

### **3. Looking Inside The Mind Of A Dying Child's Parents Sentimentality and Reason**

We are creatures of reason. Yet, at the same time, we exist within an emotional web of human relationships between child and parent, wife and husband, man and man. Our mind breathes in this dichotomy between emotion and reason. Likewise, at times our emotions drive our actions. As in the case of patient D, everyone involved is emotionally invested. In cases where a parent's adored child is on his/her deathbed, a "reasonable" ethical decision is often difficult to reach.

In the case of discussion, patient D is dying; his physician, to whom D's parents trust, proposes an EMT with a 15% mortality rate, 15% success rate, and 50% probability of side effects. In light of D's condition, the occurrence of side effects could be lethal; the possibility of death needs to be taken into consideration. Likewise, due to this high risk associated with the occurrence of side effects and the lack of evidence concerning this EMT on minors, it is fair to estimate a mortality rate of 30%.

If we were in the shoes of D's parents, how would we feel? We do not even have concrete data from descriptive research. What we do have, however, is the fact that we love our son and would sacrifice anything in order to save him. We can see here that in times of desperation, we become "drowners" in a sea of hope. Well aware that their son will soon pass away, the parents of D are desperate in finding a means of saving him.

Here, we need to ask whether or not persons, under the circumstances similar to our discussion at hand, are capable of making a composed and reasonable decision. In the case of D's parents, their consenting to the recommended EMT is most likely a paternal instinctual response and not a product of reasonable thought.

Next, we need to consider the following question: If a composed reasonable decision cannot be made, should consent be acquired from a suitable proxy and not from the parents? D's parents have experienced the many bitter stages of D's illness with him; they see their child as first priority and they will, ultimately, have to bear the death of D more than anyone else. In rare cases, however, parents are not always suitable to represent the welfare of the child. For instance, when a parent is incapable of feeling the same kind of compassion and love towards their child.

In the case of D, his parents would sacrifice anything, including their own lives. Even though they may be approaching things from an emotional standpoint and not one reason, this is natural. Accordingly, this cannot be seen as sufficient grounds for the use of a proxy.

D's parents are most suitable to represent D not because they are capable of making a rational decision based on reason, but rather because they have an unconditional love for D as his parents. On the other hand, however, this is the precise reason for their increased vulnerability to both good and evil measures of hope. Although they very well may be unaware of their vulnerability, their intention and will to save D is as strong as rock. In short, the fact they are willing to do anything in order to save D invites an abyss of vulnerability and an abundance of desperate hope.

#### Commission versus omission

In the following section, we discuss the issue of commission versus omission. In our case of discussion, D is critical and there is nothing else medicine can do. We can only wait. Our last resort is using high dosages of immune suppressors. However, while this EMT could save him, it could also turn out to kill him. Nobody knows to which will result.

We are faced with the decision of whether we choose to attempt to treat him with an EMT or let him pass away in peace. Certainly enough, we neither are causing him to suffer nor are

we hastening his death. But then again, we are dealing with a double bladed sword; that is, while we could be saving him with this EMT, we could also be killing him. In short, we are incapable of knowing to which will result; we are incapable of calculating which will be best for him. Omission will inevitably result in letting him pass away.

In these circumstances, the act of trying to save one's child and patient is psychologically easier. For D's parents, the act of trying is essential. "By doing what we can do now, we won't feel regret later," is the greatest psychological gain possible. Accordingly, by saying "we may be able to do something" to D's patients, we are not increasing the possibilities, but rather, we are decisively revealing a path where the possibility of merely waiting disappears.

#### Therapeutic Misconception

Will D's parents be willing to agree to the proposed innovative treatment knowing that it is experimental? Are they really able to comprehend that this EMT: 1) is considered an initial step towards understanding whether or not it is an effective treatment, 2) can not be considered certain to be able to save D, and 3) is clinical research that will benefit patients in the future by adding to the expanding knowledge concerning clinical medicine. In fact, will they be able to realize that by agreeing to treatment, they are placing their son on the "experimental stone." This decision is extremely complicated. As stated supra, in light of D's parents both emotionally and psychologically being desperate, they see this EMT as an indisputable treatment and as the last resort to saving their child. This inevitably points to a high possibility of therapeutic misconception.

The experimental use of high dosages of immune suppressors may be comparable to an emergent life saving surgery with a high probability of death. For instance, suppose a patient is brought to the emergency room from a lethal car accident where her organs have been severely damaged. If nothing is done, the patient will die. If we open her up and attempt to stabilize her, we may save her; however, the risk of death during operation is also extremely high. What would the parents do under these circumstances? This decision involves a psychology of "we have to do something..." a natural reaction to wanting to save one's child.

To a certain extent, this example resembles our case of discussion. However, because our case is dealing not with a proven and accepted treatment, there is a great tendency to fall into therapeutic misconception. We are dealing with the experimental use of high dosages of immune suppressors on patient D and there is no supporting evidence for it being an effective or it being a beneficial treatment. On the one hand, the emergent surgery has a high risk but a proven effectiveness; on the other hand, we know neither the degree of risk nor the value of our EMT.

#### The parent's state of mind and its significance

In our case, the circumstances are decisive. We can overlook the fact that the imminent death in our case has a great impact on the person who has to decide. If D were in a stable condition and his death were not pressing, would D's parents really agree with the experimental use of high dosages of immune suppressors? For instance, if D's condition was not as pressing as in our case and if D still had an estimated six months to live, would D's parents agree to an experiment with a 15% mortality rate? The problem we need to consider is whether or not it is appropriate to propose this EMT to D's parents when D is on his deathbed. If this treatment were not proposed to D's parents, they would not hope its success; they would not need to struggle with the decisions of doing this or doing that.

If our psychological analysis is not mistaken, once the slight possibility of saving D is suggested by his physician to D's parents, his parents will cling onto the hope of saving him until the end. Accordingly, the imperative problem is of whether or not it is suitable to recommend this kind of EMT to desperate parents, and whether or not it is appropriate for physicians and medical researchers to throw a lost hope to a person in desperation.

#### 4. Arguments For Disclosing Information Concerning EMT

Up until now, we have described the decisive importance of recommending an EMT to D's parents and the associative psychological replications. In the following section, we review the possible benefits of using an EMT on a critical patient. These arguments for the use of EMT pertain to the patient's imminent death, the patient's right to know, the disclosure and right to access to information, and lastly, the fact that the purpose of medical therapy is to save lives.

##### Argument #1: The patient's imminent death.

Comparing the benefits and risks in the case of EMT is meaningless if set on premise that "if we do nothing, the patient will unmistakably die," the fact is that even with the best standardized therapy, D can not be saved. By prescribing D immunosuppressors, there lies the possibility of bringing about his death sooner; however, we could not consider this risk without holding it contrast to the null probability of saving D with the best standardized therapy. Without question, we would not recommend this experimental treatment with a mortality rate of 100% and a survival rate of 0%.

However, with a success rate of 15% and a mortality rate of 15%, one could justify proposing this EMT. As mentioned *infra*, omission of EMT would result in the patient dying for no standard therapy is effective. In the case of a chronic illness where there is no risk of dying, a 15% success rate and a 15% mortality rate would not be sufficient in justifying the use of this type of EMT. Nevertheless, the patient presently lying on his deathbed and the ever-pressing need to do something has a great impact on the situation.

What are we to do with a 15% success rate and to an 85% mortality rate? On the premise that "if we were to do nothing, he will inevitably die," any possibility of saving the child could be considered as a high probability. Physicians would certainly recommend a treatment with a 50% success rate and 10% mortality rate in the case where omission of medical treatment lead to an imminent death.

It is possible to consider the lowering of a patient's quality of life (QOL) subsequent to EMT. In the case of D, however, the lowering of QOL is irrelevant for he is neither conscious nor in a state of pain. Accordingly, there is no evident reason for not recommending this EMT to D's parents. A 15% chance of saving D from dying is seen as relatively hopeful. Yet on the other hand, the low rate of success and apparent uncertainty indicate that this therapy is no lifeline. Thus, the proposed experimental therapy is seen to lie somewhere in-between being hopeless and acting as a lifeline.

##### Argument #2: The right to access to information.

If D and D's parents are looking for anything with even slight efficacy, they have the right to know about an EMT and the right to undergo treatment. The covering up options by the medical staff in the name of nonmaleficence is nothing more than paternalism. Trying to protect D from EMT in the name of nonmaleficence will only lead to his death. One could say, rather, that the EMT is an attempt to save D from dying. Accordingly, when acquiring informed consent, it is permissible to provide the parents information regarding EMT.

