Death with dignity is impossible in contemporary Japan: Considering patient peace of mind in end-of-life care

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Abstract
Currently in Japan, it is extremely difficult to realize the basic wish of protecting personal dignity at the end of life. A patient’s right to refuse life-sustaining treatment has not been substantially warranted, and advance directives have not been legally enforceable. Unfortunately, it is not until the patient is moribund that all concerned parties start to deliberate on whether or not death with dignity should be pursued. Medical intervention is often perceived as a worthwhile goal to not only preserve life, but also provide psychological benefit to the family, regardless of its effect on the patient. To feel they are doing something, family members tend to act against the imperative “Do not inflict on others what you would not wish done to you,” and permit extraordinary measures they would not want themselves. Another complication in
1 Introduction

A peaceful, natural death, or death with dignity, is of great interest in contemporary Japan. The deaths of famous people are frequently reported in detail by news media, and special feature articles and issues on ideal ways of dying are popular. Some physicians have even raised questions about end-of-life care in books with impressive titles such as “Peaceful Death (Heion-shi),” “Satisfactory Death (Manzoku-shi),” and “Time to Die for the Japanese (Nihonjin no Shinidoki).”(1-3) These authors argue that a longer life span does not necessarily result in a happier life and makes it more difficult to die with peace and satisfaction. They claim that current end-of-life care in Japan needs reform.

We argue that the preferences of patients and the Japanese public towards end-of-life care have not been sufficiently respected and that inappropriate medical intervention severely damages human dignity in the final stages of life. Both UNESCO’s Universal Declaration on Bioethics and Human Rights and the World Medical Association Declaration of Lisbon on the Rights of the Patient clearly state that a patient’s human dignity must be protected and respected (4, 5). Nonetheless, factors other than ethical disagreement can obstruct decision-making and lead to difficult situations.

In this paper, we point out the psychological, social, legal, and ethical dimensions of terminating medical intervention as related to death with dignity in contemporary Japan. Human dignity and death with dignity are discussed, and their current trends and difficulties are described. We also introduce practical questions and answers on termination of medical intervention formulated by American bioethicist E.J. Emanuel (2011) (6) and consider problematic circumstances specific to Japan. Finally, six underlying causes for current attitudes on death with dignity are suggested. We conclude that present end-of-life care in Japan damages human dignity and requires urgent reform through education and legislation to promote peace of mind for all concerned parties.

2 Human dignity and death with dignity

The concept of human dignity has become the basis for ethical, legal, and social judgments, as well as criticisms of medical treatments and research. The Declaration of Helsinki states that, “it is the duty of physicians who participate in medical research to protect the life, health, dignity, integrity, right to self-determination, privacy, and confidentiality of personal information of research subjects.”(7) Similar statements are made in many national and international laws.

Section 10 of the Declaration of Lisbon similarly states that “the patient’s dignity and right to privacy shall be respected at all times in medical care and teaching, as shall his/her culture and values.”(5) Gastmans et al. argue that “clinical ethicists must interpret clinical reality in the light of human dignity,” thus placing the concept at the root of clinical ethics.(8) The meaning of human dignity is ambiguous, however, with various proposed definitions.

The first definition acknowledges that dignity is part of human existence itself (9). Christianity recognizes human values on the basis of being created in God’s image; therefore, dignity is considered a fundamental concept and source of personal freedom and human rights (10). Dignity is an absolute value people possess as long as they are human, and it has been argued that everyone should have mutual respect for the dignity of others (11). Consistent with this school of thought, human dignity is given the highest priority and should never be opposed by secular, selfish considerations.

A second school of thought suggests that dignity is a part of human attributes such as a rational mind, autonomy, and self-selection. Socrates and Aristotle believed that human dignity resided in deep thinking, self-consciousness, and the ability to choose freely (12). Some moral and ethical viewpoints consider dignity as a collection of intangible, distinctly human goods (13). In addition, some authors list virtue, consistency, and pride as part of an individual’s dignity (11). They define dignity as “humanness,” “being free,” “not feeling miserable or humiliated,” or “living without losing human pride.” Others may disagree with those definitions; in fact, many would argue that people who lack the above characteristics still possess human dignity.

A different perspective reveals at least two unique concepts of dignity; one is “inherent dignity,” where every person has as a universal and inalienable moral quality which cannot be earned or taken away, and the second is “individualistic dignity,” which is tied to personal goals or social circumstances and can be enhanced or diminished depending on circumstances. These concepts of dignity can be assaulted by events outside the control of the person involved, such as a debilitating disease (15). A commentator has also proposed “dignity of identity” as the dignity we attach to ourselves as integrated and autonomous people with a history, future, and relationships to other human beings (16). This dignity is strongly associated with self-respect and feelings of worth (17).

Human dignity thus appears to have no definite characteristics that are universally agreed on. There is no consensus as to what human dignity really is, what conditions are considered to be dignified, and what constitutes a violation of human dignity. Nonetheless,
individuals usually feel they possess some form of dignity; they have a sense of their own importance, pride, virtue, and a belief that there is something important in their lives. One could speculate that most individuals have some notion of their own dignity, if not a clear-cut definition.

Another important connotation to consider is that people should respect others’ human dignity as something everyone should mutually respect in each other. The Dignity Principles from the British Medical Association Ethics Department explain that "patients should be treated with respect and courtesy, and their social and cultural values should be respected (18)."

Inconsistency between one’s own dignity and the evaluation of others’ dignity becomes a serious problem related to end-of-life care. For example, a person may lose their dignity and thus hope to die; however, others might feel there is still dignity and forcibly prolong the individual’s life. These two perspectives of human dignity - what people actually feel about themselves and what others identify in them - thus stand independent of each other.

We believe human dignity is defined as values in spirit, morality, and character that humans possess precisely because they are humans, and which people can take pride in and stand on. We would also argue that death with dignity is a way of dying that allows a terminal individual to feel and maintain dignity until the final moments. For those who suffer consciousness disturbance, death with dignity could be a way of dying that convinces a sympathetic family that the patient’s dignity was appropriately respected. We feel that what is most important for an individual receiving medical care is the feeling that his or her dignity is protected and respected. It is also important to avoid situations where a patient feels they would rather die. Finally, the patient’s dignity outlook must be given priority over the outlooks of others. We believe human dignity is the most important value a patient has in the clinical setting.

3 Domestic social tendencies and ethically difficult situations

For a long time, Japanese clinical settings have confronted several difficult situations with discontinuing life support. Police investigated doctors over the past twenty years who removed coma patients from respirators at the end of their life, and all cases resulted in the issuance of judicial documents. No physician has been prosecuted so far, but concerns among healthcare professionals on the discontinuation of artificial respiration remain great. Hospital ethics committees in Japan have given priority to legal concerns rather than ethical ones and tend to propose policies that do not admit to cancellation of medical intervention procedures such as artificial respiration or tube feeding. We argue that this represents timidity and avoidance of ethical judgment, which can lead to ignoring the human rights of the patient. Even if an expert in clinical ethics judges the cancellation of life support to be ethical, an ethics consultant would then have to explain the current legal concerns in Japan to the medical professionals. Because the withdrawal of artificial respiration by a doctor to respect patient wishes was substantially impossible and the ethics committee could not reach a conclusion, a tragic incident occurred when a family member turned off her son’s artificial respiration instead and was found guilty of murder (19).

Kodama wrote that “the medical person who performed cancellation and withholding of life support has been judged for murder after the fact without being shown legal judgment beforehand. I cannot but feel the absence of the law, and this situation is absurd (20).” Actually, no laws against cancellation of life-sustaining procedures have ever existed in Japan. The courts tend to apply criminal law on assisted suicide and murder self-righteously and forcibly, even though death with dignity differs from euthanasia. We cannot regard Japan as a constitutional state in this context.

Table 1 Practical questions by Emanuel and current situations concerning end-of-life care in both the United States (6) and Japan (by the authors)

<table>
<thead>
<tr>
<th>Question</th>
<th>US YES</th>
<th>JPN Uncertain (substantially none)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are advance care directives legally enforceable?</td>
<td>US YES</td>
<td>JPN no laws of this matter exist</td>
</tr>
<tr>
<td>Whose view about terminating life-sustaining interventions prevails if there is a conflict between the patient and family?</td>
<td>US The views of a competent adult patient prevail.</td>
<td>JPN Case-by-case, and collective decision-making is predominant</td>
</tr>
<tr>
<td>Who decides about terminating life-sustaining interventions if the patient is incompetent?</td>
<td>US Appointed proxy or a legally designated hierarchy: (1) spouse, (2) adult children, (3) parents, (4) siblings, and (5) available relatives.</td>
<td>JPN Family members without clear hierarchy or border, depending on power balance among the members</td>
</tr>
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</table>

4 Six factors that hinder death with dignity in contemporary Japan

Table 1 displays current situations concerning end-of-life care in both the United States and Japan (6). Six factors in particular could prevent death with dignity as defined above for end-of-life care in Japan.

4-1 Absence of law

As previously discussed, no written legal regulation concerning termination of medical intervention has existed to date in Japan, and healthcare professionals are uncertain about which actions are forbidden. The Tokyo High Court declared in the Kawasaki Kyodo Hospital case that patient self-determination, family
surrogate decision, or the limits of a physician’s obligation to treat were not decisive grounds to support a legitimate termination of life support. They also claimed that withdrawal of life support would go against laws prohibiting murder at the victim’s request and assisted suicide (21). In addition, no legally enforceable advance directives have existed in Japan so far. A relevant bill was once presented to the Diet in 2007, but no further discussions have occurred.

4-2 Certainty of impending death

When death is not immediate, the right to refuse life-sustaining treatment is not considered at all in contemporary Japan. The certainty of impending death appears to have become the main prerequisite for respecting patient decisions. In addition, no court, legislation, or guidelines have ever presented a clear time limit or precise definition of “impending.”

The Yokohama High Court argued that the possibility of recovery always exists, and a doctor should continue medical intervention unless the chance of survival is absolutely zero. That a physician should do his/her best and everything possible to save a patient even with slim odds of survival is not only a medical duty, but could also be a broader and non-professional obligation (21).

We believe the attitude of the court influences all ethical judgments about death with dignity from the start. Their decisions do not consider the principle that medical treatment is determined by the patient. Regardless of death, medical treatment should ultimately be an arbitrary power matter for the patient or their decision-making caretaker. However, death with dignity is currently recognized only after it becomes useless for anyone, and human dignity is stained thoroughly.

We cannot understand why the degree of terminal prognosis is connected to the permissibility of death with dignity. Such thinking equates to a position that accepts the sanctity of life as a firm premise, with no reflection or questioning of the death with dignity argument. A judicial requirement of certainty for imminent death forgets that medical care is fundamentally fraught with uncertainty. There is a strong possibility that definite determination of impending death makes death with dignity in Japan extremely difficult.

4-3 Problematic distinctions

In general, the termination of medical intervention has become a great social issue with accompanying attention. The police investigate, and then media tend to rush to a hospital and report that “euthanasia was performed.” Attitudes on withholding life-prolonging treatment are not clear, although there are big social and legal differences compared to withdrawal. The difference does not ethically exist, however, since both actions have the same effect from a patient’s perspective. Death with dignity is compatible with many ethical guidelines worldwide and the views of most bioethics scholars, but healthcare professionals bear a heavy psychological burden if their society does not consider the act to be just. Distinction issues also exist between ordinary intervention measures and extraordinary ones.

4-4 Unanimous decisions

When the opinion of the family differs from that of the patient, patient intent may not be given priority in Japan. Life-prolonging measures may thus continue at the request of the family even when death becomes certain because medical treatment policies give more weight to unanimous decisions rather than self-determination. “The Principle of Harmony (Wa no Seishin)” overshadowed respect for autonomy in most human interactions, including clinical ones, until now (22). When a patient has strong family relations and/or very clear intentions about medical care, self-determination can be sufficiently respected; however, the situation could easily change with domestic power relations or balance. At the end of life, those too physically, mentally, or socially weak to express their wishes are most damaged by inappropriate medical intervention imposed by others (19).

4-5 Principle of intervention

Medical intervention for incapacitated patients may be continued as psychological assistance for their family. Ishitobi wrote, “Family members would want to avoid a feeling of regret such as ‘We have left this or that undone’ after the patient’s death.” This regret tends to steer family members away from less aggressive intervention and a “natural course of dying. (1)” With life-sustaining procedures, they could feel they did all they possibly could for the dying family member. In this situation, the personal satisfaction and peace of mind of the family members seem central to decision-making, particularly if they are not close to the patient.

We would argue that in these circumstances, medical intervention became a valuable purpose for the family to pursue. When intervention or “doing something” becomes the goal itself rather than a successful outcome for the patient, extraordinary measures never become useless or futile since an unconscious benefit is alleviation of regret for the family. There appears to be an intervention principle involved where doing something is better than nothing, regardless of consequences. However, doing something harmful or burdensome to patients to ease familial regret is a serious abuse of medical intervention, even if the family has psychological needs.

4-6 Double standard

Japanese culture traditionally permits a double standard in decision-making, often viewed as deep consideration or a caring attitude for others. A recent national survey conducted by the Ministry of Health, Labour, and Welfare revealed that the percentage of people who want to refuse life-sustaining treatment for themselves is about 20 percentage points higher than people who want to refuse it for their family (23). This difference in attitude has been recognized for a long time in the research and clinical experiences of doctors (24-26).

5 Conclusions

The ethical quality of a nation’s healthcare system can be evaluated by how compatible its ethical norms are with long-accepted universal bioethical principles. We believe that unanimous and collective decision-making fails to respect personal autonomy, that extraneous medical intervention goes against the principles of
beneficence and doing no harm to a patient, that there is a double standard for patient justice and fairness, and that the standard of certainty for impending death completely violates ethics and human dignity.

From the stance that protection and respect for human dignity are extremely important in medical care, a system which can respect these values is more desirable than one which cannot. If the present healthcare system in Japan can injure patient dignity, it should be corrected, which we believe is starting to happen. If even a minority of patients facing end-of-life care hope for a natural and dignified death, their intentions must not be ignored without sufficient cause.

Even if there is no drastic strategy to change attitudes on human dignity and death with dignity, education and legislation are needed at the very least. Japan needs a nationwide program that educates laypersons and healthcare professionals, enabling them to recognize medical uncertainty and useless or futile medical care, consider the purpose and consequence of medical intervention, and accept different outlooks on human dignity from others. People must learn that it is inappropriate to perform life-supporting measures on a patient just for the well-being of the family. Further legislation is also needed for advance directives, termination of medical intervention, and patient self-determination. Otherwise, pending cases that ignore patient dignity will not disappear. Patient peace of mind during end-of-life care will never occur unless drastic changes take place in the medical ethics and laws of our society.

References


Three Level Structure Analysis of End-of-life Care in Japan

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Abstract

This paper is one part of the group research into “Bioethics in Asia Based on Three Level Structure Analysis” and aims to explore the Japanese structure of end-of-life care according to the analysis way Takahashi provided. This follows research by Asai (2011) who considered about the quite different responses for artificial nutrition and hydration (1), extracted the different concepts, SOL and QOL, which support for each response (2) and then analyzed the more basic ideas.
which underlie those concepts (3). We will share the first part with Asai approach but this paper will follow a different route about the other parts. It will move from (1) to (3) and from (3) to (2).

The main purpose is to explore Japanese ideas which underlie concrete moral judgments of end-of-life care. We will consider about the Japanese concept of inochi and overview how it is applied in the traditions of Shinto or Buddhism in Japan. SOL and QOL which are arguably imported concepts will be interpreted based on the Japanese concept of inochi.

The analysis of the Three Levels Structure by Asai

Asai (2011), a Japanese physician and bioethicist, analyzed the arguments for and against artificial nutrition and hydration (ANH) for elderly people who cannot eat and presented a model of the three levels structure in Japanese end-of-life medicine.2 By referring to his analysis, the structure of three levels will be overviewed.

The concrete moral judgments whether ANH should be provided for the elderly who cannot eat, when the will of the patient is unknown, belong to the first level. Asai extracted the moral values in those judgments for and against ANH. The opponents’ arguments emphasize “the significance of being natural, acceptance of the natural span of life, importance of considering the patient’s QOL and interests, utility of medical interventions, criticism of mere life-prolongation, and necessity of personhood and self-awareness” (Asai, 2011, p.40). In contrast, the proponents of ANH stress “vulnerability of the elderly, absolute prohibition of discrimination, categorical prohibition of discontinuing ANH, discontinuation of ANH being equivalent to murder, human rights such as the right to live, and unconditional prohibition of value judgments on human lives” and claim “The term of ‘natural death’ is deceptive and the truth is that it is murder” (Asai, 2011, p.40).

The second level consists of the ethical principles and norms which form the basis of the concrete moral judgments at the first level. According to Asai, the differences between proponents and opponents of ANH, “can be simplified to those who support QOL and those who support sanctity of life (SOL). In other words, this is confrontation between those who approve of the evaluation of QOL for patient… and those who forbid it” (Asai, 2011, p.40).

The third level includes the more basic theories, principles, and concepts that ground the principles and norms at the second level. Asai pointed out utilitarianism and non-religious SOL doctrine as the third levels. “QOL, subjective happiness, personhood, sentience, interests and utility are key concepts are values in utilitarian arguments” (Asai, 2011, p.40). In contrast, “Supporters of the non-religious SOL doctrine would highly value of warmth of patients and their existence” (Asai, 2011, p.40).

As he analyzed, the concepts of QOL and SOL often play an important role in Japanese medicine and bioethics, especially in the ethical arguments of terminal care and withdrawing/withholding life-sustaining treatments including ANH. Both can be said that they are at the second level and they form our concrete moral judgments. However, both the utilitarian theory and SOL doctrine at the third level are rooted in the western ethics and, as it were, imported from western bioethics. They may share some part with Japanese bioethics and therefore they are powerful in Japanese medicine. However, even if they look like explaining the ethical judgments of ANH, the different ethical theories and principles to explain them better might be hidden and such theories and principles are seen in Japanese ideas.3

The purpose of this paper is to explore the more basic background at the third level from Japanese ideas. It will be expected that such a background is able to share some part with the imported concepts of QOL and SOL and at the same time explain the Japanese original and traditional thoughts.

Desire for a natural death

Our analysis using the three levels structure in Japanese end-of-life care begins with the attention to the idea of “natural death” or “being natural in dying.” As we have seen above, the reasons given by the opponents of ANH included, “the significance of being natural” and “acceptance of the natural span of life.” It seems to imply that ANH is a kind of extraordinary medicine and “unnatural.” At the same time, in the argument of the proponents of ANH is seen the attitude that once ANH is started, the termination of it results in the patient’s death by the human intentional act and it is equal to murder and (Asai, 2011, p. 39). It seems to imply that ANH is one of ordinary medicine and withholding/withdrawing it is equal that the patients let to starve to death. They deny that it is “natural death.”

After the state of California enacted “The Natural Death Act” in 1976 for the first time, the term was given a new meaning which people can deny the life-sustaining treatment in advance and has been associated with death with dignity.4 Originally, it meant the natural way of death by natural causes, such as dying of old age or disease based on the internal causes, compared with death is caused by external causes, such as accident (manmade or natural disaster) or homicide. About suicide, the evaluation may be divided as we will see this point below. Withholding and withdrawing ANH seems to be associated with such a way of dying.

Suppose that the opponents and proponents of ANH share their basic attitude that let dying people get die “naturally,” but then the contents of dying “naturally” are different, we will start to analyze the three levels structure.5 The background why such different contents

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2 See Takahashi (2011) about the details of the three levels structure and the relationships among each level.

3 Takahashi also wrote that “Researchers of philosophy refer to the third level, but they tend to neglect cultural differences of medical practices, and rarely look back at Japanese traditional thoughts” (Takahashi, 2011, p. 2).

4 In some Japanese guidelines or official reports, “death of dignity” is described as a kind of natural death resulted by the avoidance of extraordinary medicine. For example, see the 2008 report of the Science Council of Japan (「終末期医療のあり方について—亜急性型の終末期について—」).

