

TERMINAL CARE IN JAPAN

- 1. TERMINAL CARE IN THE JAPANESE GENERAL HOSPITAL**
- 2. BIOETHICS AND TERMINAL CARE IN JAPAN**

by

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1.THE TERMINAL CARE IN THE JAPANESE GENERAL HOSPITAL

1)Introduction

The first cause of Japanese people's death is cancer, and 18 million people die of cancer in a year recently. So, on the spot of medical care, death is the everyday experience, and it is never special and rare. Nevertheless, the terminal care which treats how to care the terminal patient in their quantity and quality of life is still under trial and error, does not come to scientific and universal way. The way of the terminal care changes by each medical professional's attributes that is to say, experience, knowledge, sensitivity, etc. Treatment to acute appendicitis and acute pneumonia will not be different much in any place all over the world. But the terminal care changes completely by the way of thinking and level of sympathy to other person's death of each medical professionals. For example, in an extreme case, some hospital gives no treatment to terminal patient. A certain denomination people refuse blood and liquid transfusion. And a certain denomination refuse medical care on Saturday. They think of all as God's will. On the contrary, some start central venous nutrition, attack artificial respiration, measure urine quantity by inserting balloon catheter and give an antibiotic and steroid hormone in large quantities. In the case of Japanese medical care insurance system, it is easy to receive heavy care because of high value at the terminal stage.

It says that all people are even. We desire evenness at least at the time of birth and death, but it is very different in fact. What is the dignified death? Everyone should be treated his death with dignity. At modern society, medical professionals such as doctors

and nurses take part in life and death directly. It can't be helped that these professionals' view of life and death influence directly to their usual care, since medical care is human's deeds. Therefore uprise of each medical professional's view of life and death must be needed for level up of medical care at a general hospital. It usually says that medical treatment is holy order. This will be important point for medical treatment to keep on as holy order.

Let us serch plan to universalize medical care as scientific way in a concrete form. That is to say that without running to idealism or abstract arguments, we'd like to think this problem in the natural and actual way, within the limits of medical resources such as human resouces like doctors and nurses, medical facilities, and material sources like buildings, which we can get actually.

2) Terminal care and medical model

The foundation of modern medicine(biomedicine) methodology are Claude Bernard's experimental medicine and Rudolf Virchow's cell pathology, and there are two supports in it, one is on actual proof by animal experiment and the other is analysis by an autopsy. In the former, the way to evaluate by statistic way under arranged conditions which are possible to set in, and in the latter, the way to evaluate by morphological way finding the center of disease, seem to support it's scientific aspect. Now, in the experimental medicine, many animal models of diseases are being made and anatomy progresses up to an electron microscope level and a molecular level. Modern medical pathological model is carried in clinic as medical model of living human now and here, and come to being

insert and applied as medical model. Consequently, in clinical medicine, analyzing and generalizing have become the center of the methodology and modern medicine tends to overlook individuality which each patient has. The medical model which is based on reason for being of the man living now and here can be the real medical model of the man.

On 1977, Day, S. (New York University) brought forward an expression "bio-psycho-social health" concerning about whole person's health, and made an international organization about it. Soon after that, Engel, G. (University of Rochester) developed this expression as "bio-psycho-social-medical model" which can be applied for general physical diseases. As the theoretical background of this model, there is "General System Theory" of von Bertalanffy.

Now, this bio-psycho-social medical model symbolizes of progress from anatomical and animal experimental medicine to human medicine, but it is not enough this much. We can find bio-psycho-social aspect in animal except human, so we cannot say that the difference between animal and human is clear this much.

In the case of the terminal care and limiting situation such as fatal situation of acute stage like ICU, CCU, artificial dialysis, spinal injury and paralytic state after the fit of cerebral infarction, there needs the approach based on humanistic psychology which is based on meaning of living as human.

This psychology has risen from 20 years ago as the third psychology which surpassed psychoanalysis and behavioral medicine.

Still more, recent bioethical point of view tends to be realized as advocating patient's right and doctor's duty, but its important

point is "reverence to life". This idea is based on Kant,I.'s "the absolute value of human".