In today's age of the Internet, there is a high possibility that D's parents could look up information regarding the

experimental use of high dosages of immunosuppressors and, subsequently, request "innovative therapy." In the case where D's parents request treatment, despite realizing that 15% success rate is based on data collected with a small number of adult patients and that D's dying is ever-impending, the physician should sit down and talk with D's parents about the specifics of using this EMT. Regardless of whether or not the therapy is experimental, or whether or not the probability of actually saving D is outlandish, D's parents and physicians should sit down and discuss the various options. The disclosure of information concerning this type of EMT does not provide D's parents more options, but rather, even if it is seen as a last resort, it could provide D's parents a means to continue to believe.

The use of EMT in our case of discussion may need not to be approved by an IRB. We are not dealing with standard clinical research. We are dealing with a preliminary innovative therapy that could save D from dying. Accordingly, if the team of physicians and D's parents both consent to its use, EMT could be suitable in treating D.

##### Argument #3: The objective of medical therapy

The most vital objective of medicine is to save the dying patient. In our case of discussion, "omission," defined here as the continuing of conventional therapy, would inevitably lead to D dying. Experimental intervention, however, provides two paths: one of living and one of dying. As a medical professional, one has the duty to propose all the options that have even a slight hope of saving the patient; there also exists the issue that unless D is treated with the EMT, other pediatric patients under similar circumstances cannot benefit from possible future use of the therapy. If the treatment is effective with D, it could be used as the starting point for further evidence. A random control trial could then prove this EMT to be clinically effective against disease A and safe.

#### 5. Arguments For The Nondisclosure Of Information Regarding EMT

Several arguments suggest that, when conventional treatment is ineffective, it may be permissible to propose an EMT as an option to the patient's family on the condition that there exists a slight possibility of saving the child and that the EMT would neither harm nor lower the patient's QOL. However, there exists a few highly justified arguments against this standpoint. In the following section, we discuss those reasons against disclosing information regarding an EMT to the family of a dying pediatric patient.

##### The respect for D as an independent individual

The argument that one should respect D's human dignity is valid. Despite he being only 5 years of age and unconsciousness, D's dignity must be observed. He has the right to be protected from being treated inhumanely. Although the possibility of D's parents voluntarily consenting to the EMT is quite low, it can be considered unethical to conduct clinical research without final consent from the subject.

In the case where D could realize his physiological condition and make a decision, he may accept to undergo treatment knowing that this was, although uncertain, the only possibility of being saved. He is to decide whether to undergo or to refuse treatment based on it being a harmful approach. It is the patient's right to choose and to feel comfortable with his reasonable decision.

The patient also has the right to know and the right to disclosure. D, however, is five years old and, moreover, unconscious; he is neither capable of communicating nor of making a decision. Proxies, representing a patient with a loss of decision-making capacity, are allowed to make decisions regarding conventional therapies. In the case of clinical

research, however, the use of a proxy is recognized only when the experimental therapy has a high probability of directly benefiting the patient.

#### Double Uncertainty

In the following section, we examine the aspect of double uncertainty inherent to cases where the EMT has only a certain probability of saving the patient's life. There is a vital difference in quality between conventional therapy and this type of EMT. The probabilities of success versus risk of a conventional therapy are statistically known. For instance, let us suppose that a treatment X is effective on 70 patients out of 100. Here, uncertainty rests on whether a patient falls in the remaining 30 or the successful 70. With the use of an EMT, however, the supposed 15% efficacy is itself uncertain. In order to prove the rate of efficacy, a clinical trial needs to be conducted. Additionally, even if this 15% were proven, whether or not D would fall into this 15% is again uncertain. Our case exemplifies this kind of double uncertainty.

Even if the success rate of using high dosages of immunosuppressors on adult patients with disease A was 50% or 100% instead of only 15%, one could still find validity in the argument against recommending this treatment to D's parents based on the principle of double certainty. The mere probability of 50% or 100% is all too uncertain when it comes to saving a patient from dying. Conducting EMT in the name of saving a life, accordingly, is impermissible in times of emergence.

There exists an increased level of uncertainty inherent to the nature of EMT. For instance, the data concerning side effects of the EMT on adult patients is inapplicable. The level of uncertainty ascribed to possibly harming subjects is significantly high. One can only deny those side effects that have been seen in previous studies on adult subjects. It is possible that D may suffer and experience pain unforeseen by I or D's parents. While a patient's needs increase while being in critical condition, the same often is true regarding risk. Despite D's needs increasing, the expected benefits of EMT do not necessarily increase.

#### Cruelty

Providing false hope to persons having to face and slowly accept the tragic fate of soon losing their child is far from being an act of beneficence. Even if that hope is founded on concrete data, there is merely a 15% chance of success. Although the patient may die with an omission of therapy, EMT carries a mortality rate of 85%. Giving hope to parents who will later have to face, once again, the unbearable fact that their son will soon die can be considered to be cruel.

As explained *infra*, proposing the experimental use of high doses of immunosuppressors revokes any other options. That is, there is always the option of allowing D's parents to resign their hopes of saving their son. They would then be able to spend his remaining days quietly by his bedside. The irresponsible act of throwing a lost hope to D's parents consequently rids them of the limited and precious time left with their child; it is far from being a beneficiary act.

Treatment has the objective of benefiting the patient. Conventional therapy with a success rate of over 50% benefits the patient. A treatment with a 15% success rate and a 15% mortality rate can also be considered beneficial. However, in the case where the probabilities of harm versus effectiveness are not yet substantiated as evident, the decision of whether or not such a therapy is beneficial is impossible. To even slightly suggest the possibility of saving a dying child's life without providing any substantial means of making a decision regarding the treatment itself is, needless to say, cruel.

#### Therapeutic misconception held by the medical staff

Therapeutic misconception is considered to be one of the factors behind proposing and accepting EMT. While the parents of D inevitably are influenced by this therapeutic misconception, what about Dr. I in this case? The possibility of Dr. I having become emotionally involved with patient D's circumstances is high. In this sense, Dr. I is just as vulnerable to therapeutic misconception as D's parents. EMT is conducted not on the premise of expecting effectiveness, but rather, in order to prove a therapy's effectiveness. To justify the use of an EMT as a reason to save a life is nothing more than therapeutic misconception.

#### Justice

In our case of discussion, the issue of justice is pressing. Firstly, asking D and D's parents, in all their vulnerability, to participate in research that one is conducting could be seen as "using" them. It would be difficult for D's parents to refuse EMT based on: 1) the recommended therapy is D's last and only hope, 2) it would be quite difficult to refuse the suggested EMT in the context of having relied upon Dr. I throughout D's treatment, 3) the relationship of fidelity between physician and family would fall into strain subsequent to refusing the suggested therapy, and 4) compared to other circumstances, D's parents are very likely to be therapeutically misconceived.

Secondly, this type of EMT should not be carried out under conditions where a patient is on the verge of death. One should recruit patients with the same disease yet not in a critical state. Unlike research concerning cardiac pulmonary resuscitation, this type of EMT does not require subjects to be in critical condition. Accordingly, one should not conduct this type of EMT under critical circumstances.

Thirdly, regardless of how much Dr. I wishes to save patient D, the fact is that he has invested interests in conducting the first trial internationally on pediatric patients with disease A. Accordingly, when Dr. I explains the EMT to D's parents, consciously or subconsciously, he may phrase it in an all too convincing way. The mere fact that the medical staff may hold the subconscious desire to carry out this research points to a significant frame effect. We need not only to consider the psychological state of the patient's parents, but also of the medical staff.

Fourthly, according to the principle of justice, the IRB should not review Dr. I's protocol with priority over others. In the case of the IRB reviewing this case as urgent indicates an unfair prioritizing based on the rule of rescue. The average two months common for the IRB to review a case is a result of the numerous research protocols that are proposed. Even in the case where the circumstances are not urgent, there are hundreds of patients dying of an incurable disease. It is unjust to prioritize D's research due to our incidentally knowing D's situation personally and not knowing the many other hundreds dying. For instance, suppose that the approval of another proposal is postponed a week due to the prioritizing of D's experimental treatment. The subjects who may have participated in the postponed clinical research may pass away within that week subsequent to not being able to undergo therapy. The limited time of the IRB needs to be justly proportioned and not determined by a proposal's degree of urgency or necessity. One needs to take into consideration the effect of the research, the order of proposal and the waiting time. We need to treat equally those patients dying who lay not before us with those patients dying before our eyes.