5 A type of claims that “X is unnatural and therefore X is ethically wrong” has been seen in bioethics arguments in
are brought will be sought in Japanese traditional thoughts. Therefore, we will consider about the third level next.

Japanese views of life (inochi) and death

We will use the Japanese word inochi instead of life. Inochi corresponds to the word of life in English. Another word, seimei, has almost the same meaning. Seimei was a translated word from "life", “Leven”, and “vie” in 19th and now it tends to be used in scientific or academic context. Inochi has been used since ancient times and even today it is in common use. Compared with seimei, inochi is ordinary and popular (Morioka, 1991, p.87).

The origin of inochi is said that “i” means breath and “chi” means power and inochi stands for the power of breath. Breathing was the clear evidence that a being is alive. It was also clear that a being dies naturally when breath stops. In ancient Japan, inochi had a wide range of usage; the power of living, lifespan, lifetime, destiny, and time of death. The idea of death is seen directly and indirectly in those usages. Under the Japanese concept of inochi, the ideas of life and death include the image of a connection through breath, rather than a disconnection.

Inochi is equally given to all beings (humans, animals, and plants), not by God, but from somewhere. According to the tradition of Shinto, the Japanese indigenous belief, death is one form of kegare that is a kind of uncleanness or dirtiness and therefore should be hidden or kept away from daily life. Death as a kegare was one of the worst events which threatened and broke the order of daily life. Therefore, ancient Japanese were afraid of death and made it a taboo subject for discussion. There are a lot of expressions implicitly meaning human death, because using the word death or die directly is taboo.

Since Buddhism was introduced from the Asian continent in the 6th century, the Shinto view of death was affected. In Buddhism, there are four major sufferings; living, aging, being ill and dying. Living is a full of sufferings and being alive are always changing to dying. Nobody can escape from such a stream. Basically, Buddhism preached people to stop caring about inevitable sufferings and accept that such is life, and that as a result peace of mind can be achieved. It claimed that all beings have the potential to attain enlightenment.

For ancient people who were afraid of death, those guidance from Buddhism would be a saving for be released from the fear. It can be interrupted that giving up resisting sufferings and taking an attitude of resignation could result in being released from them and as a result being saved by Buddha. Another way of overcoming the fear of death can be seen in the Japanese history. Samurai as a career, traditional Japanese warriors, were always conscious of death, especially in fighting. Samurai needed to overcome the fear of death and were prepared for death themselves. This can be seen as the conquest of the fear of death by self. Samurai also affected Buddhism, but they developed an original style since Kamakura Era (12 century) (Watsuji, 1979, 306). Being prepared for death is relevant to seppuku (hara-kiri) in the tradition of samurai as a type of suicide. Seppuku has not been viewed in a negative light.

The death for samurai was not that it comes in the future necessarily, but that it comes suddenly. Whenever it comes, it was always needed to be prepared for own death. It meant to set one’s heart on own death in advance (Sagara, 1984, p.116). When their lords were brought to a crisis, they fight risking their lives. When they failed to save their lords, they conducted seppuku to be responsible for it. Not saving their lords but being alive were a kind of shame and unwillingness.

When samurai got mentally prepared for death, they became to realize the authentic self (Sagara, 1984, p.117). It meant that the authentic self was not to have two faces and, that is, to continue to manifest the truth if their loyalty to the lords all their lives. Therefore, to die for their lords or to follow the lords’ death without hesitating and getting upset can be interrupted as honorable and graceful. Though seppuku, samurai could prove to manifest the loyalty and the authentic self. Takahashi said that it was a kind of death with dignity and expressed the ultimate level of freedom underlies the control of own life and death (Takahashi, 2008, p. 113).

The mental preparation of samurai had a priority over maintaining their lives. It seems that such an attitude has not lost completely yet in modern Japan. Maesuke Nogi (1849-1912) who was a soldier committed seppuku, shortly after his lord, the Japanese emperor at that time, died. When his lord died, his role playing in this world also finished. A novelist, Yukio Mishima (1925-1970) also conducted seppuku after he barricaded himself in a camp of the Japanese Self Force and claimed his thought which Japan should recover the political order based on the Emperor. Some people commit suicide because they think it takes responsibility for their faults. Other people surrounding them feel their death is sad and have sympathy, and it seems that they understand it to some degree, even romanticizing it. In those cases, something more valuable than the maintenance of life looks like existing. That would be the mental preparation or the strong will of committing suicide. Some other people would respect them although they are sorry for their death, and others criticize those who take their lives as an easy way out of their troubles.

Respecting the mental preparation and the strong may underlie the acceptance of self-determination in Japan. If decision-making sacrificing someone’s own life looks unreasonable or irrational, the decision might reflect something valuable for him/her. It might be needed to keep the authentic self. It seems that the self-determination is respected not because the decision is reasonable and rational, but because the strength of the mental preparation or will.

In modern Japan, ancient Shinto and Buddhism have influenced each other and co-existed peacefully, rather
than conflicted. The guidance from Buddhism does not release the people from the fear of death completely. Many people suffer from worldly desires and have still the fear. However, we have seen the possible two ways to release them from the fear; one is the saving by Buddha and the other is the conquest by self.

**SOL, QOL and communal inochi**

The ideas of SOL and QOL are imported concepts but they have become important and even essential to discuss end-of-life care in Japan. It would be safe to say that they are at the second level which includes principles to judge or decide the method of terminal care. On the basis of the arguments of the third level above, the Japanese views of SOL and QOL would be reconsidered. Those views would be familiar with the Japanese concept of *inochi*, rather than life.

In the western concept of SOL, life is given by God and especially human beings were created from the image of God. Therefore, human lives have a special value and are sacred, compared with other lives. In contrast, *inochi* was given to all living beings from somewhere. Where is *inochi* from? Shuichi Kato (1977) wrote that Japanese people possess a common image that *inochi* is produced from a great and dynamic stream and returns there when it finishes. Then, *inochi* finally is assimilated into the stream. This is often said that we are born from nature, live with nature and return to nature. As we have seen above, when people face such a stream they have an attitude of resignation, however, that everyone eventually returns to same place could soothe in a sense.

It was believed that young children under 7-years-old belong to this world, as well to another world. That is partly because the rate of death of young children was higher. When children died young, people believed that they returned to the place from which they came. Even adults died suddenly because of a various causes. *Inochi* was flowing in one hand and therefore Japanese people have traditionally lives in dread of the end of *inochi*.

On the other hand, *inochi* is powerful and dynamic, as the original meaning was the power of breath. Such an image remains in its modern usage. For example, the expressions of “network of *inochi*” or “relay of *inochi*” can describe the property that an *inochi* is incorporated into something big or that it is individual but at the same time is not simply individual. An *inochi* has the close connection with other *inochis* in this world (“network of *inochi*”). The concept of *inochi* has not only the contemporary extent but also timeless extent. An *inochi* is relevant to other *inochis*, old or new (“relay of *inochi*”). Japanese people have worshiped their ancestors and, after they die, their descendants will worship them in turn.

These images of *inochis*’ extent, at the same time, can be explained from the Buddhism idea, *Pali*. A Sanskrit *Pali* means that all things do not have any stable substantiality and they exist under a condition by various cases, affecting each other. An *inochi* is unique and irreplaceable because it is firmly incorporated into the network and is not separated from it. In this meaning, *inochi* can be communal.

Based on those interpretations of *inochi*, the Japanese SOL can be reconsidered. *Inochi* has the dynamic power of breath which enables to be alive by itself, but it is fleeting. Once the power of *inochi* was lost, it cannot be recovered and therefore it should be respected. Moreover, an *inochi* is unique irreplaceable because it is firmly incorporated into *Pali* and is supported by the past, present, and future networks of *inochi*. Finally, an *inochi* is assimilated in some big stream after it finishes. As far as a patient continues breathing, the *inochi* does not lose the power of breath yet, as if the dynamic power looks decreasing. When the power fully is lost, it can mean the natural end of *inochi*.

The same aspect of *inochi* would support for the decision to reject the prolong life treatment with artificial respirator. Such a decision can reflect that they want to die when the power is lost. It can be another interpretation of dying naturally. The concept of QOL also can be understood based on Japanese tradition. As we have seen the *samurai’s* or other people’s mental preparation for death above. In fact, according to a survey, it is said that the fear of death is decreasing, as people become older. It can expresses a general tendency that Japanese people start to prepare for own death gradually.

However, there are many diverse situations where patients are in the terminal phase. Everyone does not have such a strong preparation or they waiver between life and death when it comes to the point. The network of *inochis* makes patients in terminal phase to feel the existence of other members of the family strongly. It may be said that Japanese people have aimed to die well or have a good end of life in the community to which they belong. Some try to avoid troubling other members of family, economically or mentally. Other refer to their social roles or what they did not do in their life (Takeda & Futouy, 2006). Those indicate that the Japanese way of evaluating QOL is connected to relation with other people, rather than not completely subjective evaluation by an atomic individual. *Inochi* was not simply individual. The evaluation of QOL looks like being made by a social individual incorporated into the network of *inochis*. We can also say that in most cultures the ideal death is one surrounded by family members, binding their *inochi* together.

9 Takahashi pointed out such an image shared in a Greek word, zoe. He distinguishes zoe from bios means for a individual life and calls zoe as radical life (Takahashi, 2009, pp172-3).

10 nanasai madeha kami no uchi (17歳までは神のうち). In modern, people have a ritual custom to thank children’s safe growth. It usually is completed when children become 7 years old.

11 締起 (Engl). Morioka also extracted one property of of *inochi* as being irreplaceable (Morioka, 1991, p. 100).

12 For example, see http://group.dai-ichi-life.co.jp/dir/ddii/report/ro0405.pdf

13 This may lead to the *uijigami* (氏神). There was a custom that a community worship the dead people where lived there. In this case, *gami(kami)* means the accepters’ spilits. See Yanagida (1975).

14 Death of a patient means the end of the patient’s personal life and, at the same time, the start of life without him or her for the family. It raises the significant change into daily life of the family, which means a breakdown of the present order. The family members play a role of recovering the broken order and a role of caring for the dead after a patient died.
Summary of three levels structure in Japanese end-of-life care

We have started with a desire for dying naturally that seems to be shared by the opponents and proponents of ANH. It corresponds the first level of three. Next, in order to explore what underlies the desire, we overviewed Japanese ancient views of life and death. By referring to the concept and original usages of inochi, we saw that Japanese views of life and death were connected each other. Under the Shinto tradition, the connection was conscious but death was regarded to be avoided from daily life. Death was the object of fear for ancient people, Buddhism gave them a possible way to release from the fear. Samurai developed another way to release from it. It was the mental preparation for death and it was depended on self-help. Those considerations formed the third level. Then, we have reconsidered the concepts of SOL and QOL based on the Japanese concept of inochi. They had a different value system of life. The part was the second level.

Finally let us back to reviews of the different responses of ANH. Those responses can be interpreted under two images of dying naturally. It appears that they are contradicting, but as we have seen they have been existing in the Japanese tradition.

What the proponents of ANH emphasize can be considered as the way of dying naturally which means to leave self to a great and dynamic stream. Self and its inochi are incorporated into such a stream. It can be connected with the attitude of resignation. We have no way to escape from death, except to be saved by Buddha or by taking in a great and dynamic stream. Our death is beyond human power. Therefore, the proponents of ANH may reject withdrawing ANH, once it is started. For it does not mean the liberation of life with suffering. The liberation should be realized ultimately by Buddha or by taking in a great and dynamic stream, not by human power. According to this way of thinking, committing suicide can mean to cut off the connection with the stream. Such a way may not be said to be natural.

However, it is certain that the attitude of accepting suicide can be seen in Japanese culture. The opponents of ANH may support for the positive preparation for death. Keeping alive under ANH may be unwilling for the people got such a preparation already. We saw the attitude of respecting authentic self in the cases of seppuku, when samurai chose to die. It meant that maintaining life does not always have a priority. Then it can be said that people who are dying by themselves follow the nature they possess within themselves.

Conclusion

In this paper, in order to analyze the three levels structure in the Japanese end-of-life care, we adopted the different approach from Asai’s approach. He adopted the bottom-up approach, from the first level to the second level, and from the second level to the third level. We shared the first level with Asai and then adopted the top-down approach, because our purpose was to explore the Japanese principles and concepts which affected the concrete moral judgments in end-of-life care.

The explanation may not be enough to explain the whole of diverse situation in Japanese end-of-life care. Especially, we did not consider about the role of family members of terminal patients. About this point, the effects from Confusion ethics can be seen in Japanese culture. Including such appoint, a hypothesis of the third level was presented will be needed to inspect the relationship with other levels further.

Figure 1: Summary of the three level analysis

References


Advance Directives in Hong Kong: ethical perspectives

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Introduction
Discussing death and all related matters is a taboo in Chinese culture. Some Chinese people believe that talking about death will increase the likelihood of its occurrence and that evil spirits will be attracted to haunt people (Chan, 2000). Nevertheless, this culture is changing subtly. Since the end of the twentieth century, both the public and the academics in Hong Kong have drawn increasing attention to end-of-life care issues (HKSAR, 2005; Hiu et al, 1997; Ip et al, 1998; Leung, 2000; Liu, 2007; Pang et al, 2007). Different disciplines such as health care, social policy and philosophy attempt to contribute to the debate on end-of-life care (Chan and Chow, 2006; Liu, 2009; Tse and Tao, 2004). One of the issues being discussed is Advance Directives (ADs) (Chan, 2004; Kong and Mok, 2006).

The ADs model form has been introduced by the Law Reform Commission (LRC) in 2006. It created some public and academic debate for one fleeting moment. It appears that the public confuses the terms ADs with euthanasia. Another problem is that research related to end-of-life care in Hong Kong is limited to descriptive studies of patients, their family as well as the health care professionals involved (Chiu and Li, 2000; Chiu & Woo, 2004; Gruber et al, 2008; Ip et al, 1998; Leung, 2000; Lee et al, 2003). Moreover, the interests of professionals in ADs merely lies in how doctors can be protected from liability and developing procedures as well as guidelines on making ADs at institutional level (Kong & Mok, 2006; Liu, 2005). However, little attention is paid to the ethical and philosophical aspects of ADs (Chan, 2004).

According to the experiences from other countries such as the Netherlands and the United States, the ADs in persons with advanced dementia – for example, Alzheimer disease- is one of the significant ethical and practical dilemmas (Black et al, 2009; Gastmans and Lepeleire, 2010; Hertogh et al, 2007). In Hong Kong, the end-of-life care treatments decision making for advanced dementia persons have relied mainly on the surrogates such as family members and health care professionals (Pang et al, 2007). However, the surrogates face several problems in making end-of-life care treatment decisions such as discerning the patients’ own wish and the interpretation of the patient’s wishes (Laurent et al, 2008; Pang et al, 2007). Under the LRC frameworks, the ADs can be considered as an advance decision making by the mentally competent adult to retain control in end-of-life care treatments if they become mentally incapacitated in the future such as dementia. ADs are especially relevant in patients with dementia but it has so far been overlooked in Hong Kong (Lee et al, 2006).

The aim of this paper is to formulate the ethical and philosophical arguments regarding ADs in person with advanced dementia. The method used is literature review. To retrieve the most relevant literature on ADs and advanced dementia, a thorough search for relevant studies was conducted in the databases PubMed, Cinahl, the Cochrane library, Philosopher’s index and Google Scholar. The following keywords were used: advance directives, living will, health care proxy, advance care planning, power of attorney, dementia, end-of-life care, end-of-life decision, do-not-resuscitate, forgoing life sustaining treatments, withdraw or withholding treatments. Original English-language or Chinese-language studies were selected.

This paper first reviews the literature in order to provide a brief overview of caring for patients with dementia and the introduction of ADs in Hong Kong. After the brief overview, the potentials and problems of using the models form ADs in Hong Kong will be evaluated and discussed from ethical perspectives. In conclusion, some recommendations for clinical practice and further research will be made.

Caring for patients with dementia in Hong Kong
The population in Hong Kong is aging, and more people now live with the effects of serious chronic illnesses towards the end of life. The high life expectancy rate in Hong Kong has been associated with the increase of the prevalence of older persons with dementia. The Hong Kong Government estimated that more than 30% of the older persons have cognitive impairments or have significant memory complaints (The Census and Statistics Department, 2006). It was estimated by a survey that more than 17% of the population aged over 70 in Hong Kong suffered from mild or very mild dementia (Lam et al, 2007).

Dementia is an incurable and progressive disease caused by degeneration of the brain cells. Persons with dementia suffer from gradual loss of cognitive functions and mental abilities as well as swallowing abilities. In the final stage of dementia, patients are incontinent, and aphasic, totally dependent and even bedridden. Furthermore, they lose swallowing abilities the capacity to communicate with others and then subsequent death. The end-of-life care decision making for patients with advanced dementia is challenging regarding prognostication (Gastmans, 2010; Pang et al, 2007).

The Hospital Authority (HA), a statutory body to provide public hospitals and related services in Hong Kong has a standard procedure of end-of-life care decision for terminally ill patients. The doctors in charge are clinically and legally responsible for medical decisions. According to the Guidelines on life-sustaining treatment in terminally ill patients which was published in 2002, health care professionals should follow the guidance in making decisions to withhold or withdraw the life-sustaining treatments with regards to patient’s wishes and consent from the families (Hospital Authority, 2002). Moreover, the health care professionals are advised to make ethical decision in accordance with the ethical principles – beneficence, non-maleficence, respect for autonomy and justice. The HA Guidelines state that it is acceptable to withdraw or withhold artificial nutrition and hydration when death is imminent and inevitable or when a mentally competent patient clearly expresses his or her
own wish. In cases where a mentally incompetent patient in terminally ill without valid ADs, the health care professionals should reach consensus with the family members, based on the best interest of the patient principle. HA concurs that withholding or withdrawing life-sustaining treatment is ethically and legally acceptable when treatment is futile. However, the concept of futility is blurred and it is considered under both medical prognostication and value-laden notions. Clinically, there is no formal procedure for making such decision in advance except for cardiopulmonary resuscitation.

Withdrawing or withholding tube feeding for advanced dementia is one of the essential and complex problems in the end-of-life care decision. Artificial nutrition and hydration are classified as medical treatment while oral nutrition and hydration are regarded as basic care (Hospital Authority, 2002). Difficulty in eating is a signal that the patient has entered the final phase of dementia (Gillick, 2000). In fact, tube feeding can cause more suffering to the patients who might suffer from clogging of tubes, diarrhea and physical restraint that prevent them from pulling out of tubing. Tube feeding may no longer be providing benefit to the advance dementia patient who is dying and the treatment goal maybe to relieve suffering (Samanta and Samanta, 2006). Geppert et al. reported that there is lack of evidence to support the practice of tube feeding in caring of advanced dementia patients (Geppert et al, 2010). Medical practices in Hong Kong are prone to life preservation. Tube feeding for the advanced dementia patients in the end-of-life care is the common practice, in which health care professionals not only are committed to provide quality care for the patients but also would be better protected themselves from legal liability (Pang et al, 2004). Nevertheless, the insertion of feeding tubes in patients with advanced dementia is controversial in the clinical settings. On the other hand, the family members often request hand feeding and withdraw the tube feeding because of the patient’s suffering or rejection to the tube (Pang et al, 2007).

The health care professionals and the family members have to face difficulties in end-of-life care decision of whether to withdraw life-sustaining treatment, often without knowledge of patients’ wills (Chiu & Li, 2000). Furthermore, there are three main difficulties encountered by the doctors in reaching consensus with patient’s family members (Tse, 2005a). Firstly, family members have unrealistic expectations on the prognosis and outcomes of treatments. Secondly, the scepticism about end-of-life care decision as institutional abandonment driven is also the hurdle in reaching consensus with family members. Thirdly, in Chinese cultural beliefs it is a taboo to talk about death related issues.

ADs in Hong Kong

In order to reduce disputes and minimize the uncertainty faced by health care professionals or family members about the end-of-life care treatment decision, ADs model forms are promoted in Hong Kong. The moral principles underpinning ADs are respect for patient autonomy and extend patients’ right to self-determination to future end-of-life care decisions. It is believed that ADs offer the persons an alternative to choose death with dignity and minimize legal conflicts (Kong and Mok, 2006).