That is to say, as holistic humanistic medical model, there needs the way which has inclusive field of view based on "reverence to life". This point of view including this humanistic psychology pursues the meaning of human existence and furthermore introduced the way of thinking of bioethics in a narrow sence (advocating patient's right and doctor's duty). Ikemi,Y. bring forward bio-psycho-socio-ethical(existential) medical model on these standpoints. By this medical model,we,for the first time, can understand a patient as "a human who has disease", and further this medical model extends the possibility to care, and at the spot of medical treatment, it contributes much to the exploitation of concrete approach including not only cure but also care.

By the research of Miyamoto group on 1982, out of 458 hospitals which have over 300 beds in whole Japan, only 1.8 percent have educational curriculum of the terminal care, though 77.9 pe notice the value of the terminal care. This shows barren methodology to the education of the terminal care. Bio-psycho-socio-ethical(existential) medical model can be influential not only for the terminal care but also for solving the case with difficult problems.

3)The goal and the peculiarity of the the terminal care

What is the the terminal care? Philologically, there are debates on the definition of the term "terminal". Some say it is said terminal when the patient has less than three months before he

dies, and some other say it should be less than six months. We call it terminal when this situation fits in both of the followings.

a) when it is impossible to cure completely of that disease in view of the level of modern medicine.

b) when the time of death is almost certain. (The period of time the patient can live does not matter.)

Therefore you can use the word "terminal" not only for cancer but also for other various diseases. But here, in this paper I will deal with the terminal care concentrating on the terminal cancer care. Since you cannot cure the patient of the disease at the terminal stage, care is mainly provided. But every medical professional must have an attitude of holding on the spirit of cure to the very end. At the terminal stage, they often say, "from cure to care", but this idea is wrong. Cure and care must be provided simultaneously at any time, any stage. A patient's condition may effect the degree of the importance of each. Sometimes one is more important than the other. Although it cannot be helped that we tend to provide care-oriented medical treatment at the terminal stage, we still have to keep on serching for the possibility of cure. Because human life is so precious.

Now, the purpose of the terminal care is to complete the quality of life in patient's terminal days. The quality of life is the satisfied condition of his own bio-psycho-socio-ethical(existential) condition.

These four items are often pointed out as goals of the terminal care and satisfies the patient's quality of life at the least level: To make it possible for the patient

- a) to have a good appetite
- b) to have a good sleep
- c) to excrete well(stools, urine, sputum,etc.)
- d) to have psychological stability

As you see, those goals can be applied for other diseases besides cancer. For example, there are indispensable for chronic diseases such as high blood pressure and diabetes and also for acute diseases such as pneumonia. Also, they are necessary factors for a healthy man to support his and maintain his level of quality of life.

I could say that essentially the terminal care is the same as care of general diseases and health supporting.

If I point out any particularity of the terminal care apart from care of general diseases and health supporting, they can be summarized in three points as follows.

1.All creatures has fate to die from the moment of their birth. They are given two things at their birth: the joy of birth and the sorrow of death. Nevertheless no one dares to think of his own death while he is healthy. Until his illness becomes so bad and he feels he is going to die, he never think of death. Usually, a patient becomes to know the time of his death before a medical professional tells him. An investigation of Japan indicates that 23.4% of cancer patients clearly feels they are going to die and 50.8% of them feels it quite a lot. In our own experiences, almost all patients knew they were going to die. But to us medical professionals who observe, death is always a matter of some one

else. It's never his own death. We strive to sympathize with the patient's death. However, since we have no experience of death or dying, it's very hard to have true sympathy with the patient.

Death is beyond our capacity of sympathy and it's almost impossible to have sympathy with someone's death. Imagine a patient who came to your hospital with a headache. An ache is a subjective fact and objective measurement is impossible. Accordingly, we unconsciously try to judge the patient's headache within our own experience of headache, when we try to understand his headache. We are only guessing the degree of the ache from our own experience of headache, in addition to our knowledge and experiences as a medical person. So we, who doesn't have an experience of death, don't have the way to understand it.