#### Slippery slope effect

There is a slippery slope effect inherent to our case of discussion. If D's experimental therapy were prioritized as an urgent review and approved, there would exist the concern of a slippery slope effect on the process of reviewing research. A priority-based review conducted with D's case may lead to a

similar process regarding other critically ill patients, other patients under urgent circumstances, and other families with a dying child. This prioritizing of urgency, likewise, may lead to proposals becoming increasingly risky with lower probabilities of success and greater side effects. Additionally, the number of urgent proposals from ambitious researchers would, more than likely, proliferate. Concurrent to this slippery slope would be the increased number of non-urgent proposed being overlooked or postponed. Moreover, critical patients like D would more and more become subjects of clinical research. Here, we need to consider whether or not Dr. I's behavior can be universalized, that is, would it remain ethical on a universal level.

an objective standpoint. For the medical staff and proxies, final decisions regarding treatment of dying patients are ever pressing. While "doing nothing" is heart rendering, the *right* thing to do is not a matter of what to do, but rather of making the best decision.

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#### The limits of information disclosure

A patient's right to access to information concerning treatment should be respected. In the case of EMT, one has the right to access to information concerning the protocols reviewed by the IRB and used to recruit subjects. The medical staff, however, should have the right of discretion regarding EMT. Even if the subject him or herself expresses the desire to undergo a certain EMT, there is no ethical obligation to go against one's conscience by carrying out this EMT. In the case where the physician feels an obligation to disclose information concerning the EMT, does he or she have this same obligation to those subjects recruited from other countries with a similar critical condition? What about research that is not published? It would be impossible to disclose all information regarding the research protocol to subjects in studies conducted internationally.

#### **6. Conclusion**

This paper has discussed whether or not it is permissible to recommend an EMT under urgent circumstances to the parents of a dying pediatric patient. The imperative problem is deciding whether or not it is appropriate to recommend EMT to desperate parents and whether or not it is suitable for physicians and medical researchers to throw a lost hope to people in desperation. On the one hand, we have examined arguments of it being permissible based on the fact that the patient faces an imminent death, that the patient's parents have the right to choose and the right to access to information, and lastly, that the objective of medicine is to try to save patients' lives. On the other hand, we have found it impermissible based on the following arguments: It can be seen as undignified treatment of D, the factor of double uncertainty, the cruelty of proposing an EMT as a last resort, therapeutic misconception of the medical staff, subconscious motives held by researchers including self-benefit, various issues pertaining to research justice, collapse of the review process subsequent to the slippery slope effect, limitations of information disclosure, the disparity between patient's decision and his proxy's decision, and lastly, the unknowable likelihood of side effects. We see that one cannot justify an overlooking of these factors based on an intention of wanting to save the life of a dying child. The members of the IRB and the medical staff involved need to remain objective even when feeling compassion towards the patient. The position of justifying the use of an EMT based on the principle of wanting to save a dying patient could be understood emotionally; nonetheless, members of the IRB need to reconfirm their decision beyond the multiple number of possible misapprehensions.

The role of an IRB is to act as a brake regarding the self-interest of medical researchers, the use of therapeutic misconception by medical staff, and the probability of risks over benefits. Dr. I requested his proposal be reviewed urgently in order to save D's life. The subject of Dr. I's proposed EMT is a dying patient being treated under Dr. I. Even the members of the IRB could fall into therapeutic misconception emotionally. However, what is needed is for the IRB to make a decision from

## *The issue of trust in the doctor-patient relationship in Japan*

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### **Introduction**

Patient trust in the doctor is essential to achieve good medical care. Without trust, a doctor could not expect patients to reveal the full extent of their medically relevant history, expose themselves to the physical examination, or act on recommendations for tests or treatments (Goold, 2002). Trust is also fundamental to bring about effective interpersonal relationships in the clinical setting. The absence of trust engenders the need for constant vigilance, anxiety or necessitates reclusiveness (Mechanic & Meyer, 2000). A recent study based upon interviews of elderly Japanese patients showed that reliability on the part of the medical practitioner is one of the most important factors of good health care. A cross-sectional survey done in the US also revealed that confidence and trust in providers were closely associated with patients overall positive evaluation of their hospitals, and was considered to be more important than patient involvement in decision making (Sebata, Sugisawa, & Fetters, Maezawa, 2002, Joffe, Manocchia, & Weeks, Cleary, 2003). Thus, there is evidence that strong doctor-patient relationships form the foundation of good medical care (Keating, Green, Kao, Gazmararian, & Wu, Cleary, 2002).

Recently in Japan, distrust of healthcare professionals has become a pervasive problem. The media regularly reports medical mistakes and accidents, a high incidence of nosocomial infection, the problematic attitudes and behaviour of doctors, and ethically questionable medical research. The media also criticises Japanese doctors for their lack of adequate disclosure of medical information and unacceptable attitudes towards their patients. A recent public-opinion poll conducted by one newspaper demonstrated that only about 60% of the general public trusted doctors and approximately 30% actually distrusted medical practitioners; the most significant reason was the inadequate disclosure of medical information (Asahi Newspaper, 1996; Nakamura, 2000).

Papers and discussions in medical journals often examine the issue of distrust of the medical profession. Many such commentaries suggest that the inadequate process of informed consent, the absence of humane qualities in the doctor, a lack of kindness, an inability to listen to the patient, the low quality of health care, and secrecy within the medical profession have caused distrust (Becker, 2000, Fukushima & Kato, 1993, Hoshino, 1999). Pellegrino has pointed out that patient distrust of medical practitioners is not a new phenomenon at all and argued that venal, greedy, incompetent, dishonest, and insensitive professionals have never been a rarity. Pellegrino has claimed that the recent commercialisation of healthcare, the high incomes of medical practitioners, hospitals that have a policy of upfront payment, the increase in the number of doctors who want nine-to five jobs and time off, and specialisation have all had their part to play (Pellegrino, 1991).

There has been some thorough analysis of the problem of patient trust and distrust in medicine, especially regarding medical practitioners. Mechanic and Meyer interviewed patients with serious illness and their work demonstrated that practitioners' ability to communicate caring, concern and compassion as well as his or her medical competence were important factors in establishing patient trust. The study also indicated that maintaining confidentiality and the doctor's role in protecting the patient's interests within the health care system contributed to building trusting relationships (Mechanic & Meyer, 2000). Thom, et al. identified factors such as clinical competency and respecting and understanding patients as people (Thom & Campbell,

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pp. 250-262 in Macer, DRJ., ed., *"Challenges for Bioethics from Asia"* (Eubios Ethics Institute, 2004).

1997). Keating et al, showed that a patient's intention to change practitioner was directly related to a breakdown in communication, the features of which were that the doctor did not explain issues in an understandable way, did not take sufficient time with the patient, and did not give him or her the full story. (Keating, Green, et al, 2002). Laine et al also suggested that patients thought that, in clinical practice, clinical competence, disclosure of medical information, and the caring attitude of the doctor were of equal importance (Laine, Davidoff, Lewis, Nelson, Nelson, & Kessler, Delbanco, T., L, 1996). Furthermore, Kao et al. suggest that practitioners who were paid on a fee-for-service bases tended to be trusted by their patients more than those who were paid through a managed care plan, salary, or through a capitated health care system (Kao, Green, Zaslavsky, & Koplan, Cleary, 1998). It also emerged that that the quality of paramedical staff, facilities of medical institutions, and knowledge of past unethical clinical research were also influential when considering the issue of patient trust (Anderson, 1990, Kao, Green, et al, 1998, Keating, Green, et al, 2002, Laine, Davidoff, et al, 1996, Matthews & Feinstein, 1988, Mechanic, 1998, Pearson & Raeke, 2000, Thom & Campbell, 1997, Thorne & Robinson, 1988, Thorne & Robinson, 1 1989). Based on these findings, various educational interventions have been implemented in order to enhance patient trust (Matthews & Feinstein, 1988, Mechanic, 1998, Thom, 2000).

In Japan, however, there have been no studies that examine this issue. Little is known about what actually affects trust in relationships between Japanese doctors and patients. Although there is anecdotal evidence from many sources, we do not have reliable data to consider the determinants that affect patient trust in our country. In addition, there is no research that compares western countries and Japan. Therefore, we conducted a qualitative study using in-depth exploratory interviews with Japanese people who have had experience with the health care system, with the aim of revealing the real state of patient trust in Japan. We also wanted to identifying relevant factors affecting trust between Japanese patients and doctors. We hope that the outcome of our study can demonstrate some ways in which patient trust can be enhanced.

## 2. Methods and Subjects

The study employed in-depth interviews employing the constant comparative method used in grounded theory (Chenitz & Swanson, 1986, Strauss & Corbin, 1990). Semi-structured, individual interviews were conducted between December 2001 and November 2002 in the Kansai Area, mainly in Kyoto. Inclusion criteria for our participants were 1) that they were between 20 and 70 years old, 2) could communicate using Japanese, 3) either the interviewee or his or her family member had been an outpatient had stayed in hospital that had lasted longer than a month, and 4) neither the interviewee nor his or her family member or close relatives were health care professionals. We used these criteria because we thought such people were likely to have sufficient interaction with the medical profession, and would be able to provide us with realistic information and reliable insights into the issue of patient trust.