LRC issued its final report on ‘Substitute decision-making and ADs in relation to medical treatment’ in August 2006, with reference to the legal and health care system in Australia, Canada, England and Wales, Scotland, Singapore and the United States. The LRC suggested promoting ADs initially by non-legislative means. It put forward a model form of ADs which can be used by those wishing to make decisions as to their future health care. The government agrees with LRC’s view that it would be premature to formulate a legislative form of ADs. A consultation paper on the introduction of the concept of ADs in Hong Kong was issued by the government in response to the LRC’s recommendations. The government consulted the medical and legal professions as well as the general public on the implementations of ADs during the consultation period from 23 December 2009 to 22 March 2010 (Food and Health Bureau, 2009). Accordingly, the Hong Kong Government has no intention to actively advocate or encourage the public to make decision to their end-of-life care as it states that this is entirely a personal decision, to respect individuals’ freedom of making decisions (Legislative Council Paper, 2008-09). The Government would rather encourage the health care professional and organizations not only to revise their own guidelines but also to educate the public on ADs by using the information package. The guidelines and procedures for handling ADs will be formulated at institutional level.

The introduction of ADs by LRC and the government have created some debates among both the general public and the professionals. For debate among the general public, it appears that the term ADs is mixed up with euthanasia. For instance, some of the religious leaders are against ADs because they worry about the progress towards euthanasia and deontological doctor’s duty of not to kill (Kung Kao Po. 2006; Law, 2006; Wu, 2006). Mass media narrate the concept of ADs as ‘passive euthanasia’ or ‘modified euthanasia’ (Hong Kong Daily News, 2008; The Sun Newspaper, 2006; Siu, 2010). In other words, Hong Kong people confuse the concept of ADs with euthanasia, withdrawing or withholding life-sustaining treatments. On the other hand, the general public, patients groups and non government organizations have shown concerns about the written ADs that might limit their end-of-life care treatments or quality of health care services received in the future. The responses from general public reflect that ADs might not facilitate the doctors to reach consensus with the patients and family members on the end-of-life care decision.

It has been generally acknowledged that the medical profession’s role is critical in shaping and constraining health policy in Hong Kong (Gould, 2006). The current academic discussion about ADs is dominated by the medical professionals, in which mainly divided into two aspects. Firstly, the health care professions discuss ADs under the framework of end-of-life care, which are mainly the descriptive studies. Secondly, following the recommendations by the government, the doctors attempt to contribute towards not only criticizing the applicability of the ADs in Hong Kong but also formulating the procedures and guidelines in handling ADs (Au-

Other professions also endeavour to participate in the academic discussions. For instance, the legal validity of using a non-legislative model form is challenged and the legislative status of ADs has recommended from a legal perspective (Liu, 2005 & 2007). Moreover, from the philosophical perspective, Ho Mun Chan argues the ‘familial’ advance directive that the adult shares decision making on the ADs with his/her family members is culturally applicable in practice (Chan, 2004). He further explains that ‘familial’ ADs are not only to solve the philosophical problem of demented patients’ personal identity but also to balance the notions of individual autonomy and family involvement in medical decision making in the Hong Kong context. In other words, philosophical discussion is one of the crucial notions in dealing with the cultural beliefs and practices. It would thus be of interest and value to learn the ethical and philosophical perspectives on ADs.

**Potentials of ADs in Hong Kong**

Although ADs remain a challenge in clinical implementation and the theoretical perspectives, ADs are valued not only to expand the autonomy of the patient in the future but also to minimize the uncertainty faced by the surrogates about the end-of-life care decision. From a psychological perspective, ADs are beneficial because they reduce anxiety and increase self-respect of the patients (Brown, 2003). In addition, it also can offer patients real mental comfort or reassurance, allowing them to retain control of their end of life health care even after they have become incompetent (Gastmans & Lepeleire, 2010).

According to HA guidelines in 2002, health care professionals are encouraged to consider the suggestions by Beauchamp and Childress (2001) on ethical principles, which are respect for autonomy, beneficence, non-maleficence and justice. The potential ADs will therefore be analysed under these ethical principles.

**Respect for autonomy**

In the advance directive debate, respecting a patient’s autonomy is an important value. ADs are considered as the counter of the excessive medical paternalism. It prioritizes the patient’s autonomy while it limits the monopolization of decision making by the medical professions that might ignore the wishes of the patients. The individual autonomy is required for respect even though it is not an absolute dominion.

Human autonomy should be seen within the network of a person’s relation and world. The person is best thought of as a human agent, a being of this embodied kind, who acts and interacts in a cultural and historical context in which he or she is embedded (Hughes, 2001). The demented patients are in relation with their own family, relatives and friends as well as the care providers, health care institutions and systems in Hong Kong and their world. The Chinese concept of holistic and social personhood, (regulated by the principle of filial piety and organized in a social hierarchy), provides distinctive perspectives in the end-of-life care decision making particularly in the case of the elderly (Hui, 2004). The individual is considered as an integral part of the family and therefore the wills of the family members should take into consideration and hence decision making belongs to the family rather than the individual only (Bowman & Singer, 2001). The will of the patient is highly respected while the consensus is made with the whole family. In Chinese culture, the patient can be seen as autonomous person even if he/she gives up the care decision making to the family members (Fan & Tao, 2004). Therefore, respect the autonomy of the patient in the Chinese context is not only the issue of self-determination but also the familial determination.

The family and the doctors in fact bear a very heavy burden to make life and death decision for the demented patients. ADs do not free the doctors from responsibilities in making the ultimate end-of-life care choices (Loewy, 2010). However, ADs help them make emotionally stressful decisions in difficult circumstances (Hackler, 2004). Given the denial of death in Chinese culture, ADs help to create a window of opportunity for shared end-of-life care decision making (Hertogh, 2009). Therefore, in the familial-valued context, Chan (2004) criticises that individual autonomy is excessively patient-centred so he suggests that making ADs in Hong Kong should be a sharing process by the family members and the patients. It assists to articulate the will of the patient which upholds the patients’ autonomy while at the same time the family members’ wishes are also taken into considerations.

**Beneficence and Non maleficence**

An advance directive is an instrument that serves as a basis of discussion with doctors, other health care professions and family about end-of-life care treatments of the patient with dementia (Loewy, 2004). For the patients’ best interests, the patient should be well informed and make ADs regarding to their own values, goals, personal and cultural preference as well as the medical conditions. During the discussion process, it is not only the patient’s wishes are made known but also the medical health education about the end-of-life care is given to patient and the family members. It might assist to realistically adjust the expectations on the prognosis and treatments outcome of the patient and family members.

According to the principles of beneficence and non maleficence, the doctors share the responsibilities to guide and educate the patient in selecting options for medical treatment in order to improve the quality of care to the patients with advance dementia. Withholding or withdrawing tube feeding in caring patients with advanced dementia is to avoid prolong suffering by futile treatments. Therefore, ADs are a platform for health care professionals to discuss the end-of-life care with the patient and the family members in advance in order to improve the health care services standard and patients’ quality of life.

**Justice**

Health care professions should treat all patients according to what is fair or due to them (HA, 2002). On the other hand, the patient cannot claim unlimited rights without regard to the impact on the scarcity of resources.
Weber (1993) urges that self determination or autonomy should be viewed from the perspectives of distributive justice and hence an understanding of a right to demand and get whatever is wanted should be avoided. Additionally, the health care professionals also share the responsibilities to assist the better allocation of scare resources in the clinical practices. Therefore, ADs will promote or forgo the futile treatments and the unnecessary medical expenses will be saved. Moreover, ADs are considered as an education tool for the general public because some of the patients and/or their family members make absolute health care decisions without considering the competing right of others or the limited resources.

Problems of ADs in Hong Kong

Practical problems

Although the introduction of ADs in Hong Kong is still at a budding stage, some foreseeable problems can be articulated with reference to other countries’ experiences. ADs have been available in the United States for two decades but patients in the United States are reluctant to make plans for a critical situation and draw up ADs (Zimmermann & Rodin, 2004). Available literature shows that only small numbers of Americans have an advance directive and that ADs play a limited role in facilitating harmonious end-of-life care decision making (Tillyard, 2007). Messinger-Rapport et al (2009) reiterate that five reasons might articulate why ADs are less successful than originally hoped in the United States. First, the doctors may not know the patient has an advance directive. Second, the surrogates may not know the patient’s wishes. It is also a question of whether ADs can reflect the wishes of a person about a certain moment when it is formulated at an earlier time under different circumstance. Third, the family members might override patient’s advance planning because they may disagree with patient’s decision. Fourth, the doctors may not be able to communicate with each other about a particular patient’s wish as they may work in different institutions. Fifth, it is difficult to translate the documents into an action plan as the different interpretations of medical terms between the doctors and the patient. In addition, ADs give little information about the patients’ idea of quality of life, value and goals (Asselt, 2006). Therefore, ADs might not help doctors to make the difficult choice of whether life-sustaining treatments should be withheld or withdrawn in the best interests of the patient.

Moreover, similar to Hong Kong, a common assumption of American patients is that having an advance directive automatically will limit health care decisions on the patients (Hertogh, 2005). It is argued that the demented person is a ‘new’ person because he/she is radically different from or is not psychologically connected to the person who wrote the ADs. The view of the person with dementia is one of the crucial philosophical problems but this notion is less discussed in Hong Kong. The philosophical consideration is mainly focused on the issue of autonomy (Chan, 2004).

The end-of-life care decisions for people with dementia have long been intensively debated in the Netherlands society. It is a very common clinical experience that patients with dementia regularly contradict their own ADs (Hertog, 2005). The surrogates face a dilemma on how to balance the actual references of the person with dementia against the patient’s earlier opinion laid down in a now forgotten AD. Hertog et al. (2007) conclude that reduced in the end-of-life care decision for the patient with ADs.

Cultural beliefs and taboos

Making ADs especially with the elderly is in fact breaking the taboo of talking about ‘death and dying’ in the Chinese culture. Although the traditional Chinese value has been challenged or loosened, the influence of the traditional Chinese value is still found in Hong Kong. For instance, filial piety is not totally forgotten in present-day Hong Kong. It is still upheld by most Hong Kong people as a value that they should treasure and practice in ways that they find suitable and appropriate. Also family members might show their filial piety by never forgoing treatments (Hui, 1999a). Dealing with the cultural taboos or beliefs is one of the essential challenges in the introduction of ADs.

Moreover, there is a popular saying in Chinese: ‘doctors have the heart of parents’, indicating that people expect doctors to act lovingly as parents do, and accord them a level of respect commensurate with elders and parents (Hui, 1999b). Furthermore, Chinese patients are generally quite modest and compliant so it is not uncommon in Hong Kong for doctors to have a paternalistic attitude in their dealings with patients (Chan & Rhind, 1997). Respect for an individual’s right to self-determination is a weak notion in Chinese culture. The life-and-death treatment decisions are to be made by doctors who are required to seek support and acceptance rather than consent from the patient and/or the family members in clinical practices (Tao, 2006). Under such circumstance, the patients and family members are passive to make clinical end-of-life care decision. In Spain, two main challenges are identified from the limited use of ADs, in which are the Spanish society neglects the concepts related to end-of-life care decision making and the passive attitude towards clinical decision making by the patients (Simon-Lorda et al, 2008). The Spanish experience suggests that the introduction of ADs in Hong Kong would not change the passive attitudes of the patients to make ADs or advance planning on the end-of-life care.

Current Autonomy Vs Precedent Autonomy

In advance directive debate, respecting a person’s autonomy is highly stressed and hence the problem of personal identity of the dementia person arises (Kuhse, 1999). It is argued that the demented person is a ‘new’ person because he/she is radically different from or is not psychologically connected to the person who wrote the ADs. The view of the person with dementia is one of the crucial philosophical problems but this notion is less discussed in Hong Kong. The philosophical consideration is mainly focused on the issue of autonomy (Chan, 2004).

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the Dutch dementia debate raises an urgency of a careful discussion on the limits of precedent autonomy. It also raises another important ethical question on how far the self-determination ought to be respected.

It seems to be well accepted that demented people are unlikely to be capable in making their own end-of-life care planning or ADs due to progressive cognitive function deteriorating. If the elderly are not cognitively sound, their preferences will be overridden by the surrogates such as doctors and the family members (Chan & Pang, 2007). That is to say the autonomy of the patient especially to the elderly is conditional. On the other hand, it is also a fact that despite significant cognitive impairment, mildly demented patients are able to value their situation and express a relatively positive view towards making end-of-life decisions (Lee et al, 2006). In short, the current autonomy of the demented patient is infrequently respected while the precedent rational autonomy is valued. Thus, a valid ethical dilemma faced is how to take account of the current preferences and values of demented patients in the ADs or end-of-life care decision making in order to show respect for the current autonomy. This falls into the same conclusion with Liu (2005) that the model form of advance directive affirms the same approach with the HA Guidelines 2002 to deal with the end-of-life care decision in clinical practice. However, the model form of ADs would not facilitate to extend the autonomy of the patients with advanced dementia.

Discussion and Recommendations
The above ethical arguments about the ADs in Hong Kong should be balanced. Balancing is the process to weigh the different moral values (Beauchamp & Childress, 2001). The potential usefulness of ADs to different stakeholders is well recognised. The crucial underpinning principle of ADs is to respect autonomy and thus provide an avenue for individuals to exercise their right of self-determination. ADs facilitate the communication among health care professionals and patients as well as the family members to retrieve a clear indication of the patient’s wish about end-of-life care. Furthermore, it is a process for patients with dementia and family members discuss the end-of-life planning in advance and have realistic expectations on end-of-life care. It also helps the doctors to fulfill their professional responsibility to patients as they deliver end-of-life care treatments based on the patient’s will and the principle of the best interest. The model form of ADs offers adequate legal protection to the doctors especially in the withholding or withdrawal of medical treatments. Nevertheless, it is necessary that legislation includes provisions such as to protect doctors from liability when they act in good faith (Liu, 2005).

On the other hand, predictable problems of using ADs should be seriously taken into consideration. Recognising some of the practical problems in using the ADs, the Hong Kong Government proposes two main actions to promote ADs. One of the main actions is to formulate the guidelines and procedures for handling ADs in consultation with the relevant professional bodies. It is no doubt that formulating the guidelines or procedures is essential. Nevertheless, some of the essential problems should be further explored, which anticipates the successfulness of using ADs.

Although one of the main challenges to introducing ADs in Hong Kong is the taboo of talking about death and related issues, cultures and taboos will not change in a short period of time. ADs have provided a platform for the stakeholders to deal with these sensitive but important issues. ADs also arouse the general public’s awareness of the end-of-life treatment and advance care planning. As the concept of ADs is new to the general public, another main proposed action by the Government is to make the concept of ADs accessible to the general public by formulating an information package. The aim of formulating the relevant package is to educate the general public about ADs and the concepts of advance care planning. The education should not only focus on the promoting the concepts of ADs and advance care planning but also extend the scope to the ‘life and death education’. The question then is who are to be the educators? The government identifies some of the stakeholders such as health care and legal professionals, hospitals, organisations providing elderly care and patient groups. As death is the important and great event of human life, the humanity in medicine is recommended to integrate into health care professionals’ academic training.

The philosophical considerations contribute not only to the need to revisit the fundamental notion of ADs and the related issues but also to facilitate the implementation of ADs in clinical settings. The current interpretation of autonomy is closely tied to the concepts of self determination, decision capacity and competence. Nevertheless, the concepts of the term “autonomy” are a multifaceted notion. In this paper, the relational autonomy, current and precedent autonomy are discussed. Another important facet of autonomy, bodily autonomy, pays a crucial role to interpret the autonomy of the patients with advance dementia (Dekkers, 2004). Bodily autonomy is understood as autonomy of the body. The patients with advance dementia express their wills by bodily ways. Therefore, the best interest principle always plays a role even if the patient has an AD.

Which health care setting is the best position to make the ADs with the patients and/or their family members? The doctors tend to engage patients and families in discussions about the end-of-life care only late in the course of illness. These practices suggest that the doctors take ADs as a means to persuade family to forgo treatments (Fried & Drickamer, 2010). As primary care focuses on health promotion, the primary care setting is particularly well-suited to the establishment of ADs (Pugno, 2004). However, the primary health care services are being dominated by private practitioners in Hong Kong (Gauld & Gould, 2002). In order to better allocation of limited resources, the Government should distribute more resources in the primary care to promote the establishment of ADs.

In the end-of-life care of the terminally ill, it is important to enable the patient to die with dignity (HA, 2002). The engagement of the patients in the end-of-life care decision is a way for them to express their views, values and belief. ADs are considered as a tool to respect the choice of the patients and hence promote dignified death.
Conclusions
In caring for the patients with dementia, the health care professional and the family members face dilemmas of making an ethical end-of-life care decision in Hong Kong. The model form of ADs is introduced in order to respect the wishes of the patients and shrink the disputes among the health care professionals as well as the family members. From ethical perspectives, ADs are launched regarding the principles of respect for the autonomy and best interest of the patients. The current academic debates on ADs in Hong Kong are mainly focused on the implementation of ADs in the clinical settings while the philosophical and ethical perspectives of ADs are neglected.

ADs are studied from the ethical and philosophical notions in order to evaluate the foundation potential and problems of using ADs. ADs are analysed under ethical principles. Self determination of the patients with dementia can be extended and respected while the surrogates can make an ethical end-of-life care decision based on the ADs. Furthermore, ADs will facilitate to save unnecessary medical expense in the end-of-life care treatment. On the other hand, the effectiveness of the ADs in the clinical settings is in doubt with reference to the other countries’ experience. Promoting ADs in the death denial context like Hong Kong, it is not only breaking the taboos but also facing challenges to change the public’s attitudes. Additionally, ADs respect the precedent rational autonomy of the patients with advanced dementia while the current autonomy and the bodily autonomy are neglected. In balancing both arguments, ADs are valued because the quality of life and the dignity of the patients are withheld. It is well recognized that ADs in a model form rather than a legislative one is a small step towards a more open environment for such sensitive discussion with the general public in Hong Kong.

This paper attempts to fill the knowledge gap in the research from the ethical perspectives and to contribute to the ethical notion about ADs. Furthermore, further research is suggested about the different facets of autonomy and personal identity of the patients with advance dementia in Hong Kong. The ethical notion of advance care planning in the Chinese context is also a substantial area in need of further research.

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Death Anxiety in University Students

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Abstract

Objective: The aims of this study were to evaluate medical and nursing students’ approaches to death and to determine their effects on the choice of education field.

Method: The Thorson-Powell Death Anxiety Scale, consisting of 25 phrases, was applied to 161 second grade university students who divided into two groups. The health group consisted of medical and nursing students. The control group was composed of environmental engineering, biology, fine arts students. The data has been computerized; for group comparisons chi-square, Student’s t and two-way ANOVA tests were used; frequency (percentage) and the mean±standard deviation were used for summarizing the data.

Results: The death anxiety of women was found to be higher than that of male students in both health and control groups, and this difference is statistically significant (p<0.05). The death anxiety of the health group (52.60) was slightly higher than the control group (49.69), but this difference was not statistically significant (p>0.05).

Conclusion: Higher death anxiety may affect the choice of some members of the health profession but there appears to be no relationship between death anxiety and choosing the profession.

Key words: Medical ethics, Medical education, Death anxiety, Death anxiety scale

Introduction

Death, besides being a subject of clinical medicine oriented towards the attempts to delay or postpone it, is also a case discussed in the agenda of bioethics within the framework of such notions as euthanasia, dying with dignity etc. The relation between death-medicine does not merely consist of direct connections; but each philosophical, social, psychic, cultural, legal and other dimension of death has affects on the intellectual substructure of medicine.

By nature, professions of health have a close relation with death; the ones who select these professions get acquainted with this relation during their training and start to experience witnessing death. It is strongly possible that this close encounter will inevitably affect death anxiety levels, death-related thoughts and behaviors towards fatal diseases of the trainees. On the other hand it might be alleged that the ones who consciously select these professions which are based on the fight against death already have a special interest for death or may have anxieties-obsessions with death itself. Based on these deductions, many studies have been conducted on the death anxiety among nursing and medicine school students.