2. In order to satisfy those goals of the terminal care above mentioned, it's indispensable that a patient is free from pain. With pain, you never accomplish those goals. However, most pain of the terminal cancer is hard to be killed. For, there are bio-pycho-socio-ethical factors which effects degree of pain, in addition to the basic pain caused by cancer itself. We call it "total pain." "A man has pain in the way he has lived.". Vicious circle is easily formed between pain and its factors. It occurs like this;

"Have an abdominal pain" (pain from stomach cancer itself)→"Can't sleep well due to pain"→"psychological response such as indisposition or irritation"→ "feel stronger pain than before." It becomes worse and worse and goes endless. This can be said to be a kind of interactive action between physical and psychological

factors. Therefore, cancer pain is somehow different from other chronic pains, and we must grasp it totally (bio-psycho-socio-ethically)

3. A man is originally an lonely existence. He is born from his mother's womb alone and dies alone. However, man can never live by himself and can not bear loneliness. Men support each other and together form a group such as a family or a society. Especially, the Japanese, a farming people, have tendency of forming a group in which they support each other. The concept of "amae" (like the English word of dependence) also originates from this basic reliance among them. Of the patient can spend his last period with having warm relationship with many people, especially with intimate close people, and with being recognized of his meaningful life by them, then he can be satisfied with his own life, thinking that his life was very meaningful. Only when one dies with satisfaction with his meaningful life, without loneliness, surrounded by (many) beloved people, we can call his death "dignified death." In old days, in the middle of the Heian era, there was a Buddhist priest called GENSHIN. When a patient was dying at his place he would lay the patient in the place called MUJYOUIN and connect the patient to the image of Buddha called "Amidanyorai" with a five colored cloth.

Both the patient and people around him would chant day and night. And when the patient had agony, people around him would listen to him and write down what he said at any time. During this process, his agony would turn into joy.

This is a reasonable death with close relationship with others and suggests an important idea of the roles of the patient's family and a medical professional at the terminal stage. This ancient method was called "Gyogi" (formation or courtesy) and it gradually became ceremonial. And then became a universal care which anyone can do. As we know, Mother Theresa in India who was awarded Nobel prize for peace a few years ago, stayed with and took care of people who were going to die, with holding their hands. Also we often see pictures of hospice where a nurse is holding a patient's hand. Thus, it is important to search for the way to make up "the hour of death with intimate relationship."

I summarized the goal of the terminal care based on those three points mentioned above, into "control of whole physical body" (especially coping with pain), "psychological stability," and "dignity as a human," as shown in the ^{table}~~chart~~ 1-1.

4) The Attitudes required from a medical professional in the terminal care (therapeutic self)—the issue of telling the fact to the patient and daily care

The terminal care is often claimed to be difficult. Probably, it's because the terminal care must consistently be a total care. It is not simple enough to think matters only in the part of a patient. The kind of care varies depending on the medical professional's attitude. Thus the medical professional's personality and his/her attitude determines the concept of the care itself. Accordingly, the terminal care significantly involves with the matter of "therapeutic self". Care is handmade and hard to see from outside. It's based on the knowledge, but knowledge is only a

part. Care is actually supported by sympathy overflowing from inside toward somebody's death. In other words, care is in the area of wisdom. If I could call knowledge "science," I should call wisdom "art".

More scientifically, care can be described as holistic openness of a medical professional which enables him/her to understand the patient as a whole person (bio-psycho-socio-ethical interpersonal communication) (Ikemi 1982). In order to make the medical professionals possible to come to such understanding, education is necessary. The effective method for this education is the group activity based on Balint Method. Medical professionals must consistently discipline themselves by actively taking these education and increase the quality of therapeutic self in order to grow as a medical professional. Having many experiences and evaluating these experiences scientifically are two indispensable things which we must always pay attention to, for they made the foundation of the therapeutic self.

In the present situation, there are so many patients suffering from cancer who come to general hospitals, that cure and care are given to those patients without appropriate provision and readiness in the part of medical professionals.

Apparently medical professionals must make effort to increase the quality of their therapeutic self. But in reality we already have a chance to be exposed to those terminal patients. In that case what attitude is required from us? Such attitudes can be a strategy to increase the quality of therapeutic self. The following is some suggested attitudes.

1. Don't try beyond your capacity

If your care for your patient is beyond your capacity, after all it will result in putting the patient into a miserable situation, because, by doing so, you, the medical professional will get worn out.

Terminal care is already a hard task. You should engage in it under your capacity. The more terminal the patient's situation gets, the sharper his/her nerve becomes and he/she observes medical professionals with that sharpened nerve. Then he/she finds out medical professional's false attitude which comes from too much effort beyond their capacity and he/she gets disappointed.

2. Make a physical & non-verbal approach to the patients

It's painful to be beside the terminal patient. There might be a gloomy silence. At that time you can think what to say as you touch the patient with your hands. For example, you can rub the part where the patient feels pain, or hold his/her hand in the form like you feel his/her pulse. Patients like to be touched as well as a baby feels peace in its mother's hands. The origin of the medicine is to put a hand on the place where the patient feels pain.