Three researchers (AA, MO, and EN) conducted the interviews. Each interviewer interviewed one participant and we conducted on average three interviews a day. All interviews were recorded with the permission of the participants and transcribed. The transcribed results were then independently analysed and coded based on grounded theory. The participants' statements were labelled by the three interviewers and classified. The process was repeated until the final interview was completed. Using the concept of theoretical sampling, we chose each interviewee's characteristics (gender, age, place of residence, and kind of disease) for the next interviews.

All interview participants were recruited by the Japan Research Center whose main professional activity is conducting both public-opinion polls and market research. The investigators in charge of the Kansai Area conduct approximately 30 public-opinion polls and market research surveys a year. We asked the investigators to find people whose personal backgrounds were compatible with our target subjects. Informed consent was obtained twice. That is, when the investigators from the recruiting centre asked respondents to participate and

when we actually started interviewing. An honorarium was paid to all participants. We concluded this part of the study when we judged that we had confirmed theoretical saturation.

In the interviews, we began by asking the participants about their personal backgrounds, present state of health, past medical history, and family history. Subsequently, our participants were asked to describe a doctor who he or she thought was trustworthy, describe a medical practitioner who the participant thought was unworthy of trust, describe the experiences that led them to trust doctors, and tell us about the events that had led them to be distrustful of the medical practitioners. In addition, we asked our participants about other factors related to the establishment or destruction of trust in the doctor-patient relationship.

Unlike previous research regarding patient trust, our interview sessions were exclusively conducted outside of the hospital setting, and our recruitment method was completely independent of the researchers or researchers' university. We decided to utilise this method because we thought that if the participants were recruited through the hospital system where the researchers were working, or from the hospitals where the researchers had acquaintances, the participants would be unwilling to describe any doctors who the participant thought was untrustworthy, and the experiences that had led them to such a conclusion. In addition, we preferred to interview residents from diverse districts in the Kansai area. This study, interview protocol, recruitment method, and consent process were reviewed and approved by the research ethics committee at the Kyoto University School of Medicine.

In the process of developing categories and subcategories, research team meetings and electronic communication were utilised to discuss the accuracy of the lists of codes, subcategories, and categories during the interview period and the subsequent writing of the paper. Research team discussions were also used to select interviewees' representative statements. We repeated these processes until we reached complete consensus.

### 3. Results

Between the months of December 2001 and November 2002, we conducted a total of 25 semi-structured interviews. Participants were non-medical professionals between the ages of 42 and 68 with an average age of 54; 92 percent of participants had visited a medical institution and 64 percent of participants had a past medical history (Table 1). The average length of each interview was just over an hour. All interviews were transcribed. Results of this qualitative investigation go some way to explain why patients either trust or do not trust their medical practitioners. Sample categories and subcategories of trust and distrust within the context of healthcare are shown in Table 2.

#### The doctor's competency

##### *1-1: The outcome of medical treatment*

The outcome of medical treatment was a crucial factor in determining whether or not a trusting relationship could be established. Whether the medical care given was successful, or whether the patient was satisfied with its consequences, had a significant correlation to the establishment and maintenance of a trusting relationship. Events that made our participants distrustful of their doctors included a mistaken diagnosis, delay in making a diagnosis, prolonged pain and suffering, unsuccessful interventions, witnessing deterioration of the medical condition of family members, incompetence when performing basic medical procedures, and the aimless continuation of ineffective treatment. The fact that different doctors gave the participant different explanations about a medical condition also undermined the development of trust. Some respondent stated: "My doctor, who was a young resident, failed to diagnose my pneumonia.", "The best doctor is the one who effects a cure."

Patient trust could not be nurtured when a medical practitioner did provide good medical care or conduct procedures that the patient considered to be necessary. Physical examinations or laboratory tests that the participants thought were essential that were not carried out, long waits between appointments, and delays in referrals to specialists also brought about a

lack of trust in the doctor. Incompetence, or a feeling that the doctor was not up to date with new knowledge also undermined the growth of a trusting relationship. By contrast, spending enough time with patients and examining them thoroughly was found to be the cornerstone of a trusting relationship. Participants stated: "Even a general practitioner in a private clinic should study more. If this is not possible, then he or she should refer his patients to specialists in a bigger hospital immediately.", "Nowadays, few doctors look patients in the eye. Why is that?"

**Table 1: Participant's characteristics**

Participant	Age	Sex	Present Illness	Past History
#1	53	female	asthma	subarachnoid hemorrhage, pneumonia
#2	65	female	hyperlipidemia	gastric ulcer
#3	68	male	hypertension	primary aldosteronism
#4	58	male	hypertension	myocardial infarction
#5	61	female	diabetes mellitus	gastric cancer, acute pancreatitis
#6	66	female	gastric ulcer	ovarian cysts
#7	57	female	diabetes mellitus	myoma uteri
#8	42	male	hypertension, chronic pancreatitis	acute hepatitis
#9	48	female	post operation of duodenal cancer	duodenal cancer
#10	46	female	none	none
#11	46	female	myoma uteri	none
#12	49	male	rheumatoid arthritis	none
#13	48	male	gastric ulcer	none
#14	44	male	diabetes mellitus	acute glomerulonephritis
#15	47	female	hypertension	myoma uteri
#16	49	female	ulcerative colitis	none
#17	56	female	diabetes mellitus	duodenal ulcer, iron deficiency anaemia
#18	65	female	diabetes mellitus	none
#19	55	female	diabetes mellitus, hyperlipidemia, hypertension	none
#20	53	male	post renal transplantation	renal failure
#21	56	male	hypertension	appendicitis
#22	52	male	hypertension	leg fracture
#23	64	male	hyperlipidemia, hypertension	none
#24	42	female	mastopathy	none
#25	54	female	none	liver hemangioma

*1-2: The doctor's personal and social background*

Our participants suggested that the patient gave special attention not only to a doctor's medical competency, but also his or her personal and social background in determining whether he or she was trustworthy. Characteristics that contributed to patient trust included a high rank in the hospital system, age, adequate clinical experience, being male, and good personal connections. The participants were likely to put trust in a practitioner from a famous university, who had also studied or worked abroad, and who was also able to practice in a Western country. Some participants make comments like the following: "My doctor does not usually explain my condition to me in detail, but I trust him because he is very famous.", "When I had surgery my anaesthetist was a young woman. I wondered if she was reliable."



Patient trust in healthcare institutions had similar features. Our participants tended to find famous institutions, bigger hospitals, and university-affiliated hospitals more trustworthy. Conversely, doctors working at small clinic were often called "Machi-isha "(doctor in private practice) with a note of scorn and the patient's use of the name implied that the practitioner in private practice was, in general, inferior to one who worked in a big, famous, university-affiliated medical institution. Remarks like "You can count on K University hospital. Nothing will go wrong there, " were typical.

However, our participants' trust in a practitioner that had its basis in the personal or social background of the doctor, or the institution was sometimes changed because of experience as a patient. For example, trust in a renowned medical institution deteriorated when it turned out that a participant's family member had care as an outpatient that was of a very low standard. He remarked: "I have no trust in that hospital. I thought that I could trust the doctors there because the hospital is the most advanced and biggest centre for heart disease in Japan. But, my wife, who had seen a doctor regularly at the hospital for her heart problem, gradually became worse and even when she complained to her doctor about her condition, no new interventions were attempted, and her drug therapy remained unchanged. I took her to a different hospital - a smaller community one - and the doctor told us that an urgent operation was needed. This series of events caused me to distrust that the first hospital. "

**Table 2: Categories and subcategories of trust and distrust within the context of healthcare in Japan**

Category	Subcategory
1 . Doctor's competency	1 - 1 . Outcome of medical treatment
	1 - 2 . Doctor's personal and social background
	1 - 3 . Issues of reputation
2 . Doctor's appropriate responses	2 - 1 . Doctor's manner and attitude
	2 - 2 . Communication of medical information
	2 - 3 . Priority of patient interests
	2 - 4 . Limit of care and supererogation
3. Emotional aspects in doctor-patient relationships	3 - 1 . Patient's emotions
	3 - 2 . Doctor's negative feelings toward patients
	3 - 3 . Care
	3 - 4 . Friendship

### *1-3: The issue of reputation*

A series of interviews with our participants revealed that they tried to gather information to judge which medical practitioner or medical institution was trustworthy. Before actual contact was made, assumptions regarding trust were often formed, based upon the doctor's reputation. Our participants were also influenced by media reports of medical error and misdemeanours. Personal communication regarding a doctor's competence and reputation in a community also affected participant judgment.