A set of diversified thesis may be put forward concerning the relation between choice of health profession and death anxiety. In this respect it is feasible to think that the ones with high levels of death anxiety select health professions to search for a fight against death or conversely the ones with low levels of death anxiety do not hesitate to select these professions that have a high probability of facing death. The third possibility argues that there is no relation at all between the choice of profession and death anxiety.

The research objective of our study is to make a deduction concerning the position of death anxiety in selecting health professions by detecting death-oriented personal attitudes of a group of nursing and medicine school sophomores’ via applying a standard death anxiety scale.

Methods

The study was planned as a cross-sectional type and conducted between January-May 2007. The research has been carried out among 187 volunteering students studying at five different departments of Mersin University but the evaluation has been made through 161 students who answered all of the questions. The rest of volunteers were excluded as they did not answer all of the questions.

In this research where students from school of medicine and college of nursing constituted the test group; considering the criteria of familiarity with life notion and human body, the control group was selected from environmental engineering, biology and faculty of fine arts students.

The research utilized the Thorson-Powell Death Anxiety Scale (DAS), which is a data gathering tool used by different disciplines to detect death anxiety levels of dissimilar groups. The scale’s Turkish adapted version has Cronbach’s alpha coefficient (α) 0.84 and reliability coefficient 0.73; thus is valid and reliable as a measurement tool. Cronbach’s alpha coefficient (α) scale was calculated as 0.87 in our study.

The scale includes 17 positive and 8 negative - 25 statements in total; the participants have been asked to indicate their views for each question by using the 5-point Likert format (I completely agree; I agree; I am not sure; I disagree; I completely disagree ). Accordingly the choices have scores between 0 and 4 and the participants are able to reach a total score between 0 and 100. The higher total score indicates the higher level of anxiety.

In addition to detecting overall anxiety level, Thorson-Powell death anxiety scale measures the levels in four sub-types of anxiety. These anxiety sub-types are related to loss of physical and mental functions, ambiguity of
after-life, decay and spoiling of the dead body, undergoing pain and agony during death. In our research, the data obtained via scale has been computerized; for group comparisons chi-square, Student’s t and two-way ANOVA tests were used; frequency (percentage) and the mean ± standard deviation were used for summarizing the data. In the evaluation of scale’s scores multivariate analysis methods were not used since the subgroups were selected from the ones determined by factor analysis and that has no correlation between each other. Data was analyzed using the statistical package SPSS v.11.5 for Windows. The p values less than 0.05 were regarded as significant.

Results

Of 161 participants where evaluation has been made, 78 (61 women, 17 men) are from health group and 83 (39 women, 44 men) are from control group. The average age of students was 21.62 years (age range 18-36).

In general, the average DAS score of all students was 51.10. DAS score average of health group is 52.60, control group’s is 49.69 and there was no statistically significant difference between both (p=0.268). A comparison between genders reveals that women have higher DAS score average than men (55.20 to 44.38). The difference between females and males was statistically significant (p<0.05).

From analysis of the death anxiety scale with respect to gender and group, it has been detected that between women in health group and women in control group as well as men in health and control groups, there is no difference in terms of average DAS score (p>0.05). Distribution of health and control groups with respect to gender and death anxiety levels and numbers of participants in groups are given in Table 1.

When the death anxiety sub type scores are evaluated by comparing health and control groups, in anxieties such as ambiguity of after-life, decay and spoiling of dead body, undergoing pain and agony during death the scores obtained by the health group are higher than the control group. Amongst all three sub-types there is not a statistically significant difference between groups (p>0.05). In the anxiety of losing physical and mental functions, the anxiety level of control group is higher than health group and among the groups there is no statistically significant difference (p>0.05). Distribution of anxiety sub-type score average affecting death anxiety in health and control groups is illustrated in Table 2.

Since the number of statements about anxiety sub-types is not equal, in order to compare them with each other, their score averages have been taken from 100 as a common denominator. Following this conversion within all participants, the descending order of average score is (1) undergoing pain and agony during death, (2) ambiguity of after-life, (3) decay and spoiling of dead body, (4) loss of physical and mental functions. The order is the same for health group and control group. Sequence of anxiety sub-types’ score averages with respect to scores they receive from participants is shown in Table 3.

In terms of score averages amongst overall students, the differences are statistically significant (p<0.05) between anxieties of decay and spoiling of dead body and loss of physical and mental functions, ambiguity of after-life and undergoing, pain and agony during death. In the health group, sub-types that have statistically significant differences are: undergoing pain and agony during death and loss of physical and mental functions and decay and spoiling of dead body (p<0.05). In control group sub-types that have statistically significant differences are loss of physical functions, ambiguity of after-life and pain and agony during death (p<0.05).

Discussion

The death anxiety score averages of our participants indicate that they have mid-level anxiety and the anxiety level is significantly higher in women than men. This general profile is, to a large extent, parallel to the findings obtained from the researches conducted amongst university students in Turkey by using both identical and different death anxiety scales.

Within the scope of studies conducted in Turkey via Thorson-Powell scale, the average score of students from education, fine arts and religious studies faculties in Atatürk University (Turkey) is 52.89, is rather close to the general average obtained in our study. In another research executed in Ankara University Faculty of Educational Sciences (Turkey), lower anxiety levels have been detected; score average of students from computer teaching technologies department is 43.31 and counseling and guidance department is 48.58.

In a research carried out in 9 Eylül University (Turkey) by applying a different scale, among students from eight faculties (religious studies, law, fine arts, economics and administrative sciences, education, civil engineering, mining engineering, medicine) no statistically significant difference has been detected just like this research. Civil engineering faculty students were the group with the highest score average and school of medicine was placed in the fifth order in this grading.

At this point, based on the limited data, considering the low level of anxiety of freshman students in medicine and nursing schools, it is possible to argue that high level of death anxiety did not play a key role in their choices of health professions. However while making such an evaluation it would be proper to consider the general knowledge that families and the score students receive at university student selection exam are more influential than their personal features and interests. This consideration also accounts for the reason why in general there is not a distinctive difference among students from different departments.

In the United States, in research conducted by Thorson and Powell at the end of 1980s among freshman students from two different medicine schools, DAS score averages was found as 43.5 and 47.5. In the first study a control group was included as well. Between this group’s average score 47.49 and scores of students from medicine school, a statistically significant difference was detected indicating the low level of anxiety among medical students.

The findings of that research are incompatible with our own research results. Score averages detected by Thorson and Powell are lower than both our participants’ scores and the control group as well in the first study.
An approach that can interpret this incompatibility is focusing on time and cultural difference. Another approach may argue that this incompatibility is an indication of the absence of any relationship between choice of profession and death anxiety.

In our study in both health and control groups DAS score averages of men are higher than women. This high level is valid not only for general score average but for all anxiety sub-types' score averages as well. The findings of significant relations between death anxiety and gender variable, the high scores of women were also obtained in the research conducted in Ankara, (Eylül and Atatürk Universities, Turkey) at different periods of time.  In studies composed of non-student groups, death anxiety of women were generally higher. However, there are also studies not revealing such findings. The relative lowness of male participants' scores can be bound to the facts that human life is biologically and culturally much closer to death and having experiences such approaching and facing death can diminish the effect of death anxiety. A study which compares death anxiety levels of people from professions with low-death risks in Turkey such physiologists, accountants, classroom teachers and professions with high-death risks such as police officers, pilots and firemen, the finding indicating that people having high-death risk professions have lower DAS scores supports the final argument as well.  

The evaluation made in the above-mentioned research argues that professional life may have an effect on death anxiety level; however, death anxiety is not a factor determining choice of profession. On the other hand, in a philosophical evaluation it is asserted that death anxiety which is shaped by cultural and educational elements plays part in choice of profession. In this study which focuses on death fear and the ways to cope

### Table 1. Distribution of health and control groups with respect to gender and death anxiety levels

<table>
<thead>
<tr>
<th></th>
<th>Health group mean± SD</th>
<th>Control group mean± SD</th>
<th>P*</th>
<th>Both of groups mean± SD</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Women</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>N=61</td>
<td>55.26±15.84</td>
<td>55.10±15.76</td>
<td>0.961</td>
<td>55.20±15.73</td>
</tr>
<tr>
<td><strong>Men</strong></td>
<td>43.06±16.25</td>
<td>44.89±16.12</td>
<td>0.694</td>
<td>44.38±16.04</td>
</tr>
<tr>
<td>N=17</td>
<td>0.005</td>
<td>0.005</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>52.60±16.62</td>
<td>49.69±16.67</td>
<td>0.268</td>
<td>51.10±16.65</td>
</tr>
<tr>
<td>N=78</td>
<td>0.000</td>
<td>0.000</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

P* the differences are statistically significant (p<0.05) between health group and control group. P** the differences are statistically significant (p<0.05) between women and men.

### Table 2. Distribution of anxiety sub-type score means affecting death anxiety in health and control groups

<table>
<thead>
<tr>
<th>Loss of physical and mental functions</th>
<th>Health group Mean± SD</th>
<th>Control group Mean± SD</th>
<th><strong>P</strong></th>
<th>Total Mean± SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ambiguity of after-life</td>
<td>9.04±5.37</td>
<td>9.71±5.82</td>
<td>0.45</td>
<td>9.39±5.60</td>
</tr>
<tr>
<td>Decay and spoiling of dead body</td>
<td>13.23±3.96</td>
<td>11.00±4.35</td>
<td>0.001</td>
<td>12.08±4.30</td>
</tr>
<tr>
<td>Undergoing pain and agony during death</td>
<td>7.18±5.01</td>
<td>6.28±4.40</td>
<td>0.23</td>
<td>6.71±4.71</td>
</tr>
</tbody>
</table>

### Table 3. Sequence of anxiety sub-types’ score means with respect to scores

<table>
<thead>
<tr>
<th>Loss of physical and mental functions</th>
<th>Health group Mean± SD</th>
<th>Control group Mean± SD</th>
<th><strong>P</strong></th>
<th>Total Mean± SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>W= Women</td>
<td>18.73±20.24</td>
<td>19.20±20.97</td>
<td>0.102</td>
<td>20.01±20.35</td>
</tr>
<tr>
<td>M= Men</td>
<td>20.35±29.26</td>
<td>30.21±28.97</td>
<td>0.000</td>
<td>30.52±28.57</td>
</tr>
</tbody>
</table>

P* the differences are statistically significant (p<0.05) between health group and control group. P** all students in general, the differences are statistically significant (p<0.05).

W= Women, M= Men, SD= Standard Deviation
with it, it is stated that death anxiety level is expected to be high in health professionals and the research findings of death anxiety in medical students increases throughout senior classes is asserted.19

Among the different aspects of death, undergoing pain and agony during death was the biggest concern of the participants in both health and control groups. In a study conducted via a different DAS, it has been seen that students from Istanbul University Faculty of Medicine (Turkey) likewise stated that they feared most from undergoing pain while dying.20 It is possible to argue that since ever-growing resources of modern medicine can extend terminal period of life and this period is sometimes painful and hopeful, this sub-type of anxiety precedes the others in a vast majority of public. It is also possible to deduce that due to their anxieties concerning pain during death, the participants may have selected profession of medicine, which on the whole fights against pain.

Within the context of comparing anxiety sub-types, the fact that ambiguity of after-life also received a high score in addition to anxiety of pain during death may be based on the deduction that any type of ambiguity in general acts as a source of anxiety. Belief in the after-life is an effective medium in relieving fear of death and achieving the desire for immortality.21-22 Feeling less anxious about the decay of dead body and loss of physical and mental functions can be indirectly attached to the deduction that belief in after-life is strong and prevalent.

Conclusion
In this study which has been conducted among a limited number of participants from two groups, health and control, death anxiety levels of participants have been determined both as a whole and as sub-types and a comparison has been made between groups and genders. Within the scale of all participants, death anxiety level is medium and it is higher in women compared to men and greater in health group compared to control group. As evaluated with respect to anxiety sub-types, it surfaces that suffering while dying and what we see after death take front stage whereas not much anxiety is felt in terms of the fate of dead body and loss of vital functions.

Once evaluated as a whole and compared with other literature, our research findings are in line with the results obtained from studies conducted among similar groups. Anxiety level of health group is lower than control group and majority of sub-types. The insignificant difference can be interpreted in both ways; high level of death anxiety motivates towards health professions or there is no relation at all between anxiety level and choice of profession.

The studies aiming to identify health professionals with all their different aspects, including the motives in their professional choice, goes beyond forming a unique store of knowledge and acts as an indirect contributor to providing more effective and beneficial health services. On the other hand the fact that death, which is one of the basic concepts of medicine, has a position with extra-clinical insights in the agenda-mind of prospective health professionals can be seen as an effective tool for forming-developing medico-social sensitivity within them.

These two deductions are the points our study originated from. Our suggestion is that from this point forth, similar studies to be conducted and knowledge store on this issue to be extended.

References
Bioethics in the Islamic Republic of Iran

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Introduction
This is a research report on the three layer structure of bioethical decision-making in the Islamic Republic of Iran. This report has been prepared based on an investigation on the religious and ethical system of beliefs which is dominant in contemporary Iran (1980–now).

The three layer structure in this report refers to:
1. The basic ethical concepts, including ethical theories and religious beliefs, as the 3rd level.
2. The bioethical principles and laws, as the 2nd level, and
3. The decisions made on bioethical issues in medicine, as the 1st level.

The bioethical issues under investigation are:
a. The end of life care,
b. Reproductive medicine, and
c. Organ transplantation;

The report will focus on each group of issues according to a three-year schedule of annual reports. Thus, following the introduction and a background section, we shall discuss the end of life care, according to the work schedule for the first year.

Bioethical decision-making in the Islamic Republic of Iran has a complex and unique structure in many perspectives. Readers would first need to become familiar with the overall culture, religion and legal practice in the Islamic Republic of Iran before the discussion of bioethical issues in medical practice in Iran. Therefore a background section is provided first as a summary of the needed information, and then the basic religious and ethical beliefs and theories (3rd level) in the Islamic Republic of Iran will be briefly explained; these represent a quite unique system in Asia and may not be widely known among bioethicists even those in other Islamic countries. Moreover, the 3rd level concepts have a major influence on the delineation of the other two levels and a good understanding of our discussion depends on familiarity with the broader concepts at the 3rd level in contemporary Iran.

Background
The theocratic constitution of the Islamic Republic of Iran was approved in December 1979. Accordingly, the “Supreme Leader” is the legally recognized and legitimate clergy (faqih mojtahed) and ultimately responsible for the delineation as well as supervision over the general policies of the nation and has full power to assure all bodies including the legislative parliament, the judiciary system and the executive government are following the Shi’a Islamic rule.

The current population (2011) of the Islamic Republic of Iran is about 75 million, 89% of which are Shi’a Muslims, 9% are Sunni Muslims, and 2% are Zoroastrian, Jewish, and Christian. There is another minority of Baha’i but their religion has not been accepted as legitimate by the current law.

The Shi’a religion has an overwhelming influence over all aspects of life in the Islamic Republic of Iran, including law and ethics. The followers of Shi’a in Iran consider themselves the “followers” of Ali, the first male convert to Islam, who was the cousin and son-in-law to the Islamic prophet Mohammad. Shi’a essentially means “follower” in Arabic. Shi’a is based first on the teachings of the Quran, the holy book of all Muslims, and second on the “messages” of the prophet of Islam, Mohammad, as well as of Ali and other Imams who were his descendents, carried through “hadith”.

Shi’a favors the “hadith” attributed to Mohammad and Imams and credited to the Prophet’s family and close associates, in contrast to the Sunni traditions which are largely narrated by the Prophet Mohammad’s companions, whom Sunnis consider as trustworthy. Therefore almost all religious, ethical, political and other decisions in the Islamic Republic of Iran ultimately depend on the interpretations of the widely approved clergymen (faqih mojtahed) from Islam, which ultimately falls on the Supreme Leader’s jurisdiction. The decrees and decisions made by the Supreme Leader can be the source for interpretation of religious and ethical decision-making by all authorities in the Islamic Republic of Iran.

The 3rd level; basic ethical concepts, ethical theories and religious beliefs
The fundamental question at the 3rd level to answer is about the underlying ethical philosophy, whether it is deontological, focused on actions, or teleological, focused on consequences. Most readers might be surprised to know that generally Islam and especially Shi’a are based on a third category of moral thinking which is mainly based on prima facie obligations similar to the views of the British philosopher W.D. Ross (1877-1971). Also interestingly, the consequences of actions, especially those with a public impact, may receive considerable attention, though they are not viewed in a utilitarian perspective. Let me explain the two basic theories in more detail.

Ethics in Islam is not purely deontological. In Islam, actions are not simply divided into right and wrong; each person at any moment may have a number of obligations some of which are more important than others. A Muslim may decide to perform various actions he is obliged to, and to refrain from others that are to be avoided, based on a proper ranking of those obligations.

There are various ranks for the varied obligations a Muslim is bound to do, or “not” to do (to refrain from doing). Generally speaking, from a religious/ethical standpoint all actions may be basically classified into five broad ranks as the following:

1. Wajeb (“fariza”) refers to obligatory actions which must be done, when possible.
2- Mostahab refers to actions that had better be done, but mostly are not obligatory.

3- Mobah refers to neutral actions with a neutral ethical status meaning that there may be no obligation or duty to do or to refrain from doing those actions.

4- Haram refers to actions that had better be avoided but are not fully prohibited.

5- Makruh refers to prohibited actions which must be avoided, if possible.

This classification is only a general guideline for overall decision-making. Please notice that actions considered “mostahab” are “right” actions which one may still not do, and actions considered “makruh” are relatively “wrong” actions which one may still do. The category of “mobah” actions is not such an inert one either; commonly it signifies that the judgment to do or not to do an action is left to the person because no moral obligations will follow. An example would be the obligation to tell the truth to a non-believer.

Also, under given circumstances, some actions that belong to one certain category may move to other categories. For instance, eating pork in Islam is generally well recognized as forbidden (“haram”) but in the case that the life of a Muslim depends on eating pork, for example when no other food is available and he may starve to death, it may be OK (“mobah”) or even obligatory (“wajeb”) to eat pork at an amount needed to sustain life.

At any given time, a Muslim may be under more than one obligation and sometimes these obligations may be in conflict. There may be instances when “wajeb” obligations are in conflict with each other. For example, a Muslim must obey parents and must obey the religious directions too; what if they are opposite to one another? That is why in difficult situations, a Muslim may ask for a “decree” to resolve such conflicts. A decree in Shi’a comes from a Shi’a clergy who has studied extensively the law of Shari’a (principles at the 2nd level) and knows how to rank the various obligations depending on the circumstances and specifics of the situation (issues of the 1st level). What a Muslim should do depends on the circumstances and the relative importance of various obligations on him. As depicted here, actions are judged ethical/unethical based on the circumstances surrounding them. Most of the moral obligations are not absolute, as opposed to the Kantian ethics, and exceptions are allowed depending on the circumstances.

The following verses in Quran support this view:
Quran 9:3: “Allah and His Messenger dissolve obligations.”
Quran 66:2: “Allah has already sanctioned for you the dissolution of your vows.”

Meanwhile, it cannot be said that Islam follows a utilitarian view in bioethics. In Quran, it says: Quran 5:32, “...We ordained for the Children of Israel that if any one slew a person - unless it be for murder or for spreading mischief in the land - it would be as if he slew the whole people. And if anyone saved a life, it would be as if he saved the life of the whole people....”

The other significant issue at the 3rd level is the controversy over universal human dignity vs. a higher ethical status for Muslims over non-Muslims. Quran regards monotheist religions highly and refers to their texts with a lot of respect. These include Christianity, Judaism and probably Zoroastrianism. Quran defines Islam as “surrendering oneself to God” and in this way does not differentiate between the religion that Muhammad brought and those monotheist religions before him. The following verse refers to this fact, and also that other (polytheist) religions would never be accepted by the God; Quran 3:85: “If anyone desires a religion other than Islam, never will it be accepted of him and in the Hereafter he will be in the ranks of those who are losers.”

