically, information about benefits and risks is given in statistical terms: such as the success rate of the intervention is 80%, or the risk of becoming bedridden is 2% etc. If one can survive some type of cancer 100%, by going through excruciating chemotherapy, the decision to be made is painful but still relatively easy: it depends on how much pain and suffering one is willing or resigned to endure, to attain full remission which is a high positive good.

On the other hand, when the benefit hoped for is not certain but has only a high success rate, decision making becomes quite difficult, since all the pain and suffering to be sustained might turn out to be in vain. Thus, the addition of only one probability factor makes decision making too complicated. Furthermore, when there are several treatment options, the situation may become hopelessly hard to manage. For instance, Treatment A promises the benefit of full recovery at 80%, with the risk of mild complications at 10%

and of severe complications at 10%, while Treatment B promises the benefit of full recovery at 70%, with the risk of mild complications at 25% and of severe complications at 5%. Is there any reliable way that helps us to choose from these two options?<sup>1</sup>

Decision theory tries to show the best possible way to cope with uncertainties. But "the best" here means only "the most likely way" to attain a certain goal, based on a certain method of calculation. For an individual who needs the assurance that a certain course will help him, what this theory offers is another kind of uncertainty. One well-known version is the method to maximize expected utility. In this method, when presented with a possible intervention, what we are supposed to do is on the one hand to ascertain the utility levels of the expected benefits and adverse effects and on the other hand to identify the probability of each possible outcome. By multiplying each utility (positive and negative) with its probability and then summing those probability-weighted utilities, we obtain the total utility of one intervention. By repeating this procedure for each intervention, we can obtain the utility values of various treatments and rank them on a single scale. Then we are supposed to choose the treatment which ranks highest. However there are serious difficulties when patients want to adopt this method for their own decision making. The first problem is the difficulty of assigning a numerical utility to each risk: if a serious, though remote, risk is death, its negative utility is too high to be comparable with any other possible outcome. The second, and more important, problem is that probability, the basis of this method, depends only on the average outcomes, while the patients' concern is their own individual case, i.e. whether they themselves, not the general public, will benefit from a specific intervention. This method may well be appropriate for physicians who try to find the appropriate clinical policies, or who are in a position to give advice to their patients. It is doubtful if this method will be helpful to patients who came to see physicians with their own individual problems. A 99% rate of success may not be assuring enough, and a 1% rate of a serious risk may be confusing or frightful enough.

It may be claimed that this is exactly where patients' values become relevant. Even though it may be impossible to assign a numeric value to each possible outcome, whether a benefit or risk,

<sup>1</sup> Some suggest we could further distinguish between several types of uncertainty (Politi et al, 2007: 682). In this paper, however, we use the simpler conventional way of understanding risks, since this is the kind of information patients usually receive from medical providers or other sources.

it is claimed that patients could give a rough weight to each possibility or at least each of the important possibilities, based on their general view about life, or on their direct or indirect experiences about illnesses. Nevertheless, it is questionable how much help those values could offer for making a decision regarding their current problem. For instance, many people may want to have “a peaceful death”, not excessively controlled by high medical technology.

This kind of view is, however, too general to be applied to a specific situation at hand, since today any kind of medical intervention has a possibility of moving toward a “wild death” and it is hard for anybody to see the boundary which separates ordinary from extraordinary treatments. Or, people may have strong convictions about some specific interventions. For instance, a person may have a strong aversion to invasive surgery in general because of his own personal experience. Yet, should he have another serious disease unfortunately and once again have the option of a surgical intervention, he himself would think it is myopic to avoid the option simply because it involves a surgery. Each new situation presents new dimensions of decision making.

*“Once informed, patients are supposed to ask which treatments best promote their “values.” This assumes that patients have relevant values; some set of beliefs that is coherent and considered enough that a decision can be deduced from it. But people have better things to do than formulate principles for problems they hope will never arise. In fact, for most of us much of the time, we find out what we value by observing what we chose. It is hardly too much to say that our “values” are the explanations we give for our choices, not their source.”* (Schneider, 2005: 290)<sup>2</sup>

The sarcasm in “people have better things to do” aside, the enormous variety and complexity of clinical situations is too much for people to consider in advance about what to do if each one of those situations should arise.

#### 4. A case

In this section, I would like to put forward a hypothesis about a key element in decision making processes: gambling or taking a chance. With no resources available to deal with risk factors in satisfactory ways, patients may abandon their initial rationalistic attitude and decide to gamble on one intervention from the choices given to them. To illustrate this, we will look at a reported case of a patient reaching a difficult decision.