3. Don't impose the healthy man's theory on the patient

The relationship between a medical person and a patient is the relationship between healthy person and a sick person.

To a medical person, a hospital is a working place, but to a patient, it's a place where they expect to get well. We tend to think of medicine from a healthy person's side unconsciously. For

example, when a patient has pain we often tell him to bear it, without thinking what a terrible pain they are suffering from and say "Everybody bears it, you should be able to bear it."

With such a vain encouragement a patient loses trust in a medical professional and ^{the} relationship between a medical professional and a patient breaks out.

It may result in disappointment of a patient. The first step of sympathy is to avoid to think from a healthy person's side.

4. Recognize individuality of each patient

When we medical professionals talk our patients among ourselves, we often unconsciously refer to "Mr. X of pancreas cancer" or "Mrs. Y of lung cancer".

When we call like this, pancreas cancer or lung cancer is emphasized rather than "Mr. X " or "Mrs. Y". Unconsciously, we classify our patients by name of their physical diagnosis.

Thus we often give them care with forgetting patients' individual characteristics which includes bio-psycho-socio-ethical aspects.

But you must always remember that each patient is unique individual. Also you must find out what is needed for the specific patient at the specific moment and give him/her a sensitive care.

5. Don't take any action or utter any single word which may spoil a patient's hope

Kübler-Ross says, "A man has possibility of growing until the moment of death." This possibility is supported by hope for living. She summarized a psychological process of (American)

patients who had been told they have cancer, as follows;

At first, patients refuse to accept the fact that te have cancer, so they may go to another hospital for a different diagnosis. But when they face the same diagnosis tend to get angry, feeling "Why do I have to suffer from such a horrible disease?" Since many of the patients of cancer have led restrained lives, this anger is often very strong. This anger is often turned toward weak people, their family or nurses. And when they come to themselves, they may think,for example, "I have ten millon yen which I have saved all my life. If I offer this money to a shrine, gods may save my life." And they try to negotiate with gods. Or some may do some good work they have never done before, expecting for some miracle. When those good works don't work out, gradually they become depressed and finally accept the fact that they are going to die.

In the case of the Japanese, this sequence is not always true. Sometimes depression and anger happen simultaneously. In most cases the psychological regressive phenomenan can be seen and they become selfish like little children. You must pay attention to patients' depression, because it may happen suddenly.

Table 1-1 goals of the terminal care

area	goals
biological(physical)	to be comfortable (control of the total condition: nourishment, sleep, excretion, pain,etc.)
psychological	control of various psychological responses. liberation from fear of death--acceptance of ambivalent of death. (help a patient have psychological peace--acceptance of death)
social area	to keep dignity as a social existance (aware of his own social role: in family and a job)
bioethical(existential) area	to enlarge value of quality of life left to have the hour of death with a close relationship with others to reaffirm the meaningfulness of his life terminate his life with much sorrow by people. to keep dignity as a human (control of total pain)

Beneath this psychological process, there is always hope which exists until just before the moment they accept the fact they are going to die. When we provide the terminal care, the most important thing is that you should never take any single action or utter any single word which may spoil a patient's hope. It is this hope that you need as a basis upon which you are to make a decision on telling a patient the fact he/she has cancer, using various medical equipments on his/her death bed, providing central venous nutrition and oxygen inhalation or medicating drugs. For example, if a particular patient may lose his/her hope to live by hearing he/she has cancer, you must not tell the truth. On the other hand, if a patient is strong enough to accept the truth and still can try to accomplish his/her work with hope, using his/her last energy, then you should tell the truth. Or other patient may have strong faith and can believe in the new world with eternal life, then you can tell the truth. In this decision, the most difficult matter is to know the patient's potential nature. Since there are many factors which consist of one's personality, such as academic knowledge, experience, etc. in addition his/her potential nature, it's very hard to know the patient's real nature correctly unless there is a good relationship between a medical professional and a patient. One of the ways to find out the patient's real nature is to know his/her past life style. You need to get information on his/her past life style from himself/herself, his/her family or friends, because "One dies in the way he has lived."

Regarding conditions and advantage and disadvantage of telling a patient of cancer the truth, see the table 1-2 and table 1-3.