Our participants were likely to place their trust in practitioners whom their friends or close relatives regularly saw, and they suggested that consulting a doctor about whom nothing was known made them uneasy. One person stated: "I have never visited a new doctor without any information about him or her. It makes me feel uneasy."

Our interviews also found there was absolute trust in doctors before medical mistakes were made public. One respondent stated: "In the past I had the feeling that a doctor was infallible. "

## 2 The doctor's approach

### *2-1: The doctor's manner and attitude*

The doctor's manner and attitude towards his or her patients was found to be of great significance in the establishment of patient trust. Factors that diminished trust included not listening to the patient, lack of dialogue, not answering the patient's questions, silent contempt, refusal to disclose information, preaching at patients, and giving offhand answers. Such a lack of communication raised patients' anxiety about medical conditions. Thoughtless remarks also distressed our participants. As one respondent stated: "I want my doctor to answer my questions more completely. My anxiety level rises if I am left uninformed and ignorant.", "My doctor told me that I was a very healthy patient. But, how could he call a patient healthy who required an abdominal operation in a week's time?"

On the other hand, factors positively influencing the development of patient trust included apologising for mistakes, kindness and courtesy, openness, as well as a dignified attitudes towards and appropriate meticulousness with patients. However, pandering to the patient on the one hand, or being excessively dictatorial on the other, had quite the opposite effect on trust. As well, simply giving the patient whatever treatment he or she wanted did not inspire confidence. As one respondent remarked: "A doctor should not be a yes-man."

A medical practitioner's fairness was also a key point in constructing a trusting relationship. It was essential for our participants to feel that they were treated justly. Our interviews revealed that some of our participants felt that they had been discriminated against. Personal connections with medical practitioners or other health care staff, powerful connections with an influential community member, a letter of introduction, gifts to the medical practitioner, and the social standing of patients or their relatives, our participants reported, changed responses to the patients. One person stated: "My father, who suffered from lung cancer, could have been admitted to the hospital earlier if he had been rich and had had a personal connection with someone powerful in his town."

Finally, patient trust could not grow without the development of a stable relationship between doctor and patient. Trust did not develop in situations where there was no personal doctor. A shortage of practitioners in charge of patients in hospitals, no available appointments for consultation for outpatients, and patients irregular visits to medical institutions made the establishment of a stable doctor-patient relationship difficult or sometimes impossible. One participant reported that: "I did not have a regular doctor in charge of my care when I was admitted. So I did not know with whom I could consult about my condition or treatment plan."

### *2-2: Communication of medical information*

This subcategory mainly concerns the quality and quantity of medical information that doctors provide to their patients. Inadequate disclosure and explanation regarding medical information relevant to the patient engendered distrust. An insensitive disclosure of results and an explanation of the patient's condition without addressing his or her personal concerns and circumstances was also described as an obstacle to the development of patient trust. Even if a prior explanation about diagnostic procedures or therapeutic intervention had been acceptable, patient trust could not be maintained in cases where the explanation became inconsistent with what actually happened. For, example, one respondent said that: "My mother began kidney dialysis during hospitalisation for renal failure. On discharge, however, we were not told that my mother needed regular dialysis. So my mother stayed home without having dialysis and general edema, ascites, and dyspnoea soon developed."

Another person reported that they were not told how long a procedure would take: "I was told that the test only took 40 minutes, but it took three hours! "

Our participants placed their trust in their doctor when he or she provided them with clear and detailed and explanations. Conversely doctors who believed that they should automatically be trusted in general failed to win our participants' trust. As some respondents stated: "I think a doctor who explains to me in a way that I can understand is reliable. ", "He gave us a 2-hour

explanation about my father's heart condition and explained the process of the operation in detail. We were informed not only of the benefits of the surgery, but also its risks."

The full disclosure of information, and the clear explanation of conditions and procedures had the power to transform a participant's negative first impression of a practitioner. Furthermore, good communication of medical information deserved, our participants pointed out, some inconvenience. Respondents stated that: "I felt that I could not trust him because he was very old. But he gave me a clear explanation and I thought that he was good.", "I would rather travel for one hour and see a doctor who explains things to me properly, and gives me good advice and care, than see a neighbourhood doctor who does not do these things." However, the relationship between patient trust and good communication was not a simple one. Our interviews did not suggest that adequate disclosure by itself always developed trust. Our participants sometimes trusted doctors who did not give sufficient information if the practitioner was an authority in the field. It was also pointed out that frank and complete disclosure of medical information did not necessarily mean "good" communication. Although one of our participants was upset when she knew that her doctor had withheld a diagnosis of ovarian cancer from her, other participants were ambivalent about truth telling in regard to the diagnosis of cancer. Some preferred a white lie and thought that it was not necessary for the doctor to disclose all relevant medical information if there was a trusting relationship. As one respondent stated: "Circumstances may justify a lie."

### *2-3: The priority of patient interests*

Extremely strong patient distrust came about when our participants suspected that the practitioner thought that patient interests were of secondary importance. This lack of trust also arose when participants felt that they were being exploited for reasons other than the promotion of their own health; for example, when the financial interests of the doctor or the hospital took precedence over the patient care. One participant witnessed a case where a homeless person who required urgent residential care was denied hospitalisation, provided with only token treatment, and forced back on the street. In another case, a hospital urged a member of one of our participant's family to leave as soon as the residential fee got cheaper (in Japan, hospital fees become cheaper after a 3-month stay). In other cases, some doctors ordered excessive laboratory tests in order to make money.

One participant expressed it as follows: "It is completely unacceptable for a doctor not to treat a patient according to his or her needs. It is the doctor who determines whether or not the patient needs care in hospital, and sometimes doctors ignores a patient's needs and deny necessary admission because the patient has no money."

There was a feeling amongst the participants that "things were better in the old days". There was consensus among them that a fine doctor is never calculating and many thought that in the past, doctors were more altruistic. Some participants referred to "Akahige (Red Beard)," a character in a novel written more than 40 years ago, as a great doctor. Akahige was a doctor who provided the poor with free medical care and worked tirelessly as a patient advocate in the Edo era (Yamamoto, 1962).

Hospital policies also had a part to play in undermining trust between patients and doctors. One respondent stated that: "My doctor said, that this his hospital was designed to care for acutely ill patients and your mother is now in a vegetative state and stable. So, you need to find a new hospital for her."

Being used as means to an end, or feeling exploited completely undermined trust. One respondent recalled that: "When I underwent angiography for my primary aldosteronism, the radiologist let his resident practice the procedure on me while pretending he had carried out the test."

In the same way, our participants said that they felt some misgivings about university affiliated hospitals, as they were places where patients were used inappropriately as experimental subjects.

### *2-3: The limit of care and supererogation*

Our participants complained that "outpatient care often resembled an assembly line". As well, doctors often failed to give adequate time to their patients. However, our participants had a great deal of insight into the limits of medical care that individual doctors could provide. They indicated that they understood that factors like an excessive number of patients in clinics or hospitals, too much overtime, understaffing, and various kinds of restrictions set by national health insurance all had their part to play. Some participants also perceived medical mistakes to be unavoidable because of the limits of human ability. Taking these factors into consideration, they attempted to distinguish between errors that occurred that were unavoidable, and those for which practitioners needed to take some responsibility.

On a more positive note, respondents noted that their doctors often went beyond the call of duty. For example, one participant was able to have her baby in a hospital where there was no obstetric department, because of her doctor's assistance. Another woman recalled that her husband was allowed to stay all night with her in a small obstetric hospital. Another participant recalled her doctor coming to see her everyday in hospital, although he was not on call, and another woman recalled a doctor being particularly attentive to her daughter when she was ill. One mother recalled that: "No matter where my doctor was and no matter when I called, even in the midnight, he came and treated my daughter."

## 3 The emotional aspects of the doctor -patient relationship

### *3-1: The patient's emotions*

Our interviews suggested that patients sometimes felt that they had no choice but to trust their doctors, as the world of medicine was not fully comprehensible without their assistance. As well, reliable information about whether or not a medical practitioner was trustworthy was often unavailable. At the same time, however, the respondents' health problems often required resolution, and if there was absolutely no trust, it became impossible to decide whether or not to take drugs prescribed to them, have surgery, or invasive diagnostic procedures. Nevertheless, they felt that patients were sometimes left to their fate. Some of our respondents put it as follows: "When I started my drug therapy, I tried to find out about each drug. But it became too difficult. I felt that I simply had to trust my doctor." Another said, "If you can't trust your surgeon, it becomes impossible to even go into the operating theatre, let alone have surgery."