The protagonist in this case is Meg Gaines, Professor at the Law School of the University of Wisconsin-Madison, as related in a newspaper article, “Awash in Information, Patients Face a Lonely, Uncertain Road.” (Hoffman, 2005):

*Nothing Meg Gaines endured had prepared her for this moment. Not the six rounds of chemotherapy for ovarian cancer that had metastasized to her liver. Not the doctor who told her, after Ms. Gaines was prepped for surgery that he could not operate: a last-minute scan revealed too many tumors. “Go home and think about the quality, not the quantity, of your days,” he said.*

*Not the innumerable specialists whom Ms. Gaines, then 39 and the mother of two toddlers, had already mowed through in her terrified but unswerving effort to save her own life. Not the Internet research and clinical trial reports, all citing the grimmest of statistics. Not the fierce, frantic journey she made, leaving home in Wisconsin to visit cancer centers in Texas and California.*

*Now, just about out of options, Ms. Gaines faced an excruciating decision. Her last-ditch chemotherapy regimen did seem to be working. Three medical oncologists thought she should stick with it. But two surgical oncologists thought she should first try cryosurgery, injecting liquid nitrogen into the tumors to shrink as many as possible, and then following up with chemotherapy, allowing it to be more effective.*

*The catch? Ms. Gaines’s chances of even surviving the procedure were uncertain.*

*“Who will decide?” she asked a surgeon from Los Angeles.*

*The doctor then recited what has become the maddening litany of medical correctness: “We’re in the outer regions of medical knowledge,” he said, “and none of us knows what you should do. So you have to make the decision, based on your values.”*

*Ms. Gaines, bald, tumor-ridden and exhausted from chemotherapy, was reeling. “I’m not a doctor!” she shouted. “I’m a criminal defense lawyer! How am I supposed to know?”...*

*Ms. Gaines was out of time. She had to make a decision. She felt the chill of mortality and the full weight of nearly a year of drastic operations, blood clots, a punctured lung, chemotherapy, research, traveling, countless specialists and unanswerable questions bearing down on her.*

*“Who’s in charge here?” she thought that night, wishing someone would just issue her marching orders. “Oh. I am.”*

She endured a long ordeal of fighting ovarian cancer, and now again she had to choose one from two treatments: continuing the chemotherapy which seems to be working on one hand and cryosurgery first, to be followed by chemotherapy on the other. There is some sign that the present chemotherapy will improve her conditions, but there is no guarantee of its effectiveness. The other option seems more promising, at least in

<sup>2</sup> The observation that the word “value” is often used to explain or justify the choice already made will be instructive in light of the following argument in this essay.

theory, but it has a devastating risk: death. Then how did she reach a decision?:

*"When Meg Gaines was a little girl, her father, a lawyer, was transferred to Belgium; the family arrived scarcely 20 years after the end of World War II. She grew up keenly aware of European history, visiting concentration camps and battlegrounds, learning about military strategies.*

*What was the best way to fight her war against cancer, she asked herself that night in 1995, as she struggled to decide about treatment. Stay the course with chemotherapy or risk the cryosurgery first, which, back then, was a relatively experimental and possibly lethal procedure?*

*"What made sense to me was to bring in the air force and bomb the hell out of the tumors and weaken them," Ms. Gaines said. "Then go in with the infantry. And so I decided to do surgery plus chemo, not just chemo."*

*As it happened, the Los Angeles surgeon found only one big tumor. The others, which had earlier scared off the liver surgeon in Wisconsin, were just blood density irregularities and benign cysts.*

*Eighteen months after Ms. Gaines's cancer was detected, she returned to her job, teaching criminal law and supervising students defending prisoners...."*

She gives a reason for her choice: in World War II, the Allied Forces adopted the strategy of bombing German cities first and then attacking the weakened Germany with land forces, with much success. The same strategy would work in her war against cancer, she hoped. Yet a little reflection will uncover how unreliable this war analogy is. In wars, this strategy does not always lead to victories. For instance, during the Vietnam War, the American military used the same strategy, and failed miserably on Vietnam soil. If she had been only a bit more objective and rational, she could not have made the treatment decision, which was based simply on this World War II episode. Moreover, as a criminal defense lawyer she must have been familiar with litigations and the various strategies employed there (which are wars, so to speak). A strategy which was successful in one case will not necessarily be successful in another case, and everyone is aware of the diversity of such situations. Every new case requires examinations of its characteristics and comparisons with past cases.