6. Involve patients' family in the medical team

The patient's family know the patient best. It's very important to get information on the patient from his/her family to know the patient accurately. To make it possible, having a close relationship with the family is very important. This relationship must be absolutely trustful. So a medical professional must make close contact with the patient's family and explain the detail situation of the patient so that both of them can grasp the patient's needs correctly and meet them positively. As a matter of fact, care taking by the patient's family is the best, because the patient has been with his/her family for many years and he/she feels no reserve toward his/her family. Also his/her family takes care of him/her with love, without being bothered by hustling time. But the family doesn't have enough knowledge of medicine, therefore medical professional must instruct them what may be done, or rather what should be done for the patient. In such an environment, patient-oriented relationship between a medical person and a family becomes close and both a patient and his/her family will be satisfied. A patient's family want to do whatever they could do for the patient so that they don't regret later.

7. The core of whole person approach is a physical approach

At the terminal stage, a patient's physical agony increases because of nourishment problems, infection, bleeding, etc.

You must approach these factors which causes agony, properly. If you succeed in controlling these factors, you will make a foundation on which inter-trusting relationship between a medical professional and a patient is built. A patient trusts a doctor who is good at giving an injection rather than good at talking with him/her.

It is true with the area of the terminal care that the fundation of medicine is to make a well thought out medical plan under the accurate diagnosis. You must make thorough physical check up accurately before you try a psychological approach.

On the whole person approach in the terminal care, with physical approach as is core, we summarized our idea "TPEG (Terminal Patient Evaluation Grid)" in the table 1-4).

8. Cure and care must be improved simultaneously

Current study on cancer is daily improved. Many new ways of cure has been developeed. Yet, the development of ways of care is so slow. Only cure is advancing and care is far behind. It's not an ideal situation. Even though number of leukimia cells decrease in the patient, if he can't eat even tofu(bean curd, very tender food) because of pain in his mouth because of severe stomatitis, it doesn't help. So, cure and care must improve together.

These eight points mentioned above are most basic points, nevertheless generally speaking, even those most basic points are not sufficiently provided. We must make effort to build a standard of terminal care which any one can do at any place at any time.

5) Conclusion

As many as 180,000 people are dying of cancer a year in Japan, most of whom are dying in the hospital under a medical control. Nowadays, we seldom see a persn die surrounded by many family members with lamentation.

For the medical professional who are working in the general hospitals, it is the biggest task to get over the conflict: we are giving the advanced medical technology to patients and yet we are not helping patients die solemnly.

To accomplish this task of ours, we must develop the whole person medicine, based on the "bio-psycho-socio-ethical medical model", into the terminal care.

It is often said that "hospice" refers to the spirit and doesn't refer to a building itself. In this sense, we hope the idea of "hospice in my mind" is born in every single medical professional's mind.

Table 1-2 Factors of telling a cancer patient the truth

1. BIOLOGICAL ASPECT

A) Factors of the patient

Kind of disease

- 1) cancer which a patient notices without hearing the truth from a medical professional (ex. breast cancer, throat cancer, skin cancer, etc.)
- 2) cancer which tends to convalesce satisfactorily (early stage cancer, cancer which has possibility of cure with an operation and other methods, cancer which doesn't transfer to another part of the body, so easily, cancer which develops slowly)
- 3) cancer which requires a patient awareness of his own situation (taking medicine for a long period, radiotherapy, etc.)

Age of a patient

- 1) a little child: tell only his/her parents
 - 2) puberty: tell the patient after judging the relation between him/her and parents
 - 3) adults and old folks consider factors besides age.
- Tell those who don't have mental disease, hypochondria, neurosis or a tendency of committing suicide.

B) Factors of ones who tell, the medical professionals

- 1) have an advanced medical team which can respond to any needs and any physical condition of the patient, promptly and accurately. (This team must be able to follow up the patient even after telling that he has cancer)

- 2) have a capability to observe sufficiently a patient at any time.
 - 3) can cope with a patient's agony such as pain sufficiently.
 - 4) can provide a comfortable environment at a hospital
- C) Time of telling

- 1) when a patient's total physical condition is good and he can hold hope for future
- 2) when an operation worked out well and a patient has stability both physically and psychologically, then a patient starts to have hope.
- 3) when a patient delivered from pain or means of getting rid of pain seems to be available.