Unfortunately, some readers have interpreted this verse to mean that followers of any religion other than Islam will not be accepted by the God. In this case, obligations that a Muslim has towards another Muslim, such as not to lie to them, may not hold as strongly to non-Muslims especially those without a recognized religion. However, a lack of support for universal human dignity may still cause few problems in Iran. The reason is that in the Islamic Republic of Iran, everyone must be formally registered as belonging to one of the recognized religions: Shi’i Islam, Sunni Islam, Judaism, Christianity, and Zoroastrian which are the religions recognized by the current Iranian law. The only possible exception is the minority of Baha’i who is not recognized in law and its followers may be discriminated against if identified as such. Fortunately, there are very few situations in healthcare that such a distinction may happen.

It is difficult to make a general statement on the standpoint of Islam on universal human dignity and human rights. It may be helpful to note that a person’s “rights” may be translated into “duties” or “obligations” on others to treat that person in a certain way. Thus Muslims may not be obliged by the same duties towards non-Muslims, as they are towards fellow Muslims. An action that is forbidden (haram) towards a Muslim may be “not recommended” (makruh) or just OK (mobah) towards a non-Muslim, and an action that is obligatory (wajeb) towards a Muslim may be “recommended” (mustahab) or “OK” (mobah) towards a non-Muslim. Accordingly, human rights may be looked upon in the perspective of “duties” of an individual Muslim (or the Islamic state) towards other individuals, and not their “rights”, as in Western schools of ethics.

The 2nd level, biomedical principles and laws

The Islamic methodology for bioethical decision-making is based on an important principle of “facilitation” or “circumventing of hardship”, which is derived from a directive in Quran:
Quran 2:185: “God intends facilitation for you and does not want to put you in hardship.”

This verse forms the principle for “circumventing of hardship” and is further supported by hadith which says, “The best of your law is that which brings ease to the people”. This principle forms the basis for a fundamental rule which says: “hardship necessitates relief”.

Another important tradition and law in Islamic bioethics is that: “no harm” should be inflicted or reciprocated. A different way of saying this principle is that: “harm must be rejected”.

One may conclude that harm has no legitimacy in Islam; the prophet’s statement explicitly forbids and
removes harm from any consideration. Following this statement, many laws have been set up to provide protection from harm in all aspects of human interaction, especially where one person's action may cause harm to another (as opposed to self-harm).

However, harm is relative to the person who experiences it. What appears to be wrong prima facie and is regarded by one party as a harmful act may not be considered wrong or unjustified by another. Therefore it is the human experience and the “situation” that clarify the matter of harm. In any case, law requires us to follow a decision that leads to “the least amount of harm” and damage to one’s total well-being.

In Islam, the statement of “no harm, no harassment” (la zarar wa la zarar fi islam) forms the main principle for non-maleficence in medical ethics; for social relations and transactions, the statement of “protection against distress and constriction” (al-usr wa al-harah) forms the underlying principle.

Many Islamic ethicists raise the point that Islamic principles in bioethics do not follow the priority ranking that is observed for the principles of Western bioethics, namely respect for autonomy, non-maleficence, beneficence, and justice. For instance, as opposed to the dominant principle of autonomy in Western bioethics, there is a principle of consultation (shoura) in Islam which is the dominant feature of Islamic communication ethics. Also, to balance the likely benefits and harms to society vs. the individual, the principle of proportionality (tanasub) between individual and social interests of the community may be applied.

In Islam, preventing harm has “priority” over promoting good; this kind of ranking principles principle may be used in the analysis of harm vs. benefit when for example, a medical procedure prolongs the life of a terminally ill patient without advancing a long-term cure. It also allows for choosing among the treatment options when the associated benefits incur different costs and risks to patients “and” their families.

A general principle underlying a lot of bioethical decision-making in Islam is the principle of “public good” (maslahat). The usage of the term maslahat (public good) can refer to actions that are approved by community members as “reasonable” because of either promoting good or protecting against harm; it also can refer to actions that usually agree with what reasonable people do.

There are three broad categories of issues that may fall under the general classification of “public good” in Islam:

1- Primary or essential needs (al-zaruriat): Religion, life, reason, lineage and property form the essentials that need to be protected as essential public goods.

2- General needs (al-hajiyat): These include religious duties (ibadat), everyday life situations (adat), interpersonal relationships (muamalat), and the penal code (jinayat). For example, a sick person or a traveler is exempt from certain obligations while sick or in travel (life situations); also transactions which are beneficial to advancement of one’s life are thus allowed (interpersonal relationships).

3- Secondary needs (al-tahsinat): These include supererogatory or “noble virtues” which may be regarded as praiseworthy but do not belong to the primary and general group of needs. Saving human life by organ donation would be categorized under this group.

The role of reason and wisdom in ethical decision-making is also very important, especially in Shi’i; an agent may use one’s reason and wisdom to apply moral judgments to the particular situations that come along. Right and wrong are “objective” qualities that can be discerned through reason and wisdom, and therefore an agent is enabled to “reject probable harm” (daf’ al-zarar al-mohtamal). The acceptance of moral “reasoning” in Islam is based on the existence of innate dispositions (fitra) in humankind which are endowed by the creator; humans can thus evaluate and judge the moral aspects of their actions.

To provide solutions to new problems that may emerge in society on an everyday basis, “analogical reasoning” (qiyas), sound opinion (ra’y), efforts to promote the good of the people (istislah), the selection of the “most beneficial” of several rulings (istithsan), conventions and customs of the region (urf), and other forms of reasoning may be used.

One of the classical juridical traditions in Islam is instituting good (amr bi al-muraf) and preventing evil (nahy an al-munkar); this tradition requires Muslims to inquire about the reasons behind ethical decisions that are made for the institution of the “public good” and prevention of public corruption (mafsada).

Now we can turn to the end of life care in the Islamic Republic of Iran and examine how these principles and laws are applied to the various situations that are commonly seen in medical ethics.

The 1st level; end-of-life care in the Islamic Republic of Iran

End-of-life care issues are some of the more difficult challenges in medical ethics. Ethical decision-making in cases of euthanasia, physician-assisted suicide, do not resuscitate (DNR) orders, withholding or withdrawing futile treatments, advance directives in healthcare, and consent are some of the common topics under debate in this area.

We can summarize the Islamic ruling over the main issues in end-of-life care as follows:

1- Life is sacred, & death can only be decided by God; therefore deliberate euthanasia is prohibited.

2- Suffering pain may be a form of a spiritual test or trial; therefore freedom of pain is not an acceptable excuse for ending one’s life, and active euthanasia is prohibited.

3- However, undue suffering is not acceptable in Islam either; therefore if treatment to relieve pain & suffering does not intend death but death is somehow hastened in the process, it is still acceptable to attempt to relieve pain; palliative care is legitimate.

4- Man is not the owner but only a steward of his body; therefore to reject treatment by a patient may be sinful. Thus a patient has an obligation to seek treatment, and should not refuse or reject treatment that is recommended by the physician. Therefore, the autonomy of a patient to reject treatment is limited.

5- However, death is a divine plan and a transition to afterlife; therefore futile treatments to delay death are
not acceptable especially when they may financially constrain the family of the patient or the community.

Generally in Islam, death is considered as a departure from one state of existence to the next. Death is a part of the divine plan and as such should be accepted with peace of mind. Islam teaches that a human's life on earth is only a test and a good Muslim should endeavor to reap the benefits of following the God's teachings during his/her temporary life on Earth for an eternal life in heaven. A Muslim does not resist death or fight to avoid it against the will of God, but rather accepts it as part of the divine plan. Muslims are encouraged to reflect on death frequently and expect it at any moment. Not even the prophet would attempt to avoid death if it came.

The Quran says: Quran 3:185: "No soul can die except by God's permission."

Quran 32:11: "The angel of death, who has been put in charge of you, shall cause you to die, then to your Lord you will be returned."

Quran 67:1-2: "Blessed be the God who has the dominion in his hands and has power over all things. He who created death and life, he may test which of you are best in deed, and He is exalted in might, oft-forgiving."

Life and death are in the hands of the God, and not for humans to decide. Deliberate euthanasia is therefore prohibited in Islam. However, undue suffering is not acceptable in Islam either and if in the process of providing adequate analgesia death is hastened, it still may be permitted to provide relief. What is important is that the primary intent should not be to hasten death, but to relieve the pain and suffering.

In Islam, life is sacred because God is its origin and its destiny. The sanctity of human life and the belief in that death does not happen except by God's permission, have been stated in Quran:

Quran 3:145: "it is not given to any soul to die, but with the permission of God at an appointed time".

Quran 6:151: "Do not take life which God has made sacred except in the course of Justice".

Quran 5:32: "...whoever slays a soul, unless it be for manslaughter or for mischief in the land, it is as though he slew mankind..."

The saving of a life is also considered as having high merits in Islam. Therefore, healthcare providers must make any reasonable effort they can to prevent premature death.

Muslim jurists from different schools have ruled that once invasive treatment has been started to save the life of a patient, life-saving equipment cannot be turned off unless the physicians are certain about the inevitability of death. However, the Islamic belief is that death is an inseparable part of human existence, and thus, treatment does not have to be provided if it merely prolongs the final stages of a terminal illness but cannot treat the life-threatening condition.

Although the primary obligation of a Muslim doctor is to provide care and alleviate pain, it must be remembered that pain can be a form of test or trial, to verify a believer's spiritual state: Quran 2:153–57: “O all you who believe, seek assistance through patience and prayer; surely God is with the patient ... Surely we will try you with something of fear and hunger, and diminution of goods and lives and fruits; yet give good tidings to the patient who, when a misfortune befalls them, say, 'Surely we belong to God, and to him we return'; upon those rest blessings and mercy from their Lord, and those; they are the truly guided”.

Quran 21:35: "Every soul shall have a taste of death: and we test you by evil and by good by way of trial, to us you must return".

Therefore, pain may be an instrument in revealing God's purpose for mankind and in reminding the patient that ultimately all belong to God and return to him for a new stage.

However, many Muslim scholars agree that patients in pain from terminal illnesses may receive analgesic medicine until the time of death, which is in line with the principle of facilitation of hardship. Although no one is allowed to deliberately end a patient's life, using analgesic treatments may be permitted for a dying patient, even if death is hastened; this is based on the principle that says: “actions are judged by their intentions”.

It must be noted that autonomy is of less significance in Islam as compared with Western ethics; life is a gift of God and whenever there is effective treatment, it should not be rejected by a patient. Treatment cannot be denied from a patient even by the patient's own request. However, a patient cannot be compelled with force to receive a painful life-saving treatment (such as chemotherapy); it is for the patient to understand that his refusal may be a big sin and that his afterlife well-being could suffer from such decision. As such, respect to autonomy or avoidance of pain may not justify refusing treatment.

Some Islamic teachings consider pain and discomfort to be the expression of God's presence; and as such, freedom of pain is not an acceptable excuse for ending one's life. It is possible that suffering of a patient is a divine plan for his spiritual purification. However, if there is no medical justification to continue (futile) treatments and this may only prolong the dying process, Islam allows the use of palliative care, as opposed to curative treatments. But it is better to avoid palliative care which shortens the patient's life.

According to Islam, the length of one's lifetime is determined by a divine decision. Therefore Islam does not recognize a patient's right to die voluntarily. Life is a divine trust and should not be terminated by any form of euthanasia. No patient has the right to receive assistance to die; life is a divine trust and does not fully belong to the patient. Humans are responsible for the right stewardship over their bodies, which are considered a gift from God. Muslims have duties toward the God and fellow humans that should not be neglected. Autonomy over one's body is recognized in Islam but has secondary importance to the afore-mentioned responsibilities. Therefore, human life is not to be terminated by any form of active or assisted euthanasia.

Suicide is commonly held as abominable in Islam and strictly prohibited. Unbearable pain because of illness is not a justified excuse either. Quran 4:29: “...and do not kill yourselves; surely God is Merciful to you”.

According to Islamic teaching, Muslims should be ready for the moment of death when the time comes; in Islam therefore it is not acceptable to resort to futile
treatments in order to put off death. In cases where there is a reason to withhold or to continue the treatment, availability or limitation of resources may be important in decision making; Islam emphasizes on helping each other whenever it is possible. Age, gender, social position, etc should not be used as the basis for selection of the patients to be saved, but the priority is for medical need and the probable outcome of intervention. Justice may need to be taken into account too. Among unconscious patients, the decision should be based on the expected results of treatment and with due consideration of the best interests for the patient.

When the patient is a child, Muslim parents have the responsibility to consider these issues to the best of the child's interests after consulting with the physicians. Children in Islam are valued as individuals with inherent rights; they should be treated with respect. When the question of withdrawal of life support is raised for children, most parents in Iran find it unacceptable; they do not want to be seen as playing a role in their child's death. However, in a situation that the child is not on life support and a DNR (do not resuscitate) decision is being made, most parents do not object to the decision.

Islam values the spiritual health, and moral considerations of the persons involved in decision-making, besides the physical health and comfort of the patient. Some Muslim jurists believe that in all cases it is possible to reach a collective decision not to prolong the life of a dying patient after consultation with the involved physicians and family members.

The principle that says: "No harm shall be inflicted or reciprocated in Islam" (la zarar va la zarar li Islam) is the basis for making distinctions and ruling over life support treatments in dying patients. An important distinction is over killing a patient through active euthanasia versus letting him die. For example; withholding or withdrawing treatment in a brain-dead patient would not be considered unethical. Islam allows a dying patient (or his guardian) to refuse treatments that may not improve their condition or quality of life. Also, Islam may allow a patient to refuse treatments that may delay death, after consultation with the doctor and their family. Most Muslim jurists believe that once invasive life support has been started to save the life of a patient, life-saving equipment cannot be turned off unless the physicians later become certain that death is inevitable. Such cases are permitted when (financial) resources are limited and delaying the inevitable death of a patient through life-support is not in the best interest of the patient or the public. Therefore they can allow death to follow its natural course.

In recent years, living will has been used for such cases in the Islamic Republic of Iran. Legally speaking, in Iran a decision to end the life of terminally ill patients at their request is beyond a doctor's obligations, and there may be no legal immunity for physicians who unilaterally and actively assist a patient to die.

Sanctity of life is a fundamental principle in Islam. Every moment of life has value and must be preserved. Taking a person's life may only be justified in rare circumstances, such as for murder. Although the Islamic belief is that all healing ultimately comes from God, Muslims have a duty to seek out medical attention when ill and they must receive appropriate medical care. The physician also has an obligation to attempt to heal the patient. However, according to Islam death is an inseparable part of being human. Therefore, treatments that only prolong the final stages of a terminal illness are not obligatory.

When a Muslim is near death, those around him/her are supposed to give comfort, and remind the dying of God's mercy and forgiveness. They may recite verses from the Quran, give physical comfort, and encourage the dying person to recite from Quran and to do prayers. It is also recommended, when possible, for a Muslim's last words to be the declaration of faith: "I bear witness that there is no god but the God (Allah)."

Generally in Islam, especially among Sunni Muslims, those with a dying patient are encouraged to remain calm, pray for him, and to begin preparations for burial soon after his death. One should strive to be patient, and remember that it is God who gives life and takes it away, at the time that only the God determines. It is not for humans to question the God's wisdom in death and it is forbidden to mourn excessively. It is said that when the Prophet Mohammad's own son died, he said: "The eyes shed tears and the heart is grieved, but we will not say anything except which pleases our Lord."

However, such an emphasis on refraining from excessive mourning is not observed among most Shi'a including those in Iran; grief is normal when one has lost a loved one, and it is natural and permitted to cry loudly. Shi'a Muslims in Iran commonly cry in a loud voice and hold many mourning ceremonies on the 3rd, 7th and 40th day after someone's death. After that, there are anniversaries where the relatives and friends may gather to remember, recite and cry over the dead person. Iranians are very well familiar with death. Many of the elderly live at home with other family members and die at home. Almost all family members are involved in burial rites and the expression of death in these rites is often dramatic.

Muslims usually wish to die at home when possible. Death in a clinical setting at a hospital is not a favorable Islamic tradition. The dying person may expect to be visited by friends and relatives. This is a time when Muslims seek each others' forgiveness for mistakes that may have committed. The use of a hospice would therefore be an advantage for a patient whose death is judged as inevitable by the physicians. However, the use of hospice is still not an established way in the Iranian society. Many hospice services are provided at private rooms in a hospital or a nursing care facility, but they are not available at a nationwide scale and the majority may not have access to specialized services available in a hospice. The attitudes of the nursing staff towards dying patients may also need to change (Iranmanesh et. al. 2008-2011). Besides the need for a change in the attitude of the physicians and specially nurses and other supporting staff, two other major problems in protecting the dignity of the dying patients in Iran remain. One is the relative lack of progress in provision of professional services such as palliative care in a hospice setting, and the other is the financial difficulties of many patients and their families associated with the small depth and breadth of the insurance coverage and the relatively high costs of professional care for the average Iranian income.
Disclosure of end of life issues and truth-telling to patients and their families in Iran

In Iran, physicians’ paternalism towards their patients is common; they may make decisions without involving the patient in the process. Many physicians have not received proper training to understand the need for better communication with patients or learn the skills to do that. They often recommend what they believe is the best option for the patient, based on medical and moral factors as well as prior experience. This issue was examined in a study by a group of oncologists regarding disclosure of cancer information to patients in Iran (Ghavamzadeh, 1997). Most cancer patients in Iran are referred to oncologists by general practitioners, internal medicine specialists or surgeons. Many cancer patients feel anxiety or fear after being informed of the fact they have been referred to a cancer specialist; therefore sometimes the referring physician does not inform the patient or his/her family that they are being referred to an oncologist. In many cases, the patients have not been informed of the cancer diagnosis or its possibility.

A culturally relevant factor to this issue is the significance of the concept of “family” among Iranian patients. Relations in the family and the associated sentiments are strong and are usually dealt with great care. The difficulty faced by a family member affects other members of the family and the expression of feelings could become a very sensitive issue. The diagnosis of cancer strikes not only the patient but also the family as a whole. When a patient is informed directly or indirectly about the diagnosis of cancer, his or her psychological balance may become severely disturbed. Sometimes a severe reaction can endanger the medical situation and the treatment process; such a reaction may happen irrespective of the educational level or economic class of the patients (Ghavamzadeh, 1997).

Therefore, the common tradition among physicians in Iran has been to reduce information to cancer patients and patients with poor prognosis and to respond to their questions in a very general way. Although nowadays some patients press the doctors to get more and more-detailed information about the meaning of their diagnosis, the cause of their disease, and its prognosis, experienced oncologists often resist and do not provide information about cancer and poor prognosis except when they are legally required to. Generally physicians prefer not to tell the patient directly, even if they are compelled to provide the diagnosis to the legally responsible person. The diagnosis is generally disclosed to only one member of family. When the doctor decides to disclose the information and diagnosis to a patient, he usually considers the patient’s age, intelligence, and emotional stability, what the patient already knows of the disease, the structure of the patient’s family, and the social status of the patient and his family. A common practice is to tell the information to selected members of the family; a selected member may simply appear to be better able to understand the diagnosis and prognosis and yet remain stable and continue to cooperate with the physician in providing information to the patient’s relatives who are legally important for decision making and economic support. A patient’s son-in-law, daughter-in-law, or grandson may provide such liaison. Finding such a person is sometimes difficult; questionnaires filled out by the doctor’s secretary, a ward nursing staff, or admission personnel are in part designed to help find such a person. However, if the patient is a child, for legal reasons the diagnosis is disclosed to his or her parents.

A more recent study to assess Iranian patients’ preferences for disclosure of information and their participation in decision-making has given different results (Asghari, 2008). This study showed that Iranian patients were interested in receiving information about their condition and participating in clinical decision-making. No variable was found to be predictive of such attitude and therefore the authors recommend that the physician should explicitly ask the patients about it. In this study the desire to receive information was somewhat greater in women than men and was also correlated with their education and their estimation of the severity of their own disease.

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Policy Analysis of Measures Taken against the H1N1 Influenza Virus of 2009

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1. Introduction
To prevent influenza infections using cutting-edge science, technology, and other knowledge, international efforts have been made and various domestic systems have been established in countries around the world. However, instead of a decrease being seen, virus transmission has accelerated on a global scale, in large part due to an increase in the number of itinerant people.