Thus, we could say that her decision was not the result of rationally comparing and ranking the alternatives, based on her "values," as is envisioned in the standard informed consent doctrine. Then, how did she reach the decision and what role did the reason of the war analogy play in her decision making process? I will present two possible scenarios which, hopefully, are not so implausible.

Let us recall that the choices presented to her were a) chemotherapy alone or b) cryosurgery to

be followed by chemotherapy, both with potential benefits and risks. One possible scenario is that somehow she recalled the successful war strategy during World War II, and hoped the same strategy might work in her case. But, as we saw above, there was no guarantee that this would be the case. This suggests that she decided to look away from the severe risks involved in the cryosurgery and to hope for its success in her case. She decided to narrow her perspectives and focus only on the possible positive results of the surgery. Another possibility is that she was worried about the benign improvements from the present chemotherapy, and she hoped a more drastic intervention might open up a new horizon. But how did she make the jump to this new level, against the advice of some professionals? At that time, she recalled the war strategy and told herself that there are cases where drastic measures bring forth good rewards. She relied on this example, as if grabbing at a straw, to convince herself that there is a good reason to go through with the surgery.

Indeed, there may be other possible scenarios, but I would like to contend that generally speaking, at the time of decision making, the patients decide to mainly look at the promising aspects in the choice they make, and to discount, or look away from, the risk factors: the risk factors which they needed to know so badly in the initial stage of information gathering. At first, they try to gather as much and as accurate information as possible pertaining to their own problems, but that intellectualistic attitude cannot be maintained until the end, since there is no theoretical solution to find a sure way to success and recovery in their own particular case, because of the risk factors in any alternatives they encounter. They are forced to choose one treatment, and yet cannot decide by simply tossing a coin. They need a reason for a treatment, however thin and one-sided it may seem to other people, and once they find one, they decide to stick to it. This is to gamble, or to take a chance, on one treatment, hoping it will succeed. Here the original intellectualistic attitude is transformed into a more emotive attitude, not unlike prayer.

## **5. How other theories see the decision making process**

In their definitive work on informed consent, Faden and Beauchamp discuss a lot on "substantial understanding" but do not say much about the decision making process itself. They mention factors like novel and alien information, lack of time, and stresses coming from anxiety or fear, as barriers to substantial understanding. Yet once the patients achieve sufficient understanding

about their condition and treatment choices, the authors seem to imply that autonomous decisions follow naturally for the patients. They do mention the difficulty of making decisions, describing “such specific task-oriented competences as the competence to decide while in agonizing pain whether to undergo a specific medical procedure that carries a risk of a particular type and degree” (Faden and Beauchamp. 1986: 289) but this kind of observation is found rarely and is mentioned only in passing.

The following passage may be instructive to see the general orientation of their approach, and also to test my hypothesis:

*“Both of these factors—time in which to make a decision and the belief that there are alternatives—are typical features in informed consent situations that professionals frequently can manage for the better but often do not. In many clinical situations, especially in surgery, consent is formally solicited and information given immediately prior to treatment, when there is little time to make a decision. By this point the patient has already made a decision for surgery, perhaps by default. A major behavioral commitment to taking some action is made merely by voluntarily entering the hospital. It is not surprising that a typical response in such a situation is to distance oneself from information that challenges the original decision for surgery—including, paradigmatically, the kinds of risk information typically included in a core consent disclosure. This style of coping with acute decisional stress helps explain why many patients’ capacity for remembering the risks of treatment is lower than for any other category of information. Who would want, on the eve of surgery after having disrupted one’s life, gathered one’s courage, and entered the hospital, to change one’s mind? And thus who would want to pay attention to information that challenges the wisdom of the decision.”* (Faden and Beauchamp. 1986: 325)

The authors suggest that the kind of information disclosure a patient receives just before surgery should have been given before hospitalization. This would have improved the patient’s understanding and would have led to better decision making. But “better” in what sense? It is better only if we can assume that substantial understanding leads to a more autonomous decision and then further to a better outcome. However, as we saw in the above case, an autonomous decision is not possible simply because a patient obtains substantial understanding. Indeed, substantial understanding may make an autonomous decision making more difficult. Furthermore, it is not necessarily definitely better, in terms of a good outcome of a

chosen treatment, which is the main concern for the patients. There is no assurance of success in any chosen course in the world full of uncertainties.