When there was insufficient evidence to determine whether or not a doctor was competent, patients sometimes based their opinions on the doctor's character. As well, when the illness was not serious or life threatening, they tended to see a practitioner with whom they had a good personal relationship. When the illness was more critical, they looked for someone with a good professional reputation. Some respondents were simply terrified of any encounter with the health care system, or disliked certain doctors without justification. As well, hospitals were sometimes seen as frightening places: as one participant stated: "I was really terrified when I was brought to the angiography room. It was as if I was being sent to a battle field."

Our interviews also revealed that patients also had a sense of obligation to certain healthcare providers. For example, families would continue to see a particular doctor out of a sense of gratitude for his work with other family members. This was particularly the case with older patients, and people from rural areas. This sense of duty sometimes prevented our participants and their families from changing from a doctor whom they did not trust, and caused some frustration.

"Some patients cannot change their physician of whom they are distrustful. They cannot do so because they feel indebted to the physician."

### *3-2: Doctors' negative feelings toward patients*

An expression of negative feelings toward patients by the doctor had a dramatic effect on trust and intensified the patient's suffering and discomfort. A medical practitioner's failure to

control his or her temper and expressions of displeasure always had the effect of undermining trust. However, our participants did not believe that doctors should never show emotion. If a doctor became angry out of concern for a patient, and used strong language to educate and improve health, this was often seen as appropriate, and as a mark of care. As one respondent stated: "A doctor I know well is very kind to children and old people in the clinic. However, he is very firm with patients whose noncompliance causes their health to deteriorate."

### *3-3: Care*

Empathy and compassion for a patient went a long way towards establishing trust. Our participants also thought that caring for the patient's psychological well being was vital to developing trust, a sense of security and peace of mind. A doctor who was trustworthy was likened to a talisman whose existence lifted a huge burden from the patient. At the same time it was suggested that the human side of medical care was underdeveloped in Japan. As one of participants stated that: "I need humane care, I do not want to be dealt with medically."

### *3 - 4: Friendship*

The development of friendship between doctor and patient was considered to be of great value by our participants, as they saw it as the best way of achieving good communication. However, they suggested that as things stood, there were considerable barriers between medical practitioners and patients in Japan at the present time. The ideal relationship between doctor and patient was compared to a fraternal bond, or that between a teacher and student by some participants. Some respondents stated that: "It would be the best if I had a brother who is also a doctor.", "I felt very happy because I could get familiar with my doctor."

## **Discussion**

The current study gives us important insight into issues associated with trust in as connected to the doctor-patient relationship in Japan. Factors that contributed to patient trust included the doctor's competence, his or her appropriate responses, and positive emotional behaviour on the doctor's part. Our participants also placed their trust in the doctor when treatment went well. Issues like the doctor's age, sex, rank in hospital, and the university from which he or she graduated also affected patient trust. The doctor's reputation was important, as was appropriate behaviour and the proper disclosure of medical information. When the doctor did not prioritise the patient, trust was destroyed. However, sympathy and compassion promoted trust, as the participants wanted a close and friendly relationship with their doctors. At the same time, however, participants expressed the idea that they sometimes felt they had no choice but to trust the practitioner, regardless of their relationship.

Previous research suggests that factors that influence trust include technical and interpersonal competence, respect for patients, honesty, agency/fiduciary responsibility, maintaining confidentiality, the doctor's control of care, disclosure of incentive and conflicts of interest, issues related to the constraints imposed by health care plans, and the method of doctor payment ( Kao, Green, et al, 1998,, Mechanic & Meyer, 2000, Thom & Campbell, 1997). The outcomes of our investigation were mostly compatible with these findings and, at the same time, substantiated the aforementioned claims concerning the Japanese media and arguments put forth in other articles (Asahi Newspaper, 1996, Fukushima & Kato, 1993, Hoshino, 1999, Nakamura, 2000).

Furthermore, the current study suggests that patient trust in the Japanese clinical setting took different forms, consistent with other publications regarding trust (Goold SD, 2002, Mechanic & Meyer, 2000, Illingworth, 2002). Trust based on a doctor's personal and social background or upon his or her reputation for competence can be categorised as social trust, and at the same time, expectant trust. Trust established after the patient actually saw the doctor and communicated over time can be categorised as interpersonal, experiential, and evidence-based trust (Goold SD, 2002, Mechanic & Meyer, 2000, Illingworth, 2002). It can also be said that, as

Yamagishi defined, trust based on clinical competence can be classified as a fulfilment of an expectation of competence, while trust that stemmed for a doctor's appropriate response to patients as well as positive emotional relationship can be categorised as the fulfilment of an expectation of goodwill or good intentions (Yamagishi, 1998).

On the other hand, unlike many prior studies, our participants did not refer directly to confidentiality, control, or disclosure. There are several possible explanations for this omission. Firstly, our respondents may not have had felt that their privacy had been put at risk. Secondly, our participants may not have been overly concerned about this issue because they did not have so-called stigmatised conditions, like HIV, or genetic disorders. Thirdly, it may have been the case that our participants took it for granted that their doctors would simply maintain confidentiality. At this time it is difficult to determine the relationship between confidentiality and patient trust in Japan.

It is most likely that participants did not refer to issues like the doctor's control of care, disclosure of financial incentive, conflict of interest, and constraint to care resulting from health plans because, currently, the Japanese national health care plan has not introduced managed care. Japanese doctors are either paid on a fee-for-service basis or earn a fixed salary. As well, insurance companies do not have the power to intervene in a medical practitioner's decision making for each patient, and doctors can send patients to specialists without the risk of incurring any financial loss.

However, our current study suggests that because of the fee-for-service payment method, Japanese patients suspected that their doctors performed needless tests and wrote prescriptions that were unnecessary in order to earn more money. It seems that doctors who are financially calculating are not trusted in any culture. Regardless of place, doctors who put their patients' interests first, whether in the clinical setting or in training, engender and maintain trusting relationships with them. The current research -consistent with other studies- indicates that the emotional aspects of the doctor-patient relationship such as expressions of caring, sympathy, and compassion were strongly associated with patient trust in the Japanese clinical setting. In our opinion, however, the emotional dimensions we identified were personal and partial rather than reflective of the professional interpersonal competence or impartial benevolent attitudes of the doctor. Our participants expected friendly and personal connections with their doctors, not unlike the kinds of relationships they had with family members. Thus, friendship seems to play a significant role in establishing trust in doctor-patient relationships in the Japanese health care system. Our study suggests that Japanese human relationships, referred to as "amae", which means dependence on those with whom we have close relationships still has a tremendous impact on relationships in the clinical setting in our culture (Doi, 1995). Furthermore, this cultural factor helps to explain the importance our respondents placed on doctor's supererogatory action, which can be regarded as personal and partial treatment for a particular patient.

Several issues deserve further attention. Firstly, our interviews showed that patients sometimes felt that they had no choice but to trust their doctors. This finding we gained from the interviews with Japanese participants is consistent with the concept of "unavoidable trust" or "ineradicable trust" that various western moral philosophers also refer to (Illingworth, 2002, Pellegrino, 1991, Zaner, 1991). Such trust without choice may be quite common across diverse cultures and even universal in the relationship between laypersons and professionals. It might then follow that the inevitability of trust in professional makes the ordinary people vulnerable to the limits of the specialist's good will (Baier, 1986, Illingworth, 2002, Pellegrino, 1991, Zaner, 1991). In certain circumstances, trust may need to be created - even self created-in the minds of those who need help from professionals. Johann Wolfgang Goethe (1749-1832) wrote that we cannot trust medical doctors but cannot survive without them. This remark has some contemporary application.

Secondly, our study indicated that some Japanese medical practitioners held inappropriate attitudes towards patients, and sometimes even behaved unethically. Our

interviews provided us with some telling examples. These included forced discharge from hospital and refusal of care for financial reasons, subtle and apparent discrimination against patients, poor communication skills, no disclosure of relevant medical information, and poor hospital care. These reports may indeed be the tip of the iceberg, as these issues are not discussed openly in Japan. Our sampling strategy - completely independent of the researchers - gave us unique insights into the real state of affairs. If we had recruited our participants from one of university hospitals where the researchers were working or through our own network, no participants would have been frank enough to reveal their experiences. Further studies are undoubtedly needed, as are strategies to prevent such issues from arising in the future.