In order to utilize knowledge gained from medical and pharmaceutical studies to defend society and benefit human beings, various technologies involved in development of new medicines, advances in treatment techniques and studies into infection prevention systems have been integrated as elemental technologies in one integrated system. To apply such technologies in the real world, effective policies need to be developed. However, their implementation is determined in the political process, which is formed by opinions of experts and the heavy influence of mass media, influences politics in its turn, creating an intertwined relationship, as seen in the processes of policy-making, policy implementation, and policy evaluation.

How can society respond to threats from unknown infectious diseases such as the new, more virulent types of influenza or SARS, or to other situations beyond anticipation? Is it possible to make better policy judgments by utilizing expert knowledge and a wisdom that prevents public opinion and sentiments from running wild? Like other natural disasters, epidemics require serious attention and preparation. However, as Torahiko Terada has said, “it is easy not to be frightened enough or to be too frightened, but it is difficult to be reasonably frightened”(Terada 1961). After all, when surrounded by media coverage that can easily be whipped into a frenzy but cooled down just as easily, and overwhelmed by various subjects both jocular and cruel, can citizens learn to act in a socially appropriate manner? I would like to reflect upon the chaos caused by the H1N1 influenza from the perspective of the social sciences and consider the relationship between scientific technology and society. From a social sciences perspective as well, how to develop policies for preventing infectious diseases such as the new influenza that have great risk of causing tremendous damage is an extremely intriguing topic.

2. What happened in 2009
The new influenza virus was detected in Mexico in 2009 and rapidly spread first to the United States and Canada and then across 214 counties in just nine weeks; as a result, the United Nations World Health Organization (WHO) declared an influenza pandemic on June 11 of that year (Kawaoka, Horimoto 2009, Sena 2009, Sotooka 2009). Although there have been many cases in which virulent influenza caused serious social crises, such as the Spanish flu pandemic of 1918, the crisis of 2009 was the first time that modern Japan has needed to implement defense measures against infection on a full scale (Crosby 2004, Hayami 2006).

Specialists in Japan had previously fusséd about the danger of the unknown avian flu (N5N1), which was highly lethal and potentially mutagenic. As a part of the measures against it, action plans were being prepared at both the national and municipality levels. This was the point at which the new influenza was detected. The government announced to the public that the flu was considered to be highly lethal and they would stop it at the borders of the country. They also said that a priority approach would be taken for vaccination as vaccine production would not meet the demand. They encouraged people to stay home, wash their hands, gargle frequently, and stock up on water and food. TV and newspapers provided space for various specialists and authorities, reporting the status of the flu daily in a provocative and sensationalistic manner. As people started paying more attention to sanitation, they bought...
up sanitary masks and other supplies, the shortages of which resulted in increased public anxiety.

Fear was also amplified by footage of quarantine officers in white protective gear getting on planes that had just arrived at the airport from overseas and making thorough investigations and scenes, in which people suspected of febrile symptoms were placed in strict quarantine. When high school students in the Kansai region cities of Kobe and Osaka were found to be infected with the ‘new-type flu’, the Minister of Health, Labour and Welfare made an emergency statement to the public on TV telling people to act calmly; however, his statement had the opposite effect, increasing the sense of crisis surrounding domestic infections. Where infections were found, patients, schools and entire regions were immediately attacked by accusations and hit hard by rumors. Family members of patients and principals of their schools made apologies in front of the camera. The media repeatedly reported such scenes, turning them into a kind of kangaroo court the likes of which are frequently seen in Japan following various incidents.

In retrospect, we can see that the outbreak was not of a highly pathogenic influenza as initially suspected and its infectiousness was no different from the infectiousness of ordinary seasonal flu. The epidemic ceased, and many vaccines hastily developed and manufactured or imported were left unused. Of course, some efforts paid off. Patients who were not accepted at high fever—outpatient clinics were sent to general hospitals, where all kinds of efforts were made to keep infections under control while giving medical treatment and focusing on preventive measures. Some schools were temporarily closed if necessary, and people were exceptionally conscious of sanitation. All of these efforts contributed to minimizing the damage from the flu. Japan’s fatality rate among people contracting it was 0.2%, which was extremely low compared to Mexico (2.9%) and of the United States (3.3%) (Figure 1). Although this new-type influenza shook the world, its global death toll from it was 18,097, which is less than is common for this type of epidemic. In Japan, the damage was even less than damage from the usual seasonal influenzas in terms of excess mortality (Japan Medical Association 2010).

During this process, our experiences gave rise to many issues to be considered from the perspective of the social science—measures to be taken in addition to what we can do medically and pharmaceutically against new-type influenza. Let us now take a look at those issues in order.

3. Seriousness of the issue and difficulty of prediction

In recent years, the highly pathogenic avian flu has been raging, mainly in Southeast Asia. Scientists suspect that the flu, which is currently only infectious among birds, may in the near future mutate and become a highly lethal avian flu that is also infectious among human beings. The WHO and the governments of many nations have developed various strategies against this possibility. After the WHO updated its definitions of pandemic phases and alert levels in 2005, Japan came up with the Action Plan for Measures Against New Influenza in the same year. Based on this, the local governments established their own action plans.

A certain pattern detected in the epidemics of the past influenzas and the spread of the avian flu to poultry farms within the country had raised concern about the possibility of human-to-human spread of the avian flu. It was in this atmosphere that the new influenza exploded in Mexico and spread throughout the United States, leaving an impression that the flu might be an extremely ferocious, highly pathogenic avian flu. The flu was suspected of being highly virulent due to its fast rate of infection and high mortality rate. Although gene analysis revealed that it was not avian flu (H5N1), but swine flu (A/H1N1), the WHO declared an influenza pandemic, and Japan automatically implemented measures in accordance with the manual, which had been prepared and intended for the worst avian flu.

Let us look into this experience from the standpoint of policy analysis. There are usually three approaches in policy analysis case studies (Dune 2003). The first approach is to study cases from the “past” to see whether they were right and consider what the problems were. This is post hoc analysis, but it is often used in the field of social science as a research method to gain knowledge on what happened then or what should have been done. However, whether these cases in the past could be applied to the present and the future is another matter. Generally speaking, it an effective approach when evaluating the policies of the past in retrospect. Descriptive analysis or normative analysis is the main tool used in this approach.

The second approach is to study the “present.” In this approach, we explore what get good results in ongoing cases and deal with issues through experience. In areas such as clinical medicine, this is generally very important. However, from the social science perspective, since not enough data is provided, our perceptions would be intuitive and tentative only, requiring analysis from a normative viewpoint. The third approach is to put the emphasis on predicting what should be done in the “future.” The purpose here is to describe an efficient, effective policy scenario to make the future desirable; thus, it is an analysis that comes from a future-predicting perspective. This is essential when considering what policies to develop in the future, but it does not contribute to solving the issues of the present and only provides uncertain predictions for the future. However, this approach is the main one employed in the field of policy science where policy-making is scientifically studied.

At this point I would like to explore how the response to the flu pandemic was from the viewpoint of evaluating the past and also from the perspective of policy-making to gain knowledge that can be utilized to develop better policies in the future. Here, benefits, risks, and costs are the crucial factors to determine whether a policy is a good one or not.

First of all, the reason why it is difficult to establish measures against new types of influenza is because it is impossible to predict their virulence or spread in advance. We have no way of knowing what kind of flu may spread, as a result of mutation, how infectious it may be, and what the rate of fatality or spontaneous recovery
is. Information on public health has to be collected through various channels around the globe, and as soon as there is a suspected case of an unknown disease, an epidemiological study team is sent to test its pathogenicity. This information is shared among nations to prevent infections and to establish effective policies in each country. Such steps have already been undertaken by means of international cooperation. Here, hard science, in mainly the medical and pharmaceutical fields, is expected to play an important role in determining what kind of virus is afoot, containing it within the area already infected, immediately developing and manufacturing appropriate vaccines, and spreading effective treatment methods and prevention measures.

However, infectious disease specialists have different predictions and perceptions concerning what type of virus will be born next and how pathogenic it will be. It requires a certain amount of time and funding to develop and manufacture vaccines or to prepare preventive medicines on a national scale. Since the apprehension of scientists that an unknown and highly lethal influenza will emerge in the near future has been considered well founded, the perceptions of infectious disease specialists have been emphasized in the process of policy-making for the development of specific countermeasures.

In this respect, there is an interesting case of a policy adopted by the government of the United States that should be considered here (Neustadt & Fineberg 2009). In 1976, moved by the opinion of an infectious disease specialist who suspected that a new type of highly lethal swine flu may have erupted in the United States and by the CDC (Center for Disease Control) which had been highly influenced by the specialist, the government, which feared a pandemic like the Spanish flu, adopted a policy of unprecedented scale involving the vaccination of all citizens within the country. However, the government faced many political and logistic challenges in implementing this policy. For instance, it took eight months to manufacture the vaccines and the government found itself having to come up with a grandiose plan to vaccinate citizens for the first time. Further, because private insurers refused to compensate policyholders for possible side effects of the vaccines, the process was suspended; it resumed when the government promised compensation for people suffering debilitating side effects. Another political factor was the consideration on the part of Gerald Ford who had assumed the Presidency after Nixon’s resignation towards the 1976 Presidential Election. In the face of dissent from staff members who said that vaccinations were a bet with no chance to win either way and would bring no positive outcome in terms of the election campaign and opposition from America’s three major TV networks, President Ford made a firm decision for the people of America. As it turned out, only one person died from the flu, and a few more were seriously infected at a US army base; no broad contagion occurred within the country.

The policy had been initiated as an emergency project on an unprecedented scale. The system of mandatory vaccination came at a huge expense and shook the entire nation. However, even this came to a halt when the assumption of a crisis collapsed. But the matter did not end there. The plan was aborted after the vaccines prepared for 100 million people had been given to the first 40 million, but this resulted in a tragedy with the subsequent deaths of 32 people from a disease called Guillain–Barré syndrome, a possible side effect of the vaccination, and a few hundred more suffered from other aftereffects. The lesson learned from this experience was that we should not only listen to infectious disease specialists and respect their opinions, but also verify whether the risk has been properly evaluated and examine the logic, probability, and social compatibility of vaccination from the viewpoint of non-specialist third parties.

Ulrich Beck calls modern society a “risk society” (Beck 1998). We live in difficult times where we have no choice but to believe what scientists have to say about various dangers that we cannot detect with our five senses. Even the estimates of specialists are limited by the boundaries of our knowledge of the moment. The degree of risk of infectious disease, nuclear disaster, earthquakes, and various other calamities is indicated by hard-to-understand scientific figures and probability rates that have not heard of and we cannot even understand. In today’s society, scientists in the front line predict what the risk will be using statistics and a probabilistic approach. When incorporating scientific knowledge into the policy-making process, it is difficult to find a metric upon which to base political and social judgments. In other words, policy-makers need to consider how they can secure the validity boundaries both of experts and the public, on the premise that scientific rationality is different from social rationality (Fujigaki 2003). The issue is the difficulty applying scientific knowledge, which cannot provide flawless predictions, to the real world, and how we fallible humans must decide on what course to take despite our lack of predictive capability. Such principles as disclosure of information, transparency of discussion, clarification of decision-making processes, stakeholder participation and their representativeness, and preservation of a wide variety of choices are what secure social rationality. It is particularly hard for scientists to convey information in a way that allows the layperson to understand what has and has not been scientifically elucidated. If this line is blurred, then people will never be able to avoid the kinds of failure repeatedly experienced in the past as seen in the reaction to the BSE (bovine spongiform encephalopathy) crisis or in the risk assessment for the Fukushima nuclear accident both of which involved scientists (Kobayashi 2007). In these cases, discussions among scientists were focused only on ascertaining the empirical correctness of their understanding of the issues, thus skewing judgments in the actual world where politics, economics, and social attitudes also need to be considered.

3. Difficulty of policy selection

When people cannot sense any risks on their own accord and need to rely on complicated and advanced scientific predictions, where do the politicians and administrative officers who play the role of converting those predictions into specific policies come in?

First of all, politicians need to gauge the anxiety of the public and discuss what measures need to be taken in its context. When a highly lethal and contagious disease is
detected and there is a risk of affecting an entire nation, how do they deal with it? The degree of risk is likely to be highly uncertain. The disease may cause serious damage or it may not. Decision-makers surely listen to what scientists have to say, but they cannot fully understand or realistically grasp the probability breakdown of the possibilities presented. If they are to prescribe some sort of measures, huge costs and efforts come into play. Even if they accept these costs, implementation may not be possible quickly enough or may be flawed or futile. On the other hand, if they decide to do nothing and the risk becomes reality, politicians have no means of avoiding blame from the public. The ultimate decision-maker is the government; but politicians, who fear a backlash against controversial policy, may try to avoid doing anything. Of course, the cost of missing the opportunity to act is huge too. When considering the possibility of causing critical damage to the populace, policy-makers may well choose to go for a more tolerable failure as the lesser evil to doing nothing. This was the choice the Ford administration in the United States made in the case mentioned above.

However, even infectious disease specialists may have different outlooks and come to different predictions. Will the opinion of a less-informed scientist who happens to have a strong political network or be good at expressing what he or she thinks be adopted? And when the media becomes interested in the issue, scientific disagreement that is presented wrong may end up amplifying the anxiety of the public. Currently, for instance, in the aftermath of the Fukushima disaster, the range of opinions that exist among specialists concerning the risk of radioactive contamination is fostering a sense of popular distrust toward science, scientists, and needed measures. A similar situation could develop in the context of various more-or-less invisible risks.

Escalating media attention will stir up the anxiety of the public. That is the nature of the news. Officials are restricted by slippery public opinion, as citizens cry “what are the politicians doing?” Politicians obsessed with the need for “political leadership” will have no choice but to project an image of being the leaders of the discussion, even though they are not experts on the subject, and as a result they may be pushed and forced to make decisions that are uninformed or ill-advised, seeking an expedient answer.

The administration will then accept such political decision and implement specific measures. The best way to proceed in the case of a potential pandemic is on the basis of standard procedures laid down in manual form in advance. However, in the case of the new flu, the only thing prepared in advance was a crisis-management manual intended for a highly virulent avian influenza. Even after the virus turned out to be a low-virulence swine flu, national and local government, medical institutions, NGOs, and businesses were forced to follow through with top-level measures intended for a worst-case scenario since no appropriate measures had been prepared. From the perspective of specialists in the domain, it seems like the right approach to prepare for the worst. For instance, the action plan prepared by Kumamoto Prefecture stipulates that “at the beginning, we take powerful measures because the pathogenicity and infectiousness are unknown, but as soon as they are clarified, we switch to appropriate measures based on what the government will do” (Kumamoto Prefectural Government 2010). In reality, however, to use discretion and adjust the response flexibly while carefully watching how things develop is already at this point an impossible task for the administration alone.

At medical institutions, immigration and quarantine control facilities, and schools, people were in extreme confusion as they found that the top-level measures described in the manual were impossible to follow through in the first place. Even after it was revealed that the flu was not a truly horrible strain, but was only as serious as an ordinary seasonal flu, people onsite were not able to think or act flexibly. Thus, the whole system gradually faltered and failed. Just how effective, for instance, was the “border strategy” to strengthen quarantine control implemented from April 30 through June 18? This experience raised fundamental doubts about whether this border strategy would really be effective with virulently infectious diseases (Kimura 2009). An organization called the Fever Advice Center, established to secure well-ordered treatment systems, found that it had no choice but to accept any patients with fever, and was quickly overwhelmed. At first, when patients were identified they were immediately hospitalized. But this approach had to be stopped because the number of the beds was inadequate to support it.

It is also necessary to investigate whether the priority sequence of vaccinations was really appropriate after all. Excluding healthcare professionals, vaccinations were given in order to pregnant woman, people with pre-existing diseases, children from age one to school age, , children in the early elementary grades, guardians of children under a year old and guardians of those who could not be vaccinated among priority cases. In addition, , children in the later elementary grades, middle school students, high school students, and elderly people (aged 65 and over) were vaccinated in order of priority. This sequence seems to give priority to the socially vulnerable. On the other hand, the infection in fact spread mainly among young people who were in contact with a group of people outside the home on a day-to-day basis, such as schoolchildren and university students, who are the main vehicle of transmission. Studies show that it would be more effective to vaccinate these young people before the elderly, who do not often go out in groups, if the goal is to stop the spread of infection to the entire society. This would suggest that it would have been more effective to give priority to vaccinating students in elementary schools, middle schools, high schools and colleges as they are the primary source for the spread of infection. The question of how a limited number of vaccines should be used generates a conflict between scientific validity and political considerations.

A desk plan was prepared that specified preventive measures and treatments of the H1N1 influenza, but in retrospect, there were many inadequacies in the plan’s adaptability to real life. Community medical institutions mobilized all staff to treat patients, but the greatest problem was that people on the line had limited freedom to deal flexibly with reality. While society needs to be
protected a state level, communities also need to have a certain freedom, so that flexible, specific measures can be taken effectively in each scene. These needs must be properly balanced in all relevant policies.

It is essential for the government to secure trust by showing that it understands public anxiety and is addressing issues properly. On the other hand, while no one has the “best answer” to the question of how people should respond to risk, the government still has to make decisions that reflect a stance of the complex question of how expertise and expert opinions should be applied to the conditions of real life. It is important to verify or foster broad public acceptance and support for scientific findings with public health implications. The government also needs to take on the difficult task of finding the best solution for the entire society while reconciling a wide variety of interests such as citizens and businesses the balance between which it is responsible for. The final decision is to be made by the government, but they are required to seek social rationality in the process leading up to the decision. Upon doing so, it is vital to balance the “discourse of truth” and the “discourse of consensus” from the perspective of risk communication. But at the same time, it is also important to secure a channel for a continuous dialogue on other options to anticipate and eliminate any unexpected problems (Yamori, Yoshikawa & Amisiro 2005). In 2009, the prompt response of the Japanese government deserves credit, but leadership was lacking to modify approaches as needed while paying careful attention to developments and they lacked the capacity to effectively implement measures. On May 9, the minister made a sensational appearance on TV and excitedly announced that the country’s first case of the new flu had been detected. This attitude was seen as strange in a government official. The minister should have demonstrated that he understood the scientific prognosis for the spread of this disease and intended to handle matters calmly and rationally.

4. Media response and public response

In this case, the media was able to inform the public of the flu crisis in a helpful manner, educating people in a timely fashion with information on sanitation such as hand washing methods, coughing etiquette, and the need to stay away from crowds to prevent infection as much as possible. This had an immense effect that could hardly have been achieved by government and health organizations.

However, there was a big downside to this media involvement. As media coverage became extensive, specialists and “self-proclaimed” authorities emerged and spread various unsubstantiated theories. This gradually changed the quality of the information that the media passed on. Not only official broadcasts and science programs but also variety shows and other entertainment shows began to cover the flu, exaggerating the scale of the problem and inducing anxiety. Media coverage was becoming a media circus, making the flu look like an existential threat (Figure 2). The people as well as politicians were influenced by this media coverage, which in turn spurred the media response, resulting in a vicious circle. Patients were vilified, as were people responsible for schools and other locations where the virus could spread. Despite the fact that anyone could get infected, some people directly contacted those infected or their schools to blame them, while others contacted the administrative bodies to find out which school infected people went to or what company they worked for, as if they were hunting down a criminal.

Figure 1: 2009 H1N1 influenza - Number of people infected and case fatality rate by country

The larger the space, the higher the number of people infected. The darker the color, the higher the case fatality rate.

Although the media did try to pass on accurate information about preventive measures and treatment, the value of this activity was overwhelmed by the impact of continuous reporting of how many were newly infected, where they had been infected, and how people were running around hastily buying up everything on shelves siege. It was shown that the Japanese media are not capable of responsibly handling the reporting of scientific information. It may that they are enslaved by bad habits of commercialism that made them think that they could not draw attention if the content was not entertaining, or they could not differentiate themselves from others and as a result lose viewers if their content was not sensationalistic. Although Japanese mass media are private companies, there is a basic requirement that they exhibit a high degree of public and social consciousness and to provide moderate reporting that is scientifically based. Further, because the national government did not provide a scientific explanation, the media focused on reporting factual information such as how many were
infected and where the hotspots were and was unable to provide the public with information from a broad perspective. As a result, they kept sending out the misguided message that the flu was a high-risk infectious disease, which is another result that needs to be reflected upon.