Rather, this passage suggests more about the psychological state of the patient after making the decision. As pointed out in the text, the decision for surgery was made prior to hospitalization. The information the patient used when making the decision might have been far from substantial, but still he made the decision and entered the hospital. When he was an outpatient, he must have received some information about the proposed surgery, including the benefits and major risks attending it. In addition, quite naturally, he must have weighed the merits and demerits of going through the surgery. Even though he knew there are risks, some potentially life-threatening, he finally gathered his courage and decided to take the recommended course. Having made up his mind, there is no point in reviewing the decision making process or in comparing various risks and benefits all over again. This will simply destabilize his state of mind. Instead he would be better off not dwelling on the possible adversities. That is, he decided to gamble on the surgery and to pray for the best possible outcome. This may well be true even of the people who made decisions after receiving “substantial” information about their diagnosis and treatment options. There is no alternative which guarantees the best result, and the substantial understanding of alternatives will serve to show more vividly the uncertainties inherent in each option.

Becky Cox White, in her book, *Competence to Consent*, takes into account what I call the gambling factor. Among the capacities that she mentions define competence to consent is, in addition to the familiar capacities like that of processing information and of reasoning about alternatives, “the ability to resign oneself to the choice.”

*“People rarely face situations in which there is one, and only one, perfect choice. Rather, they must usually make “the best choice, all things considered.” They may, therefore, harbor doubts that their choices really were the best ones. Their cognitive emotions may be in flux and their felt emotions may include ambivalence, and if their choices are unpopular, others may repeatedly attempt to persuade them to reconsider.... Nonetheless to proceed with the tasks ahead, he must persevere in his choice. Persistence in one’s decision, both publicly and privately, is necessary for all parties to get on with what needs to be done. This persistence is particularly difficult if the ensuing course is in any way onerous, because it will require him to undergo disagreeable experiences. Such choices are best undertaken*

*with a sense of purpose and commitment to the designated end. Persons are more likely to succeed if they can dedicate themselves to a course of action. Their perseverance, especially in the face of uncertainty or dismay at what may follow, is what is meant by resignation.*" (White. 1994: 178-179)

She goes on to discuss "Its relationship to decision making."

*"Many choices are only one among several possibilities. Often estimates of burden to benefit ratios and probabilities are uncertain; often the database is incomplete. There is, therefore, a certain amount of hesitation about the correctness of any serious decision. Insofar as possible, information deficits ought to be corrected; but it is probably never possible to eliminate them completely. Ultimately it becomes necessary to proceed in spite of these limitations. That one makes a choice does not, in and of itself, erase the concerns that attend it. As a result, persons may find themselves in the position of having to reassure themselves on an on-going basis about their choices.*

*The decision maker can usefully review the process that led to the decision, recalling the factors that told both for and against the ultimate choice. (Clearly, this review will require the same capacities that went into making the decision in the first place.) Resignation to a plan allows decision makers to undertake the tasks required for its successful completion. The relationship of resignation to decision making, then, is that this capacity empowers persons to act on their decisions. Persisting in one's choice allows its implementation and, hence, the promotion or preservation of the values that are the aim of the decision.*" (White. 1994: 179-180)

She rightly points out that patients have difficulties making medical decisions and, even after making decisions, remain skeptical as to whether their decisions are sound and appropriate, due to uncertainties surrounding medical interventions. Furthermore, to proceed in this environment, they need some kind of reassurance at all times.

Still, we might wonder if we could call the attitude of resignation a capacity. From the viewpoint of medical providers, the patients who change their decisions quite often or who express doubts or anxieties about the decisions many times are hard to manage, hence those who persevere are seen to be more capable of receiving medical treatments. From the viewpoint of the patients themselves, however, they are more or less forced to follow the course they have chosen, in spite of various uncertainties, and that attitude may not be something they could proudly

call a capacity. Also, it is doubtful whether they "are more likely to succeed if they can dedicate themselves to a course of action." If one's subjective attitude alone could greatly influence the outcomes of various undertakings, the world would be a far happier place than it is now. Finally, again it seems unlikely that the patients, once resigned, are willing to "review the process that led to the decision, recalling the factors that told both for and against the ultimate choice." Such a review would lead to facing again the doubts and confusions they had to go through before making the decisions. People are unlikely to want to navigate in this uncertain world over and over again, as can be seen from the previous quote taken from Faden and Beauchamp.

If the above comments on White are acceptable, the kind of reassurance patients obtain must come from discounting risk factors in medical interventions and hoping for the best possible outcome in their particular cases. This is exactly what is proposed as the gambling phase in the decision making process.