Thirdly, our respondents indicated that a psychological trade-off among different dimensions of trust took place. This trade off seems to work on two levels. Firstly, patients used different criteria to determine doctor's trustworthiness. If information about competence were unavailable, the patient might decide to rely upon the doctor's personal attributes. It can be argued that such trade-offs occur because patients need to trust the medical practitioners when they need medical care. This phenomenon substantiates the inevitability of trust in the doctor-patient relationship. Secondly, trade-offs occur between different practitioners on the basis of different characteristics. Our interviews suggested that when patients believed that they had a serious medical condition, they looked for a doctor who was an authority. However, in cases where the condition was less severe, patients chose to see practitioners with whom they had a good personal relationship. It might be the case that a patient might want to see a doctor who is both competent and personable. However, such doctors were a rarity.

It is important to note also that Japanese patients felt a sense of duty to continue their relationships with a family doctor, and this alone could prevent them from leaving a medical practitioner. This particular feature of Japanese doctor-patient relationships might change significantly as globalisation takes hold, and as Japanese patients become more conscious of their rights. It is also possible however, that if patient dependency, that is - "amae", a sense of indebtedness to others, and respect for social duty rather than individual right might prove an unshakeable feature of Japanese culture. If this is so, then the particular cultural factors we have discussed will not change.

There are limitations to our study. Firstly, our participants were recruited from the Kansai area only and it is possible that regional issues might have influenced their responses. The attitudes and beliefs expressed in our interviews may not be representative of the general public in Japan. Secondly, our qualitative study cannot provide quantitative information. However, our primary aim was to achieve in-depth understanding of patient trust and distrust in the present Japanese clinical setting and this limitation does not devalue our study. Thirdly, we interviewed people aged between 40 and 60. They were mostly outpatients with chronic, but not life-threatening conditions. Different perspectives might be obtained by interviewing Japanese people with other kinds of personal, social, and medical backgrounds. For examples, a recent study suggested that patients' responses regarding important dimensions of trust varied according to the nature of their illness (Mechanic & Meyer, 2000). Finally, different people may define trust in a number of ways. In this investigation, we did not define the meaning of trust or present a specific definition to the participants. However, in our opinion, all of the participants used it in the way commonly accepted in Japanese. Namely "believe (Shin) and rely on (Rai)".

## **Conclusion**

The present research suggests that Japanese patient trust in medical practitioners is multi-dimensional and affected by various factors. Patient trust is also psychologically complicated. The outcome of our study suggests that some dimensions of trust we identified share features with those discussed in previous studies conducted in western countries. However, some features may be, we think, unique to our culture.

Trust is essential not only in the doctor-patient relationship, but in all human relationships. When we trust the wrong person, it is possible for serious consequences to ensue.

Those who are physically, emotionally, and sometimes financially vulnerable cannot afford to rely on the wrong medical practitioner. Therefore, medical practitioners have the obligation to be trustworthy. This is made all the more important because patients cannot help but trust them (Illingworth, 2002).

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# 日本人の医療に対する信頼と不信の構造<sup>1) 2) 3)</sup>

## —医師患者関係を中心に—

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本研究は日本人が経験している医師との関わりの中から、信頼と不信の要因を明らかにすることを目的として行われた。25名の成人男女に対して半構造化面接を実施し、グラウンデッドセオリーアプローチの手法を用いて分析したところ、①医師の医学的能力に関する要因、②医師の態度・言動に関する要因、③医師-患者の感情、コミュニケーションに関する要因の3つのカテゴリーが見出された。それらはさらに①-1. 医師についての評判・伝聞、①-2. 医師の個人的・社会的特性、①-3. 適切な処置と治療の結末、②-1. 医師の診療態度・接遇、②-2. 十分な説明と納得、②-3. 患者の利益の優先、②-4. 背景要因となる限界性、③-1. 医師の配慮・共感、③-2. 医師のコミュニケーション能力と疎通性、③-3. 患者の感情、の10のサブカテゴリーに分類された。医療に対する信頼の場合、能力と意図を切り離すことは難しく、感情的側面が重要な要因であることが明らかになった。

キーワード: 医師-患者関係、信頼、不信、グラウンデッドセオリーアプローチ、質的研究法

### 背景—医療不信とは何か

最近、医療事故、医療訴訟、倫理的に問題のある医学研究など、医療に関する否定的な事件の報道が増加している。朝日新聞記事データベースによると、見出しまたは本文に「医療事故」、「医療ミス」、「医療過誤」を含む記事は、1990年代は年間16件～25件であったものが、1999年に71件に増え、2000年以降は年間141件～222件に達している。さらに、事故だけではなく、保険医療費の不正受給など金銭的な不祥事や組織的な腐敗、診療のあり方や、医療者の言葉や態度に不快感を持ちたり傷ついたりした経験をもつ人の告発などを含めると、医療に関する否定的な報道の数はさらに増加する。これは単にそのような事象の発生数が増えているだけではなく、世間の関心が高まり、大きく報道されやすくなっていることや、関連した特集記事などがよく組まれるようになったことも影響しているだろう。

否定的内容の報道がこれだけ増加すると、世間一般の医療に対する信頼が低下しても不思議ではない。実際、新聞社が3000人を対象に実施した「身近な医療」世論調査では、医師を「信頼している」と答えた人は62%、「あまり信頼していない」と答えた人は30%であったが、信頼していない人の割合が3年前の調査よりも増加していた(朝日新聞, 2000)。またインターネットで公開されている医療系雑誌が主催する「医療不信・不満に関する電話相談」の内容分析によると、2002年11月の一ヶ月間の相談411件中、不信・不満の対象が明確な事例は271件で、そのうち医師に対する不信・不満が226件(84%)を占めていた(メンタルヘルス, 2003)。

一方「医療不信」という語を前述のデータベースで検

索すると52件ヒットした。医療、病院、医療者などに対する不信感といった意味で使われているようだったが、明確な定義はなかった。そこでNACSISのWeb検索で「医療不信」をタイトルに含む和書を調べると、1990年代に出版されたものが4点存在した。内容は死との対面、患者と医師、患者と家族、公的介護保険制度、医療保険制度、臓器移植、死生観、誤診、臨床試験、病院の選択、カルテの開示、患者の権利、終末医療など、多岐に渡っている。つまり「医療不信」は患者個人の側から捉えると、医師(主治医)との関わり、という限定された人間関係の問題になり、社会問題として捉えると、医療に関する様々な問題を非常に幅広く扱うことになるようだ。本研究では前者の立場を採用し、特定の医師の言動や治療行為に対して、患者やその家族が抱く否定的な態度と感情として捉えることにする。

現代社会において「不信」が生じているのは医療だけに限ったことではないかもしれない。しかし医療は人の生、老、病、死、のあらゆる局面において、現代人の生活と深く結びついている。医師を信頼する、しないに関わらず、人は生涯にわたって医師と関わりを持たざるを得ず、無関心、無関係のまま済ますことはできない。都市化、長寿化、核家族化した現代ではなおさらである。その点で「政治不信」「学校(教育)不信」などと比べても問題の重要性、人々の関心の深さ、切実さにおいて、他に類をみない。人が老、病、死と向き合うとき、その傍らにいる医師に対して信頼を持ってないとしたら、それは極めて不幸なことであると言えよう。

### 心理学および医学における信頼の研究

心理学の領域では「信頼」は主に3つの方向から研究

されてきた。いずれも「信頼」を対人相互作用の中心的な概念として扱っており、人が社会の中で生き抜くために不可欠であると考えられる立場もある(Rotenberg, 1990)。精神分析の立場に立つエリクソン(Erikson, E. H.)は、乳児期の発達課題は基本的信頼(basic trust)の獲得であると考へた(Erikson, 1963)。乳児は自分の欲求に応じてくれる環境(特に母親)との関わりを通して、自分の身体の安全と精神的な安定を得、それが自分および自分を取り巻く環境に対する信頼感へつながっていく。そして獲得された基本的信頼は、生涯にわたってその人の人間関係の基礎となる。エリクソンの理論は信頼をパーソナリティ特性のひとつとして扱う研究に影響を与えている。

信頼を対人コミュニケーションの重要な要因としてとらえているのが、对人的信頼研究の立場で、信頼を特定の人間関係や状況によって変化する変数と見なしている。信頼の測定は「一般的信頼」(general trust)と「特定の信頼」(specific trust)に分けられ、一般的信頼の測定には Rotter の対人信頼スケール(Rotter, 1967)が広く用いられている。Rotter(1967)は对人的信頼を「他者の用いる言語、約束、話し言葉や書き言葉に表された陳述を当てにできるという期待」と定義している。