2. PSYCHOLOGICAL ASPECT

A) Factors of the patient

- 1) a patient who has self strong enough to be one of the medical members, even after he is told he has cancer, without giving up to living. (degree of his intelligence or sophistication doesn't do a lot. It's a matter of strength of self.)
- 2) those who weren't healthy already before they acquire the disease, may tend to accept the fact, because they are used to be sick.
- 3) have a family who can support the patient to the very end.
- 4) have a family or friends who can understand the patient's past life style correctly.

B) Factors of ones who tell, the medical professionals

- 1) a medical team which can willingly listens to the patient's needs (sympathy)

2) make an appropriate judgement toward the patient's regression, dependence (amae), selfishness or reserve.

3) can support a patient in the process of accepting his own death unindicatively.

C) Time of telling

1) when a patient can face fear of death positively and when he has enough energy to get with his disease and also when he has strong self-esteem.

3. SOCIAL ASPECT

A) Factors of the patient

1) one who takes an important role in a society.

2) one who feels responsibility to the task he will leave behind and to influence he will cause after he dies.

3) have a family or friends who are trustworthy enough to rely on matters after he dies.

B) Factors of ones who tell, the medical professionals

1) a medical team which can find out and draw a meaning of the patient's life and encourage him with it.

2) a medical team which can support a patient by a group therapy and a sel-help group

3) a medical team which can produce cheerful, bright environment in a unique society of the hospital

4) a medical team which can support the family who are suporting the patient.

C) Time of telling

1) when a patient becomes anxious about unfinished work and also when he still has ability of action and giving indication

4. BIOETHICAL OR EXISTENTIAL ASPECT

A) Factors of the patient

- 1) can understand that dignity of death means dignity of life (living)
- 2) can understand how effectively he can live and that time is not quantity but quality...
- 3) can understand the meaning of his existence

B) Factors of ones who tell, the medical professionals

- 1) can support such patient's understanding of existence
- 2) a medical team which daily tries to brush up its therapeutic self (view of life and death)
- 3) a medical team which consistently have a patient hold hope for living
- 4) can sufficient discussion with the team and exchange information (internal team information system, internal team Balint group, etc.)
- 5) can approach to the patient with kindness and love, yet can encourage and help him to spend his last days meaningfully and independently

C) Time of telling

- 1) when a good relationship has been established between a medical professional and a patient, and when there is a sufficient communication between both. And while a patient can live humanly and have hope.

Table 1-3 Advantage and disadvantage of telling the truth
to the cancer patient

1. ADVANTAGE FOR THE PATIENT

A) Biological aspect

1) becomes cooperative in physical check up and treatment and participates in a medical team as one of the members, then becomes responsible for the process of the treatment of himself

2) make it easier to find a recurrence and metastasis

B) Psychosocial aspect

1) can organize social matters such as a family or a job.

2) some patient may feel peace because he was made known the truth and doesn't have to worry about it.

3) His family doesn't have to tell a lie.

C) Bioethical(existential) aspect

1) can lead a meaningful life.

2) can try to complete his work such as autobiography or life-work.

3) can summarize of his whole life.

2. DISADVANTAGE FOR THE PATIENT

A) Biological aspect

1) when it's told without proper readiness, a patient gets confused and hard to cope with. It may cause worse situation such as acute depressive condition, anxious state, increasing of anger, etc.

B) Psychosocial aspect

1) some patients may lose motivation of fighting with their

disease and give up to live or to be regressive.

C) Bioethical(existential) aspect

- 1) some patients may commit suicide

3. ADVANTAGE FOR THE MEDICAL PROFESSIONALS

A) Biological aspect

- 1) easy to explain about his disease
- 2) can provide physical check up and treatment with less problems and provide a responsible medicine.
- 3) long term, periodic observation is possible.

B) Psychosocial aspect

- 1) since there is no need of telling a lie, care become easier and more dedicated. That means it make it easier to talk with a patient and give advice properly.
- 2) being delivered from the medical case which may happen to the loss of the patient and the family from not telling the truth.

C) Bioethical(existential) aspect

- 1) make it easier to provide cure and care which will give a patient meaningful life to the last point of time
- 2) the inter-reliance between a patient and a medical professional increases

4. DISADVANTAGE FOR THE MEDICAL PROFESSIONALS

A) Biological aspect

- 1) some patients may give up living and stops being under treatment on the half way through.