## 6. Implications

There are several implications if the above argument is plausible and there is an element of gambling or taking a chance in many decision making processes.

The first could be called the paradox of information: information is sought only to be forgotten. Initially, the patients want to have as much accurate and objective information as possible. But at the time, or around the time, of crucial decision making, they try to sort out the information and to retain only the part they need: benefits of the chosen intervention, and possibly the risks of other interventions. This is necessary on her part to get started with the chosen course; otherwise they will stay tormented by possible adverse events, or remain ambivalent about the choice they made.

Physicians today take pains to give the patients accurate information about their medical condition, hopefully in lay language, so the patients can make decisions on their own. Often, however, physicians express frustrations, since the patients do not seem to understand their own conditions well enough, or even to be eager to listen attentively. But we should notice that no one decides a matter which seriously affects one's life, simply by tossing a coin. In every decision making process, there are phases of information gathering, and also of gambling and praying (sometimes they may coexist in the same mind simultaneously). The amount of knowledge required for moving from the former stage to the next varies from person to person. Some need a

very little, while others a lot, like second or even third opinions. It is not surprising, therefore, that the knowledge of some patients at the gambling phase may well be insufficient or even distorted from the professional point of view.

From this observation follows a second implication. Silent consenters are often seen as an obstacle to implement informed consent in medical settings. In order to respect, or promote self-determination on the part of the patient, physicians are supposed to inform the patient of as much information as necessary concerning his medical conditions and possible medical treatments. However, there are a sizable number of patients, everywhere, who do not pay enough attention to the disclosure, and seem to listen passively to whatever is told to them and further to consent without enough understanding to whatever is proposed by physicians. For physicians, there is every reason to come to believe that informed consent is almost a ritual or necessary evil which could not be skipped in case there should be some complaints afterwards from the patients or their relatives.

Yet it is unrealistic to suppose that seemingly passive patients do not care about their own health. The only difference between them and the so-called informed consenters may be in the amount of information needed before making decisions. Silent consenters may have blind trust of professionals in general, or some good reputation of the medical facility may be enough for them to gamble on the possible treatments they may receive. Observers may be quick to point out that this attitude is myopic or too one-sided, and that patients should be aware of the pitfalls. However, do informed consenters decide on the basis of omniscience? Both silent and informed consenters live within human limitations, and both at some point in the decision making process decide to leave matters of life and death to others and luck. In sum, silent consenters do make decisions on their own about matters which affect their lives a great deal, just as informed consenters do, even though their attitude may look vastly different from that of informed consenters.

A third implication is that some studies concerning informed consent may in fact be misguided. Once informed consent is adopted as public policy, it has to be evaluated objectively and reforms should be undertaken, if there is room for improvements. For this purpose, some scholars undertake research to measure the level of understanding on the part of patients. Some studies concentrate on how much patients remember the information they received before and during treatments periods. If they remember less than they received, it is taken to be a sign of insufficient understanding, and this is supposed to

represent a need for reform, both in the way the information is disclosed and in the patients' attitudes.<sup>3</sup>

However, if the above analysis is plausible to any degree, patients do not simply weigh the risks and benefits of treatments and then decide to take one course based on their own values. They take intellectualistic and objective approaches and also, more importantly, gambling approaches at the crucial moment of decision making. During the latter approaches, the information they received is transformed in patients' minds and may take a different shape. Hence they may answer the same question differently, depending on which phase they are in. The "scientific" research about patients' understanding often misses the dynamic structure in decision making processes.

### **7. A modest proposal**

The implications mentioned in the last section may sound quite critical of the standard informed consent doctrine, but it does not mean that we should give up its whole idea. Instead, the above argument simply implies that the official doctrine puts too much emphasis on the element of understanding, as if people can reach a decision simply through understanding their situation and their own values. Though it is beyond the scope of this paper to work out a new theory of patient-medical provider relationships, some practical suggestion may be in order.