信頼に関する行動を実験状況の中で測定しようとするのがゲーム理論を用いた実験社会心理学的研究である。対象者に「囚人のジレンマゲーム」を行わせ、参加者の行動を観察する。ゲームの中での信頼は、自分が多くを失う可能性のある危険な状況下で相手におく信用のことになる(Northouse & Northouse, 1998)。ともすれば定義や測定法があいまいになりがちな信頼研究にあって、限定された実験状況の中で変数を操作し、具体的な信頼行動を測定することができる点が強みである。

一方、医療の場面では信頼は医師-患者関係の中核となる概念であるとみなされている(Northouse & Northouse, 1998; Pearson & Raeke, 2000)。患者の医師に対する信頼は患者の不安を低減し、自分は医師にケアされているという感覚をもたらす(Mechanic & Meyer, 2000)。さらに信頼によって人間関係は協動的になり、防衛的なコミュニケーションが減少する(Northouse & Northouse, 1998)。その結果、患者の満足度や治療方針への協力、ひいては健康状態の向上につながる事が期待される(Pearson & Raeke, 2000)。しかし、Patient-physician trust に関する研究のレビューを行った Pearson ほか(2000)によると、医療における信頼研究は社会科学系諸学問の研究の影響を受けたさまざまな概念や定義が混在している上、実証的研究もまだ十分とはいえない。

医療の場で信頼が重要視される背景には、医師-患者関係がパターナリズム(父権主義)から、患者の権利や自

律性を尊重する立場に変化してきた(Emanuel & Emanuel, 1992)ことが考えられる。医療が専門家である医療者から患者に対して一方通行的に施されるのではなく、医療者と患者の共同作業であるためには、信頼に裏付けられた医師-患者の十分なコミュニケーションが不可欠となる。さらに 1990 年代に入って米国の医療保険制度にマネジドケア(managed care)が導入され、治療方針の決定権が医師から保険会社へ移行したため、医師と患者の関係が損なわれる懸念が生じた(Mechanic & Shlesinger, 1996; Kao, Green, Zaslavsky, Koplan & Cleary, 1998; Thom & Campbell, 1997)ことも無視できない要因のひとつであろう。そのため、アメリカで行われている患者の信頼研究は、アメリカの医療制度のあり方を反映したものが多く、たとえば、患者の信頼を測定する米国で開発された代表的な尺度が 3 種ある(Anderson & Dedrick, 1990; Safran, Kosinski, Tarlov, Rogers, Taira, Liberman & Ware, 1998; Kao et al., 1998)が、その項目はいずれも my doctor, your physician という表現を用いており、特定の医師について回答するように作られている。これは米国の民間医療保険の 80%~90%を占めるマネジドケア型保険加入者の場合、患者はまず家庭医や一般医が務めるプライマリケア医(primary care physician)の診察を受け、そこから紹介されて専門医を訪ねる仕組みになっているためである(三浦, 2003; 広井, 1999)。一方日本では、患者が開業医から大病院まで自由に受診し、複数の診療科を掛け持ち受診することも珍しくない。「わたしの主治医」とは誰のことを指すのか、日本では必ずしも明確ではない。また、尺度には医師が「ヘルスプランのコストよりも、あなたの健康を優先して考える」など、医療費に関連した項目が含まれるが、これは定額制あるいは包括制の診療報酬制度の下でしか起こり得ない信頼の問題で、出来高診療報酬制度の日本の実情には当てはまらない。

### 信頼の概念

前述したように信頼はさまざまな方向から研究されてきたため、信頼の概念は必ずしも明確ではない。信頼概念の整理を行った山岸(1998)は、①相手の能力に対する期待としての信頼と、②相手の意図に対する期待としての信頼を区別すべきだと主張し、彼の研究では②のみを扱っている。また、他者一般に対する「一般的信頼」と、特定の相手についての情報に基づく「情報依存的信頼」を分けている。しかし山岸(1998)も認めているように、我々は日常生活の中ではこれらを意識して区別することなく使っている。

Pearson & Raeke(2000)によると、患者の信頼(patient trust)の定義には、①医師がある種の行動を取るだろうという信念や期待の集合体とみなす立場と、②

感情的側面をより強調して、医師や医師の意図に対する確信や信任によってもたらされる安心の感覚、とみなす立場がある。しかし、いずれの立場でも患者の信頼には、医師の「意図」と「能力」の両方が含まれている。たとえば Thom & Campbell(1997)は、信頼を「医師が患者にとっての最善を尽くすだろうという患者の確信」と定義しているが、彼らが患者の面接調査から明らかにした医師に対する信頼を規定する7つの要因には、医師の診療能力や、患者とのコミュニケーション能力も含まれている。Mechanic & Meyer(2000)による調査からも、患者の信頼の概念には对人的技能と専門技能が含まれていることが明らかになった。Pearson & Raeke(2000)は、患者の信頼の源となると考えられている医師の行動は、能力、思いやり、守秘、頼りがい、であると分析している。さらに Laine, Davidoff, Lewis, Nelson, Nelson, Kessler & Delbanco(1996)の研究では、患者は医師の臨床技能、対人スキル、患者への情報の提供をほぼ同等に重要であると考えていることが明らかにされている。

山岸(1998)の概念整理に従えば、患者の信頼は特定の医師について情報に基づいて判断される「情報依存的信頼」であり、その医師が信頼できる人格特性の持ち主であるという情報を、本人との接触や評判、社会的カテゴリーなどの間接的な情報から得ることによって、自分を搾取しようとする「意図」を持っていないという期待を持つことである、との定義も可能だろう。しかし患者にとって医師の専門家としての能力を無視して意図だけを問題にすることは意味をもたないし、医師-患者関係を実験室でのシミュレーションによって研究することも難しい。現実の人間関係の中でしかとらえることができない信頼の構造を明らかにするためには、研究者が操作的定義を行うのではなく、対象者の持つ多様な概念を探っていくことが最適の方法であろう。

## 目的

最初に概観したように、最近日本人の医療に対する信頼が低下している。医師-患者関係のあるべき姿を見直し、医療に対する信頼を取り戻すために何が必要なかを明らかにする必要がある。そのための基礎的資料を得るためにも、日本における医師に対する信頼に関する実証的研究を行うことは急務である。しかし、海外特に米国と比べて、わが国では医師-患者関係や患者の信頼を扱った研究は極めて少ない。医学中央雑誌の検索でも、1990年以降に発表された「医師-患者関係」と「信頼」を含む論文はわずか52件で、その大半が解説や総論であり、実証的研究はほとんど見られない。一方諸外国で行われた研究は、前節で述べたようにその国の医療制度や国民性などを反映しているため、社会・文化的背景

の異なる日本にそのまま適用できるとは限らない。山岸ほかによる調査や実験によると、日本人とアメリカ人では、一般的信頼や特定の相手との信頼に関する態度にさまざまな違いが見られることが指摘されている(山岸, 1998; 清成・Cook・山岸・大村・鈴木・高橋・谷田, 2003)。欧米流の医師-患者モデルを直輸入しても、ベッカー(1999)が懸念するように「日本人が最近嘆く「医師不信」は治るどころか、両者の関係はむしろ冷たくなる一方であろう。」という事態になりかねない。

そこでわれわれは、日本人が現在の日本の医療制度の中で経験している医師との関わりの中から、信頼と不信の要因を明らかにすることを目的として本研究を計画した。先行研究がほとんどなく、どのような問題が抽出されるか未知数であるため、まずは仮説発見型の探索的研究として行うこととした。そして患者の個々の医療体験の中から信頼と不信の要因や構造を深いレベルで抽出するには、質的研究法が最適であると判断した。

## 方法

### 調査対象者

近畿地方在住の42歳から68歳の男女25名(男性11人、女性14人)。平均年齢54歳。

### 調査対象者のリクルート方法

以下の3つの条件をすべて満たす人を調査会社を通じてリクルートした。①日本語で意思疎通ができる70歳以下の成人であること。②本人または本人の家族が、患者として一ヶ月以上の通院治療または入院治療を受けた経験がある、または現在も治療中であること。③本人または本人の家族が医療従事者でないこと。

### 調査参加への同意書

面接調査の参加同意は、リクルート時点で調査会社の調査員と、面接開始前に面接者が2度にわたって確認し、参加や中止、離脱が自由な意志によるものであることを保障した。また、研究の目的、プライバシー保護や謝礼についての説明が面接に先立って行われ、理解を得た上で同意書に署名捺印してもらった。

### 面接場所

京都市内、和歌山市内、和歌山県内農村部にある施設の会議室または面接室。

### 面接時期

2001年12月～2002年11月。

### 面接者

研究参加者のうち3名が面接をおこなった。

### 面接方法

最初に調査対象者のデモグラフィックな背景と、通院歴、入院経験、を質問したあと、病気体験と医師との関わりを中心に語ってもらった。話の流れの中で、医師に対