In the cities and towns, people were seen here and there running around to get food, water, medicines, masks, and disinfectant, with masks always on. Because distribution of goods was interrupted and people were expected to stay home for a certain period of time to recuperate or for other reasons, they bought up everything on the shelves. This may have been a cautious and reasonable preparatory action in the beginning, but quickly this purchasing behavior took on its own life, and quickly nothing was left on the shelves; people were misled into thinking that supplies were running out, which pushed them to buy more things, resulting in a chain of frantic behaviors, almost a panic situation. (This was, however, a good opportunity to learn that we should lay in a certain amount of supplies in everyday life to be well prepared not only for natural disasters but also for infectious diseases.) It is presumed that the temporary shutdown of schools and some other buildings to prevent group infection contributed significantly to putting an end to the outbreak and minimizing its impact. In Kumamoto Prefecture, for example, 27 preschools, 57 elementary schools, 18 middle schools, and seven high schools were temporarily shut down. The total number of classes that were suspended amounts to 4,365. The shutdown imposed an enormous burden on working parents with children attending preschool or elementary school, who had to make alternative arrangements for their children. Many companies placed employees with fevers or diagnosed with the flu on leave. There were even cases in which businesses, electric power companies, and stores should be passed on to medical and educational institutions. The Higher Education Consortium Kumamoto hosted a symposium on the H1N1 influenza, which was proposed by the president of one of the medical universities in the prefecture. It was a great opportunity for faculty members at all the universities to obtain accurate scientific knowledge on the flu, and was very effective because they had a chance to meet and consult with frontline medical researchers. In 2009, the flu epidemic ceased without incurring the risks about which we had been deeply concerned. However, we should not be overconfident that epidemics in the future will also be minor. It is essential for us to acquire accurate knowledge and neither develop an exaggerated sense of crisis nor be too optimistic.

(2) Knowledge to defend ourselves as a society and popularization of social technologies

In modern society, we live in an environment where it is difficult to avoid infection once infectious diseases become epidemic. Since anyone can acquire an infection, we need to be equipped with the right knowledge and know how to overcome viruses and minimize their spread.

Firstly, one major issue in Japan is our social aversion toward vaccination (Tezuka 2010). Of course, there have been lawsuits over drug-induced suffering which were highly publicized as a major social issue. However, vaccination is a very effective method to minimize the spread of diseases in society. Measles, influenza, and many other diseases would not affect us if we acquired immunity. However, when people refuse to be vaccinated, then these diseases continue to spread and may become highly lethal. Of course, the possibility of some people falling ill or dying due to the side effects of vaccines cannot be eliminated, but vaccines are designed to save the lives of a great many in society and to deny vaccination would not be rational or socially appropriate behavior.

Once a person is infected, medical and pharmaceutical approaches such as anti-influenza drugs can be useful. However at the prevention stage, non-pharmaceutical preventive measures can be taken on an individual basis. Everyone needs to follow cough etiquette, wearing a mask or covering the mouth with the...
hands or arms to prevent the scattering of pathogens when coughing. Some people sneeze without covering their mouth on the train or in other places, but this should be considered an offensive behavior, the product of willful negligence of the risk of droplet infections and contact infections to those around an infected person. Wearing a mask is not as effective in terms of protecting the wearer from infection, but it is very effective in terms of not transmitting the virus to others. The way people cough needs to be more than a matter of etiquette; it should become one of the rules of our society, to be followed by everyone. Also, individual efforts such as staying away from crowds or washing hands thoroughly during epidemics can be very effective in preventing infections. Continuing to work or go to school when feverish is not something we should do during epidemics of infectious diseases. Staying in and recuperating at home will better contribute to protecting society.

(3) Enhancing the capacity for scientific media coverage

Infectious disease specialists and scholars in health organizations and universities are required to provide accurate, easy-to-understand information so that mass media can cooperate in offering scientific coverage to the public. I expect the media to be able to fulfill its mission in creating an atmosphere in society that helps people to calmly cope with infectious diseases without stirring up panic or causing injury to those infected.

The H1N1 virus is just one of the many new kinds of viruses and risks we need to continuously grapple with. It should be the goal of public policy to help society accumulate the knowledge and experience to cope with diseases and risks.

References


Bioethical issues and HIV stigma

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Introduction

This is a research report on the empirical study conducted among pregnant mothers to elicit their knowledge, opinion, attitude and to explore myths and misconceptions associated with HIV stigma and discrimination and the bioethical issues involved therewith. HIV stigma is explained as the prejudice, discounting, discrediting and discrimination directed at people perceived to have HIV or AIDS and at the individuals, groups and communities with which they are associated. AIDS is one of the most stigmatized disease in history. HIV-related stigma is multi-layered, deeply rooted, operating within the values of everyday life, stigma plays into, and reinforces, social inequalities. If we do not appreciate the nature and impact of stigma, none of our interventions can begin to be successful.

The Genesis of Public Health Ethics

Modern bioethics emerged in the 1960s and 1970s and began to have enormous impacts on the practice of medicine and research – fuelled, by broad socio-political changes that gave rise to the struggle of women, but little attention was given to the question of the ethics of public health. Recognising the role of moral values in decision-making was a signal contribution of bioethics in its formative period. Over the past decades a broad array of perspectives emerged under the rubric of bioethics but individualism remains central.

Knowledge on AIDS

- Only eight in ten women have heard of AIDS. (93.4 percent).
- Nine in ten urban women have heard of AIDS.
- Two out of three rural women have heard of AIDS.
- Less than 10 percent of women with no education have heard of AIDS (6.3 percent).
- Knowledge increases with education, women completed 10 or more years of schooling (69 percent).

Television is the source of information on AIDS, reported by 80 percent of women who have heard of AIDS.

Television is the common source in all subgroups including the rural and least educated populations.
The next reported sources after television are radio.

Stigma associated with AIDS and accepting Attitude towards HIV/AIDS

- Buying vegetables from a shopkeeper with HIV/AIDS (47% - pretest and 70% - posttest).
- 36% (in the post test (which was originally 10% in the pretest) of rural women say that they would not want to keep it a secret if a family member had HIV/AIDS after reading the print materials supplied to them.
- 72.67% of the respondents feel HIV/AIDS as a killer disease in the pre-test have changed their opinion in the post-test.
- On maintaining secrecy of family member’s HIV infection, 63.33 percent disagree with that point in the pre-test, in the post-test got clarity out of the print materials and this stigma is reduced to 46.77 percent in the post-test.

Ethical Issues in Public Health Communication

- Ethical issues in public health communication are explored as they relate to eight topics:
  - targeting and tailoring public health messages to particular population segments;
  - obtaining the equivalence of informed consent;
  - the use of persuasive communication tactics;
  - messages on responsibility and culpability;
  - messages that apply to harm reduction;
  - and three types of unintended adverse effects associated with public health communication activities that may label and stigmatise, expand social gaps, and promote health as a value.

It is suggested that an ethical analysis should be applied to each phase of the public health communication process in order to identify ethical dilemmas that may appear subtle, yet reflect important concerns regarding potential effects of public health communication interventions on individuals and society as a whole.

Consideration of issues concerning “Physician’s Prescriptions” in the Practice of Occupational Therapy in Japan

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Introduction

The purpose of this study is to discuss the role of the physiatrist’s prescription in the practice of occupational therapy. We surveyed occupational therapists about informed consent in the practice of occupational therapy in August 2009 (Yamano, 2011). We clarified that occupational therapists have rationales for administering therapy if clients do not consent to undergo occupational therapy. One of the reasons is “occupational therapy is practiced under the physician’s prescriptions”.

Due to the Japanese laws, practicing occupational therapy without a physician’s prescription is against law. We discuss if the physician prescribes, whether occupational therapists can practice occupational therapy for clients without consent.

Occupational Therapy Process in Japan

The laws that are the most important for Japanese occupational therapists are Physical Therapist and Occupational Therapist Law established in 1965. In Article 2-4 of the Physical therapists and Occupational Therapists Law, The term “Occupational Therapist” as used in this act means a person that is qualified license by minister of the Ministry of Health, Labour, and Welfare, use the style of “Occupational therapist”, practice in occupational therapy unless physician’s prescription.

On the other hand, Ministry ordinances concerning fees for health service care in Japan establish that it is performed with director guidance of the physician, and the occupational therapy calculates it about a thing performed under the physician or the monitor of the occupational therapist.

Occupational therapists in Japan need prescriptions to practice therapy with the law that we show after. We evaluate for clients. Then, we classify the state of functioning, and the real problem. Third, we make intervention planning. We set long and short term goals, and select and establish the way of therapy. Fourth, we practice occupational therapy. The most of clients are provided therapy from twenty minutes to an hour. Fifth, we re-evaluate for client routinely. We validate the effect of therapy by comparing previous and current results of evaluation data. If the client completes the goal, it may be the end of therapy based on assessment by physician. However, if not, we define the problem again (Figure 1).

0. Prescription by Physician
1. Evaluation:
   Interview, observation, collecting information, measurement for clients
2. Problem Definition: on International classification of functioning(ICF)
   To assess the results of evaluation and Define problem that are to be aimed through occupational therapy interventions
3. Intervention Planning:
   Goal setting, select and establish the way of therapy,
4. Intervention Implementation:
   Verification of the effects every therapy
5. Re-evaluation:
   Systematically re-collect initial evaluation data and Compare evaluation and re-evaluation data to determine if outcomes have been met and discontinuation is appropriate if not, determine subsequent action
6. completed

Figure 1: Process of Occupational Therapy

Early Studies about Prescribing Occupational Therapy

1. Standpoint of Physiatrist

Most of the early studies about prescribing occupational therapy in the standpoint of a physician are written by physiatrists. Lich mentioned that, “The prescription of occupational therapy is the selection of the activity or
activities best calculated to relieve the patient of his symptomatic pattern" (Licht, 1948 p.1032). Spencer suggested that it should use the term “Referral” rather than “Prescription” (Spencer, 1969). Martin mentioned that, “Therapists should be cognizant of the principle that an ethical, licensed therapist treats patients only with an adequate prescription or written instructions. The attitude the therapist is to take—which therapist should insist on productive work or merely invite or encourage the patient—should be indicated on the prescription” (Martin, 1971, p.511). Rask mentioned that, “The prescription should be as specific as possible. In addition to the information given in the standard prescription, it is desirable to indicate the reason for which the activity is prescribed and the anticipated result” (Rusk, 1977, p.323).

Before the 1970, based on the views that the physiatrist examined, it seemed that it was desirable to mention prescription as much as possible in detail.

On the other hand, in a Japanese paper, it seems that prescription about occupational therapy completes the relationship between physiatrists and therapists. Chino mentioned that, “Prescription of Occupational therapy is communication tool between physiatrist and therapist” (Chino 1976, p.4). Ogisima mentions that, “When occupational therapy is therapeutical, therapist must not practice without prescription. But, if therapist who has license and hardworking practice therapy, “referral” is an ideal than prescription” (Ogisima 1980, pp.3-9). Hattori mentioned that, “Occupational therapy is heterogeneous area for physiatrists” (Hattori, 1984a, p.762). “When physiatrists prescribe for patients occupational therapy comprehensively, occupational therapist will practice therapy who have special knowledge and technique. A relationship of trust of physiatrist and therapist is necessary” (Hattori, 1984b, p.80).

Ueda mentioned that “Physiatrist’s prescription is not absolute and perfect. But the attending physiatrist accepts ultimate responsibility for patients. Occupational therapists must obey physiatrist’s prescription if physiatrist prescribes contraindication or precaution statement concerning frequency or density of occupational therapy, for example. Though occupational therapists have rights and obligations to present if therapists prompt the question concerning physiatrist’s prescription, it should resolve among the members of rehabilitation medicine team as rapidly as possible” (Ueda 1992, pp.329-35).

However, Shinsya et al mentioned that, “Physiatrist should prescribe for patients on assessment strictly. The physiatrist having ability brings for patient good outcome certainly. The prescription that keeps on entrusting for therapists will lose the significance of existence of the physiatrist” (Shinsya et al 2010,p.726). Shinsya takes a stance against leaving it entirely up to occupational therapists.

2. Standpoint of Occupational Therapist

Mazer et al mentioned that, “The prescription has been and is still a symbol of a close working relationship with the physician, as well as important form of medical supervision” (Mazer et al, 1958). Kamakura delivered in the discussion meeting that occupational therapists may think to feel safe by complying physiatrist’s prescription because the Japanese law establish that physiatrists have ultimate responsibility for patients in medical (Kamakura, 1971, p.405).

Terayama mentioned that, “The prescription is order of therapy for patients with consensus between the physiatrist and the therapist. Physician should indicate risk factor for patient” (Terayama, 1976, p.7) , and “The prescription is communication tool between physician and therapist” (Terayama, 1990, p.283). Yatani mentioned that, “In Japan, therapist recognize the prescription from physician should be absolute. Physicians have grave responsibility to prescribe and to understand role of other members of profession” (Yatani, 1990, p.282).

The Issue of “Physiatrist’s Prescriptions” in the Practice of Occupational Therapy in Japan

Therapist belong to many types of organization. The physiatrist supervises the therapists in the position of general manager. Fundamentally, occupational therapists should evaluate, assess and make the plan as the profession. However, some of the physiatrists often fulfill a role, and prescribe to therapists. In that case, many of therapists consider they should practice therapy with complying prescription. So, occupational therapists who practice therapy for clients without consent consider the prescription is “absolute order”. Therefore, we consider that they have a motive to practice therapy for the client without consent (Figure 2).

We consider that the occupational therapists have motive to comply strictly with prescription. In those cases, we are doubtful that the therapists originally respect the patient’s autonomy through the informed consent. We cannot feel to therapists whose professionalism and the standpoint of caregiver is for the client. We lose a viewpoint as the employment having the national qualification and consider that we must not meet for an occupational therapist.

Figure 2: The Issues of Occupational Therapy in Japan

We consider that occupational therapists also hope to support for clients as their role for. However, especially, therapists who do not have much experience tend to consider that they value to report to the physiatrist rather than disclosure for the clients. Because they do not have authority to practice of therapy. Therefore, occupational therapists may entrust to physiatrist about disclosure. As
a result, Therapists do not respect client’s autonomy (Figure 3).

Figure 3. The issue of informed consent in the practice of occupational therapy

The Clients hopes regarding Disclosure and Decision-making method about occupational therapy

We surveyed clients of occupational therapy in August 2009. The subjects asked were 95 clients who are inpatients and outpatients in the hospital or facility for the the elderly in Saga prefecture. The respondents were 28 clients. The question is “Which professions do you hope to be informed about occupational therapy?” The many clients answered, “Occupational therapist”, or “Therapist and physician” (Figure4). We consider that the clients hope to be informed by therapist rather than physician is important.

Figure 4. “Which professions hope you to be informed about occupational therapy?”(n=28)

What it takes to develop the prescription in the practice of occupational therapy in Japan

The definition of occupational therapy is very different between physiatrists and therapists. The Japanese Association of Occupational Therapists has defined that “Occupational therapy is to provide treatment, supervision or care to those who have or may have physical and/or mental disabilities, for the purpose of gaining active life, through various occupations which facilitate, restorative or develop various functions”(The Japanese Association of Occupational Therapists,1985).

Occupational therapists value to be enabling occupations with the client’s own culture or environment. On the other hand, Chino, physiatrists and the ex-chairperson of the Japanese Association of Rehabilitation Medicine has defined that, “Occupational therapy is the practice of therapeutic exercise aimed to improve range, strength, skilled motor behavior and endurance like creative occupation, as exemplified by fancywork and craft” (Chino,2009 p21). Physiatrists value physical function. However, physiatrist’s definition is unclearly specialty between occupational and physical therapy. Probably, the physiatrists do not understand the definition of occupational therapy that therapists definite. However, therapists have trouble to promote understanding toward physiatrists in definition of occupational therapy.

Figure 5. “The Way of Decision-making in the Practice of Occupational Therapy”(n=28)

Develop prescription through dialogue, and disclosure to client

Figure 6. Whole concept of appropriate prescription system in the practice of occupational therapy
Occupational therapy requires a team approach. And, occupational therapists cannot practice therapy without information about medication, risk factor and life prognosis, for example. So, occupational therapists and physiatrists have to hold a dialogue more and more. And, they have to create mutual understanding. These things can develop prescriptions, and can lead to more appropriate “informed consent” (Figure 6).

We have two important points to develop the prescription in the practice of occupational therapy in Japan. One of the points is ethical education for registered occupational therapists and occupational therapy students. Second, occupational therapists should attempt to understand what is occupational therapy through dialogue with physiatrists.

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The Present State of Commercial Surrogacy in India and the Ethical Assessment of Physician in Charge Dr. Nayna Patel—Ethical Research concerning Indian Reproductive Medicine, Especially Commercial Surrogacy

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Abstract

India is a very important hub for medical tourism. In India, as is the case in Thailand, Singapore and Malaysia, the state exerts all of its powers in order to attract medical tourists. In India, hospitals with the newest medical facilities offer state of the art medical technologies to their patients in a variety of medical disciplines. The high levels of Assisted Reproductive Technology (ART) and commercial surrogacy are powerful primers to foreign infertility patients. The yearly increasing amount of money in foreign currencies flowing into India by orders for commercial surrogacy from foreign infertility patients in developed countries, as of 2009, has been estimated at 500 million dollars. India’s commercial surrogacy is the honor student of medical tourism second only to the top foreign currency earner, the IT industry.

Backed by the Indian government’s official sanction that strongly promotes medical tourism as a national policy, gynecologist Dr. Nayna Patel is currently performing reproductive medical activities in Anand, the birthplace of surrogacy in India. In this paper, according to the research results of a three-layer structured analysis of India’s reproductive medical (surrogacy) ethics, I will introduce the present state of surrogacy in India as experienced by the world renowned surrogacy expert Dr. Patel (layer 1), and I will investigate her ethical assessment (layer 2) as well as Hinduism’s view of reproductive technology supporting Dr. Patel’s ethical assessment (layer 3).
1. Analysis of the present state of surrogacy in India based on Dr. Nayna Patel’s experience (layer 1): Dr. Nayna Patel is the founder of the Akanksha Clinic in Anand in the province of Gujarat. From 2003 until June 2010, the number of surrogate mothers coming out of this clinic exceeded 300. The first patient for whom Dr. Patel performed surrogacy was a woman born without a uterus (Rokitansky-Küster-Hauser syndrome). Since then, and to February 2011, Dr. Patel has achieved more than 250 successful cases of surrogacy and more than 330 children have been born.

2. Analysis of Dr. Patel’s ethical assessment (layer 2) as well as Hinduism’s view of reproductive technology supporting this ethical assessment (layer 3): In Indian society where the Hinduism based caste system still strongly exits, the escape road out of poverty lies with education. However, to many females born in the class of the untouchables, the Harijan, the road of education is closed. Consequently, It appears to women of impoverished families that the big money industry of surrogacy is an attractive way to make money. But this is not the only reason. To the Indian reserve corps of surrogate mothers, surrogacy is also a fulfilling job as it allows them to get the feelings of fulfillment that accompany pregnancy. Dr. Patel relates, “To both patients who have not been blessed with a child and to ‘womb suppliers’ who are suffering from poverty, surrogacy performed at the Akanksha Clinic is a win-win situation.”

Moreover, as a fortunate fact for Indian women of impoverished families, in Hinduism, to which 80% of the 1.2 billion Indian population adhere, an understanding towards assisted reproductive technology is very high. In Hindu mythology we encounter transmissions that remind us of modern assisted reproductive medical technology. For example, there is a story in which a female deity conceives and gives birth by the injection of a male deity’s sperm (artificial insemination), and a story where a fetus is born from another woman’s womb (surrogacy). In the Hindu nation of India, where rebirth (the revolving wheel of life) and karma (cause and retribution, the natural consequences of one’s own foolish deeds/behavior/action) form a basic set, common religious ceremonies for the gods Shiva and Mahadevi coexist with assisted reproductive medical technology without colliding over contradictions.