The implications above suggest that informational needs vary, first from person to person, and second within the same person from time to time. It may be too difficult for medical providers to accommodate the diverse or ever-changing informational needs of the patients in satisfactory ways. As a compromise it could be suggested that they have several information disclosure models, from simple to exhaustive, rather than one model, for representative diseases. Then, the patient can start from the simplest one and, if he wants further information, could have access to the more exhaustive explanations. Of course the preparation of such materials requires a lot of work and is beyond the

---

<sup>3</sup> E.g. Bowling & Ebrahim, 2001. This is the introductory essay to the Supplement titled "Engaging Patients in Decisions." What they consider the general framework of decision making processes consists of the following 4 phases: 1) background factors such as Information, Personality, Experience etc, 2) the combination of Understanding risk, Patient preferences and Professional preferences, 3) Decision making and 4) Outcomes. Here again, there is no discussion about the process from phase 2 to phase 3 and it is assumed that once patients have clear understanding and preferences, they can reach the final decision naturally. This and the other papers in this supplement do address the difficulties arising from risk perceptions, but generally assume that they are the matters of communication and further empirical research.

capacity of individual medical providers. It will be possible only by the joint effort of medical societies. Still, by adopting this way of information disclosure, physicians could be sure whether the message they are trying to get across is received by the patients more or less accurately, and further escape the frustrations they encounter when facing "silent consenters."

In this connection, we may recall what was at issue in the history of informed consent litigations in the United States from the fifties till the seventies. The focus was how much physicians should disclose to patients about the risks of any medical intervention: whether a risk of 1 % should be disclosed or it should be withheld since it may scare away the patients, and thus prevent them receiving necessary treatments. First the professional standard was proposed, i.e. the amount of information physicians usually disclose to patients. Dissatisfied with the professional oriented nature of this standard, next the reasonable patient standard was proposed: what average reasonable patients want to know should be disclosed. However, this patient oriented standard, on one hand, did not solve the difficulties of demarcating the amount of information to be disclosed, since it was hard to see the needs of the reasonable patient in general. On the other hand, it was criticized for not accommodating the needs of each individual patient.

What was common in these proposals was that they centered on the duty of physicians to disclose. My proposal above is more patient oriented: if the patients want to know more, they can easily have access to a more exhaustive version, while if they want to stop at a minimum level that is also acceptable. True, there are cases where patients regret wanting to know more since the more knowledge made them more confused or discouraged, as could be seen from many patients' memoirs. But at the level of public policy, this will meet the informational needs of various patients and also decrease the troubles, legal or informal, stemming from the physicians' specific disclosures.

Those who want to define medicine as a helping profession may not be satisfied with this lukewarm compromise. They emphasize that they should also address the spiritual needs of patients. But it is doubtful how much help they could offer to the patient at the crucial moment when he has to choose one of the risky interventions. So-called professional advice is usually based on statistics, while, as contended above, the patients are concerned about their own individual cases. Indeed, however compassionate the professional wants to be to the patients, it is the patients

themselves who have to sustain the consequences of possible adverse events, not the professional who aspires to help. Therefore, there is a limit to what physicians could do, and they have to stay in the peripheral area of the patients' inevitable agony and anguish.

## References

- Bowling, A. and S. Ebrahim. 2001. Measuring patients' preferences for treatment and perceptions of risk. *Quality in Health Care*. 10: i2-i8.
- Faden, Ruth R. and Tom L. Beauchamp. 1986. *A History and Theory of Informed Consent*. New York: Oxford University Press.
- Hoffman, Jan. 2005. Awash in Information, Patients Face a Lonely, Uncertain Road. *The New York Times*. <http://www.nytimes.com/2005/08/14/health/14patient.html>. Accessed 10 Dec. 2009.
- Politi, Mary C., Paul K. J. Han, and Nananda F. Col. 2007. Communicating the Uncertainty of Harms and Benefits of Medical Interventions. *Medical Decision Making*, 27: 681.
- Schneider, Carl E.. 2005. Some realism about informed consent. *Journal of Laboratory and Clinical Medicine*. 145: 269.
- White, Becky Cox. 1994. *Competence to Consent*. Washington D.C.: Georgetown University Press.

---

## The Patient as Subjectivity: Toward a Medical Hermeneutics

- In-Suk Cha, Ph.D.

UNESCO Chair of Philosophy,  
Seoul National University, Republic of Korea  
Email: insukcha@snu.ac.kr

### Medicine as Doctoring

Medicine is generally defined as the art of healing illnesses by whatever supernatural, natural or artificial means are available to healing practitioners in their individual particular cultures. With the globalizing advancement of the empirical-analytical method, medicine has come to be widely regarded as a scientific discipline, and as such, it can be used to diagnose, treat and prevent diseases and injuries regardless of the diverse cultural traditions found throughout the world today.

Medicine, scientific or otherwise, involves a doctor and patient relationship. In scientific medicine, the doctor usually begins an examination of the patient by way of tracing the patient's past medical history and records. Then, if deemed necessary, the doctor orders medical tests, pathological and radiological, and is able to identify the illness, inform the patient of all relevant facts, and treat the patient with all possible