B) Psychosocial aspect

- 1) some patients may become harder to deal with after telling the truth. (some may get angry at a medical professional or suddenly become dependent or regressive)

C) Bioethical(existential) aspect

- 1) must carefully follow the patient after telling the truth, for this, they must make a team program.
- 2) when there isn't medical team, often doctors and nurses sacrifices themselves.

Tab. 1-4 Terminal-Patient-Evaluation-Grid (TPEG)

Dimensions	Patient		Care
	Current	Background	
biological level	general condition (pain, nutrition, sleep), present illness, diagnosis, stage, treatment, prognosis	sex, age, past history, family history, chronic disease in treatment, constitution, heredity	care in the biological level
psychological level	mood, frustration, psychological reaction, anxiety, feelings to the therapist, the neighbor patients and the family	life style: including habit and taste life attitude: dependent, independent attitude toward the past disease, personality, the level of self-control, attitude toward stress	care in the psychological level
sociological level	supportable family, economic problem, responsibility and position in the occupation, relationship in the ward	occupation, education, social position, marriage, family constitution, position in the family, conjugal relations, social position of the family, transactional pattern	care in the sociological level
ethical (or psychoecological) level	told the diagnosis or not, how he understands the told diagnosis, meaning of disease in his life trust to the therapist, life review	religion view point of living and dying, attitude toward the death of one's near relation, meaning of life	care in the bioethical (or psychoecological) level

Designed by Ikemi and Nagata, modeled after the PEG (Patient Evaluation Grid) of Leigh, H., et al.

2. BIOETHICS AND TERMINAL CARE IN JAPAN

1) Introduction

The fast developemnt of science and technology in recent years has even made it possible to control the gene. The newly gained knowledge must be used for the welfare of the human beings. The development of science and technology may lead us to the total destruction if we are not careful. We now need a new ethics to meet the new era. The value and usefulness of science and technology are created by the people. To evaluate the science and technology we need a feed-back system to see the science, the technology and human beings as a whole, and we also need a phylosophy and an ethics to be the basis of that system.

Death, in the mean time, has not been discussed much, although it can be said that is one of the climaxes of medical treatment. Bioethics will deal with death and dying as a very natural and usual matter in a person's life.

2) What is Bioethics?

Bioethics is a compound word made in Greek. The word first appeared in the United States in the latter half of 1960s. It seeks the medical treatment to match the new era and trys to find a strategy for the realization the new treatment. Accordingly, the meaning of bioethics differs a lot between the ages, the nations, the traditions and customs.

Medical treatment in recent years works as synthetical software based on natural science, social science and cultural science. Various types of sciece are put together in a patient as an

individual and work as whole person medicine. The conventional medical ethics can no longer cope with problems that came about with the new development of science & technology. Bioethics values the achievements of science and technology concerning 'life' and 'medical treatment' and find the strategy to make use of achievements so that human beings get along well with other living things in 'the earth community' and that welfare of each individuals be sought.

To decide that strategy it is characteristic in the bioethics that not only the specialists but also the public who will be effected by the decision must will take initiative. The roots of this characteristic are the civil movements, such as anti-pollution, anti-war and anti-discrimination movements, which occurred in the late 1960s of U.S.A.. The public raised question about the conventional value and ethics. From within these movements a cry against the devastation and inhumanity of the medical treatment came out and developed into the civil right movement by the patients to regain humanity. Right of self-determination came to be highly respected as the patients began to think they themselves must decide things concerning their own life and death. The idea of the right to know on the part of the patient and the doctor's truth telling duty even helped making some judicial precedents in favor of that idea. As a result, Patient's Rights Officer, also known as Patient's Representative, Ombudsman and Patient's Rights Advocate, as a specialist for the better communication of doctors and patients appeared as an occupation. He is the specialist of human relations with some knowledge of medical science and acts as a channel connecting between doctors and patients. The fact that

there are more than 2000 of them in the U.S.A. means that many people are asking the fundamental question, i.e. "What is the medical treatment and for whom?" Consent in the medical treatment, 'the informed consent' with ample information is now very important. To respect the self-decision-making right, the doctors should inform the patients with understandable words of the following, and the patients have the duty as well as right to be informed, with the help of Patient's Rights Officers if needed:

- (a) contents of diagnosis in detail
- (b) what the treatment is like and what it is for
- (c) the possibility of success of the treatment and what the patient can gain by the treatment
- (d) alternative treatment, if any
- (e) what will happen if the treatment is not made

What is characteristic with bioethics is the attitude toward truth telling and decision-making by the patients themselves and they are based on open communication, co-possession of facts, information and also the decision between the doctors and the patients. And all the participants are dedicated to improve the medical treatment to protect the irrecoverable life of the patients.