Keywords: Commercial Surrogacy, Medical Tourism, Art, Nayna Patel, Ethics

Introduction

India is a very important hub for medical tourism. In India, as is the case in Thailand, Singapore and Malaysia, the state exerts all of its powers to attract medical tourists. In India, hospitals equipped with the newest medical facilities are offering patients cutting edge medical technologies in various medical disciplines. Particularly the high levels of Assisted Reproductive Technology (ART) and commercial surrogacy are strong primers for foreign infertility patients. India’s foreign currency profits, stimulated by yearly increases of commercial surrogacy orders from foreign infertility patients in developed countries, as of 2009, have been estimated at a half-billion dollars. India’s commercial surrogacy is the honor student of medical tourism second only to the top foreign currency earner, the IT industry.

The three major strongholds of Indian surrogacy are Mumbai, Delhi, and Anand in the province of Gujarat. Other places where surrogacy is performed in the country include Bangalore, Poona, Chennai, Ahmadabad, Hyderabad and Calcutta.

Dr. Nayna Patel, a world renowned physician educated in the US with extensive training in reproductive medicine and experience in surrogacy, performs reproductive medical activities in Anand, the birthplace of Indian surrogacy, backed by the authorization from the Indian government that strongly promotes medical tourism as a national policy. This is the doctor who lives in the “city of surrogate mothers” and who has overnight become known throughout the United States as the “queen of surrogacy” as a result of an opportunity, in October 2007, to appear on the popular and long-lived American talk show The Oprah Winfrey Show (8 September 1986 – 9 September 2011).

In this paper, we introduce the present state of surrogacy in India (layer 1) as experienced by renowned surrogacy expert Dr. Nayna Patel, and probe her ethical assessment (layer 2) as well as Hinduism’s view of reproductive technology supporting this ethical assessment (layer 3).

The present state of commercial surrogacy in India (layer 1)

1) The Indian government’s stimulus policy for medical tourism and the revival of commercial surrogacy

In 2002, the Indian government made a declaration of stimulating medical tourism by offering experienced physicians with advanced medical techniques as exchange students to English speaking countries, the latest in medical facilities, low costs and the simple procedures which are attentive to the foreign patients. In 2004, the Indian government began to issue medical visas to medical tourists.

In India, where the government perceives medical tourism as an effective means to obtain foreign currencies, the Indian Council of Medical Research (below; ICMR), published the Statement of Specific Principles for Assisted Reproductive Technologies, 2000 (revised in 2006). In the original statement it was unclear whether commercial surrogacy would be accepted or declined, but, two years later, in the National Guidelines for the Accreditation, Supervision and Regulation of ART clinics in India, in 2002 the ICMR prompted an ongoing public debate concerning this guideline, in cooperation with the Indian National Academy of Medical Science (below; INAMS). In India, where “medical tourism towards India is increasing yearly by 30%” as a positive

16 16 Indian surrogacy is now a half-billion dollar industry. (Outsourcing Pregnancy [The Daily Beast: October 11, 2009]) ICMR estimates that India’s foreign currency profits will amount to 6 billion dollars in 2015.
18 medical tourism to India is growing by 30% a year (CBC News Online : June 18, 2004)
result of the “Indian national health policy’s declaration that foreign patients medical treatment is a legitimate form of ‘export’\(^{19}\)” (CBC News Online: June 18, 2004), the performance of gestational surrogacy began in 2003, i.e. the performance of what is called the borrowed womb (IVF surrogacy). In 2005, three years after effectuating the public debate, the ICMR and INAMS published a revised (2005) edition of the 2002 guideline.

In the wake of a situation that occurred in 2008 (subsequently resolved through supplementary legal action), in which the newborn child of a Japanese male physician who had utilized surrogacy in India was born stateless as the result of the pre-birth divorce of his father, the Indian Ministry of Health & Family Welfare (below; MHFW), in cooperation with the ICMR, hastily effected the Assisted Reproductive Technologies (Regulation) Bill, 2008; the 2008 ART (Regulation) Bill by which the legal position of surrogate children has now been established. The document that formed the foundation for this bill was the Assisted Reproductive Technologies (Regulation) Bill, 2006; the 2006 ART (Regulation) Bill published by the Republic Interest Legal Support and Research Center. The provisions added to the 2008 ART (Regulation) Bill from the perspective of guaranteeing the welfare of surrogate children with the purpose of prevention are as follows.

1. A guardian will be attached to the surrogate mother (7.34.(19))
2. The child will belong to the surrogate requester even if this person divorces before the child is born” (7.35.(4))

Through the enactment of this bill, although the legitimacy of remuneration for the surrogate mother is recognized,(7.34.(3)), the surrogate mother’s parental rights towards the child are completely relinquished (7.34.(4)). Furthermore, this bill has made it mandatory for the name of the genetic parent(s) (7.34.(10)) as well as the full name of the surrogate requester to be written on the child’s birth certificate.

However, in 2009, after the enactment of the 2008 (Regulation) Bill, India witnessed a recurrence of trouble concerning the nationalities of surrogate children. The surrogate twins of a patient holding the German nationality, in whose home country surrogacy is illegal, were denied citizenship in both Germany and India and became stateless. Through the Indian government’s March 2010 recognition of the twins as the adopted children of the German national who made the surrogacy request, the German government granted the twins entry into the country and citizenship. With this case as a stepping stone, and from the viewpoint that the Indian government must absolutely guarantee the welfare of surrogate children, the 2008 ART (Regulation) Bill was amended to form the Assisted Reproductive Technologies (Regulation) Bill, 2010; the 2010 ART (Regulation) Bill. The new provisions incorporated in the 2010 (Regulation) Bill are as follows.

1. Foreigners must present documents in evidence of the legitimacy of surrogacy in their home country and proof that children will be granted citizenship there
2. Children cannot be granted Indian nationality
3. In case children are not taken to their home countries within one month following their birth, they will be granted Indian citizenship (7.34.(19))
4. In case the surrogacy requester cannot claim the child, the guardian is allowed to present the child for adoption (7.34.(19))
5. The surrogate mother is responsible for the child’s health until the child is handed over (7.34.(23))
6. The requester is responsible for the surrogate mother’s health until the child is handed over (7.34.(24))

Because of a lot of medical tourists visiting India from abroad, in today’s India, as the result of having been on the receiving end of some unfavorable circumstances, together with surrogate mothers from the lower classes, surrogate mothers with high academic qualifications from the middle classes are even appearing on the scene. Moreover, surrogacy repeaters, i.e. professional surrogate mothers, are also emerging. However, in response, the 2008 ART (Regulation) Bill(7.34.(5)) stipulated that surrogate mothers had to be over 21 years of age and under 45, and that the maximum number of times the surrogate mother could challenge surrogacy in her lifetime was two with those numbers changing again in the 2010 ART (Regulation) Bill(7.34.(5).), which stipulated that the surrogate mother had to be over 21 years of age and under 35, and that the permitted number of times the surrogate mother could give birth to a child was three.

(2) The present state of surrogacy in India as experienced by Dr. Nayna Patel

Dr. Nayna Patel is the founder of the Akanksha Clinic in Anand, Gujarat, the province that has brought forth Mahatma Gandhi. From 2003 to June 2010, this clinic\(^{20}\) treated more than 300 surrogate mothers with, according to Miho Hirai’s research, the first patient to receive surrogacy treatment by Dr. Patel in 2003 a woman born without a uterus (Rokitansky-Küster-Hauser syndrome). Since that time, and until February 2011, Dr. Patel achieved more than 250 successful surrogate births with over 330 conceptions. As of February 2011, Dr. Patel was managing two exclusive houses for surrogate mothers, surrogacy houses, at a location approximately 5 minutes by car from the Akanksha Clinic, where she allows about 60 surrogate mothers to live temporarily.

Anand is a “milk town” where a population of 300,000 Hindu believers coexists with holy cows, but where the about 6 million people from Gujarat who live abroad (comprising just under 30% of all 20 million Indian nationals living abroad) can combine their homecoming with a visit to the infertility clinic. Anand, dotted with infertility clinics equipped with the newest reproductive medical facilities, has become a very important Mecca for India’s medical tourism.

\(^{19}\) India’s National Health Policy declares that treatment of foreign patients is legally an “export” (ibid)

\(^{20}\) ‘Google Baby’Follows Birth Outsourced To India [NPR: June 15, 2010]
(3) Dr. Nayna Patel’s clients

Dr. Nayna Patel’s clients requesting surrogacy are not just the wealthy class of Indian people holding Indian nationality living inside India as well as abroad, but also Westerners (Americans, British, Canadians, Germans, French, Israeli, Australians) and Asians (Koreans, Taiwanese, Japanese), totaling more than 30 nationalities. In the Akanksha Clinic, the surrogacy program is restricted to couples (with the exception of homosexual couples) who are not able to give birth to children for medical reasons.

India’s surrogacy clients before the enactment of the 2008 ART (Regulation) Bill were not only opposite sex couples without children, but also many same-sex couples from western countries. The clear specification in this 2008 bill of the possibility for singles, unmarried couples as well as same-sex couples to request surrogacy (7.32.1) was indicative, however, of the difficulties existing inside India, where a law exists (section 377 of the Indian Penal Code) that prohibits homosexuality, with the possibility for homosexuals, as they had done until 2008, to openly make use of reproductive medical tourism. With the enactment of the 2010 ART (Regulation Bill), homosexuals are no longer able to use surrogacy in India.

(4) The costs of surrogacy

In the practice of surrogacy, Dr. Nayna Patel is consciously making it her policy to use the expression “donating a womb” instead of the expression “renting a womb.” From the avoidance of businesslike terms in her daily speech, careful and thoughtful attention can be inferred to her intentions to avoid any undesirable discord accompanying the delicate medical service of surrogacy.

In the event of pregnancy and birth by a surrogate mother, the surrogacy requester pays a remuneration of approximately 700,000 yen. In case of twins being born, 25% is added to this amount. Together with a three-month remuneration payment, during the pregnancy period the surrogate mother receives living expenses on a monthly basis in the amount of 10,000 yen to increase the chance that a healthy child is born. As has been stated above, the 2010 ART (Regulation) Bill stipulates that the requester is responsible for the surrogate mother’s health until the child is handed over (legal obligation 7.34.23) to protect the surrogate mother’s rights, and that the surrogate mother is responsible for the child’s health until it is handed over to the requester (legal obligation 7.34.24) to protect the child’s rights. However, in the event that pregnancy and birth do not occur, the surrogate mother receives very little remuneration.

According to Miho Hirai’s research, the price for consultation at Baby for All, which is a surrogacy consulting company (founded in August 2009 in California, United States) associated with the Akanksha Clinic, is 430,000 yen and the cost for surrogacy at this clinic 2,300,000 yen. The clinic receives 1,600,000 yen for hospitalization costs and infertility treatment charges, after 700,000 yen has been paid to the surrogate mother. If a surrogacy requester from Japan were to sign a contract directly with this clinic, surrogacy costs would amount to approximately 2 to 2.5 million yen, or somewhere in the area of 3 million yen with the inclusion of expenses like travel. However, if a surrogacy intermediary – The Nevada Center for Reproductive Medicine (Egg-cell Service/Surrogate Mother Birth Information Center, Tokyo, Chiyoda, representative Yuki Sumi) or IVFA (Tokyo, Shibuya, representative Yuki Rowen) – were to mediate, in case of these organizations, a mediation fee of 7 million yen and 6.8 million yen respectively would have to be added. In comparison with 15 million yen that would be required for infertility treatment in the US, 6 to 8 million yen for surrogacy, in addition to such fee as mediation and travel, does not seem overly expensive, with 2/3 (10 million yen) to 1/5 (3 million yen) that of the US. India is clearly a very attractive option for surrogacy requesters.

Incidentally, the 2010 ART (Regulation) Bill (7.34.13) states that “the surrogate mother may not also serve as egg-cell donor”, thus prohibiting artificial fertilization surrogacy (intrauterine insemination; IUI), i.e. traditional surrogacy in which both uterus and egg-cell are offered by the same person, but in vitro fertilization (IVF) surrogacy using an egg-cell that is offered by a third party (gestational surrogacy) is permitted.

2 The ethical assessment of Dr. Nayna Patel, the physician in charge of commercial surrogacy in India

(1) Dr. Nayna Patel’s ethical assessment (layer 2)

The largest number of Indian women hoping for surrogacy come from impoverished families belonging to the caste of the untouchables, the Harijan. In foreign developed countries where information concerning surrogacy sanctioned by the Indian government is very poor, intellectuals in the media condemn surrogacy tourism by rich but infertile married couples from developed countries as the physical and psychological exploitation of impoverished Indian women, or as indirect prostitution. On one side of the argument, within India itself, the Manji Yamada incident (see below) was denounced as human trafficking by one of Jaipore’s welfare groups, Sati (truth).

Based on the above described state of affairs in India, Dr. Nayna Patel displays the following altruistic outlook on gestational surrogacy performed at the Ananksha Clinic in Anand, and which is often exposed to critical comments.

1) “How can people say that what women do of their own volition is exploitation? Although European people are also participating in surrogacy in America, I have never heard anyone say that European people are exploiting American women. Why is it called exploitation when it becomes an Indian issue?” Surrogacy that is performed at the Ananksha Clinic is a win-win situation for both the requesters who do not have

22 For example, an egg-cell donor was paid Rs 20,000 for the process, which takes four weeks. Cf. Time for the brown baby boom [Hindustan Times: July 21, 2009]

23 India’s Baby Factory(SBS Dateline: Feb 22, 2009 )
children and the “uterus donator” suffering from poverty. “We’ve started a project called Surrogacy Trust that offers educational opportunities to children of surrogate mothers. They are taught computers and sewing skills for free.” “Surrogate mothers are not killing anyone. They do not violate the law, and they do not act immorally. They can allow their children to have an education and they can also buy a house for their families. Moreover, they are aiding married couples without children. Where is the harm in that?”

2) However, it is necessary to lecture on protective measures so that women from impoverished families hoping for surrogacy are not coerced into surrogacy against their will. Here, the doctor expounds on the importance of maintaining a linear counseling system and of surrogacy procedures for primi(multi)paraes under the age of 35 from impoverished families who hope for surrogacy. If substantial counseling is rendered, the coercion of economically weak women into surrogacy by members of their family (husband, in-laws) scheming to seize the remuneration for surrogacy or by third parties (relatives, malignant brokers) can be avoided. Compensation for surrogacy, based on spontaneity, is set aside as a construction fund for a new house or as a children’s education fund, and sometimes for the purchase of business necessities for the husband (a motorized rickshaw, for example).

3) Surrogate mothers who have signed a contract move into the surrogacy house and prepare for birth. Based on the guidance of a physician who supervises surrogate motherhood screening (aptitude examination), nutrition, physical condition, and so on, nurses and nutrition experts look after the pregnant women who live in the house. Surrogate mothers have board and lodging inside the hygienic confines of the surrogacy house for three months before and after birth, where contact with their family is allowed. Amrita Pande, who has done research in the field, tells about how to the pregnant women the restricted but sanitary space in which they live does not appear to an uncomfortable place, and, furthermore, that by being hospitalized and giving birth here surrogacy can be performed without having to reveal it to their relatives and neighborhood.

It is important to have a substantial counseling system in which the English written guidelines are precisely explained to the surrogate mothers under contract that include illiterate women from impoverished families. “Is it so that because surrogate mothers are uneducated they cannot decide for themselves?” Dr. Nyna Patel shot back at those who regarded the illiterate surrogate mothers as children.

(2) The standpoint of the Indian women who volunteer as surrogate mothers and Hinduism’s view of reproductive technology supporting Dr. Nayna Patel’s ethical assessment (layer 3)

What would the Indian women who volunteer as surrogate mothers think about the requesters from India and abroad who make use of surrogacy tourism sanctioned by the Indian government and commercial surrogacy? Are India’s surrogate mothers, whose bodies are governed by their husbands or by third parties within the patriarchal system of Indian society, the victims of exploitation? Or, is surrogacy reproductive (clinical) labor based on the free choice of impoverished Indian women? For a better understanding an on-scene verification of India’s surrogacy is required.

In India’s society where a deeply rooted caste system based on Hinduism still exists, education is the escape road out of poverty. However, to many of the women in India’s caste of untouchables, that road of education is closed. Under such circumstances, for women of impoverished families, surrogacy, which earns them a lot of money, appears to be an attractive way to get income. Furthermore, for India’s reserve army of surrogate mothers, surrogacy appears as a fulfilling job which allows them a taste of the feelings of happiness accompanying pregnancy.

Moreover, as a fortunate reality for Indian women of impoverished families, Hinduism, to which 80% of India’s 1.2 billion population adhere, is very understanding towards assisted reproductive technology. In Hindu mythology we come across transmissions reminding us of modern assisted reproductive technology. For example, there is the story of a female deity who conceives by the injection of a male deity’s sperm (artificial insemination), and the story in which a fetus is born from another woman’s womb (surrogacy). The former is in Hindu mythology concerning the nativity of Skanda and the latter is in Hindu mythology concerning the nativity of Krṣṇa. In the Hindu nation of India where rebirth (the revolving wheel of life) and karma (cause and retribution, the natural consequences of one’s own foolish deeds/behavior/action) form a basic set, common religious ceremonies for the gods Shiva and Mahadevi coexist with assisted reproductive medical technology without colliding over contradictions.

(3) The Indian government’s standpoint on ethical issues concomitant with surrogacy

What would the stance of the Indian government be, that has sanctioned Dr. Patel’s reproductive technology, against the rumored apprehensions in the world?

1) Countermeasures taken against the issue of the statelessness of a surrogate child as represented by the problems resulting from the repatriation of Manji, a girl born on July 25, 2008, the incident in which a female fetus became temporarily stateless after being born out of a fertilized embryo obtained by the insemination of an egg-cell donated by an anonymous Nepalese woman to a Japanese physician, and then transference to an Indian surrogate mother by Dr. Nayna Patel, and again, in the instance where the parental rights of French homosexual Raymond Suoto concerning a surrogate child born on April 6, 2010 in Mumbai were not recognized in his home country of France where surrogacy is prohibited.


28 Surrogacy woes: India-born baby in French foster care [DNA: Jul 27, 2010]
Instigated by the incident of Manji Yamada, the child of a Japanese physician – the Indian government issued a travel certificate permitting Manji (Indian name) to depart from India as a stateless person and the Japanese government issued an entry visa on October 27, 2008 – the Indian government enacted the 2010 ART (Regulation) Bill that established the legal position of surrogate children born in India. As stated previously, with the enactment of this bill (7.34.(19)), foreign requesters making use of Indian government sanctioned surrogacy tourism are obliged to present two kinds of documents.

1. A certificate stating that surrogacy is legitimate in one’s home country
2. A certificate stating that one’s home country will grant citizenship to the surrogate child

Countermeasures in case a surrogate mother gives birth to a seriously handicapped child and the requester refuses to accept the child.

Legal compensation in such an event is as follows.

A guardian is attached to the surrogate mother (7.34.(19)). In the unlikely event that a requester cannot accept a surrogate child, the guardian is able to present the child for adoption (as above). In the event that a requester is not able to take the child with him/her to his/her home country within one month after the child is born, the Indian government can grant the child Indian citizenship (as above).

(4) A request for the Indian government

According to Unicef’s 2009 version of the White Paper on Children of the World, in 2005 approximately 536,000 women around the world died during pregnancy or childbirth. Of this number, 117,000 expectant and nursing mothers died in India. If we estimate that in India roughly 27 million people are born each year, then this means that of every 230 expectant and nursing mothers, one mother dies. Compared to Japan’s 39 deaths among expectant and nursing mothers in 2005 (5.7 deaths among expectant and nursing mothers per 100,000 births), childbirth in India is, as the numbers show, a great and life threatening feat. Dr. Nayna Patel relates that at reproductive treatment clinics equipped with modern medical facilities, health damages do not occur so frequently. However, it is necessary that the surrogacy sancting government of India implements investigations into the actual condition of surrogacy related health damages throughout India.

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