Bioethics was hailed and approved as new value standard all over the United States, helped by the timing and the American enterprising spirit. It was acknowledged in the ethical principles amended sharply and adopted by American Medical Association in 1980 and in the judicial council regulations prepared by the same association.

Magna Carta for the patients prepared by American Hospital

Association in 1973 shows the meaning of bioethics clearly, and the contents are briefed as follows:

- (a) the clarification of the responsibility of the medical treatmentⁿ
- (b) respect of privacy
- (c) truth telling
- (d) informed consent
- (e) autonomy and self-determination of patients
- (f) overcoming of social descrimination of the patients

The above had been decided by the individual doctors by their own ethics or view, but the doctor-patient relationship has changed so much, making it almost impossible for individual doctors to make decision.

The trend is the same in Japan as in the United States that a person now wants to make his own decision about his health, and the public supports his decision about his health.

I would like to analyze the actions that are usually considered medical treatmet or medical action.

a) medical and scientific action:

The purpose is to seek and study the cause of disease. The doctor is interested in disease itself and takes such scientific methods as analysis, universality using anatomical and physiological method.

b) medical treatmental action:

Patient care oriented action. Whole person medicine consisting of cure and care based on bio-psycho-socio-ethical(existential) medical model. Too much of this action may cause the doctor's self-sacrifice. Team

treatment is desirable.

c) medical economical action:

Medical action as money making. To operate a hospital or a clinic one has to seek rationality and profitability and needs managerial ability. But too much seeking of profit will make a doctor greedy as late Doctor Takemi called him, 'Yokubarimura no Sonchosan'. His office will go on the profit for profit principal. (medical economics)

Medical Science and treatment should be discussed from the above three stand points separately, but in reality, they are not.

Patient-oriented principal needs b) action, but we doctors have to take all three actions at the same time.

Doctors working in public hospitals have to take action b) of course, but they also have to think about a) and also c) under the name of administrative management. We have to fill and balance all three necessities. Sometimes they contradict each other. For example increase of prescription and medical examination will improve the hospital economy. These, however, should be decreased wherever possible for the sake of patients. Also to become a distinguished doctor, one needs to keep on studying and ask patients cooperate and receive examinations. We doctors suffer quite a lot from these contradictions. Bioethics should be the basic philosophy to cope with these contradictions. It should not be the castle in the air, it should be built as a basic and realistic idea for medical treatment.

Bioethics is a scientific philosophy of human beings who are trying hard for their survival through the 21st century and on,

with respect of life as its main idea. It has the ability to unify the various fields of science.

3) The development of bioethics in Japan

The idea of bioethics which has developed dramatically in the United States in 1960s is still quite new in Japan, and accordingly, we have few literatures about it. As Doctor Kimura pointed out, however, we are now in need of bold building up of our own bioethics that will suit the need of the Japanese people.

In 1981 Japan Public and Private hospital Federation published 'Hospital management, Ethics of Administration & Ethics of Medical Treatment.'

In 1982 Japan Hospital and Medical Treatment Institution Committee issued 'Manual for doctors in operation.' In Chapter 4 with a title 'The right and responsibility of patients', they have enumerated seven kinds of the right and responsibilities. Also in this manual they suggest medical treatment to improve from quality control to quality assurance. This idea has been developed from the words by Potter, V.R. (Wisconsin Univ.):

'Bioethics intends positively the use of biological science for the improvement of quality of life.' (1971)

Japan Medical Association started to use the word 'bioethics' in 1971 and it is advocating bioinsurance, the health insurance system with the idea of bioethics.

We now would like to discuss some problems of bioethics in America, taking in to consideration especially the different situations of Japan and the United States.

(a) In the United States, the first to be considered is the

right of the patient and the duty of doctors and judicial precedents are the basis of decision making. It does not implicate positive, spontaneous ethical action, like humane communication between doctors and the patients, restoration of humanity in medical treatment, daily living style for the improvement of quality of life, which comes spontaneously when we see life anew.

(b) In bioethics, life and death are the most important themes. Humanism in medical treatment should be systematized and realized more positively as part of the holistic treatment for the sake of health throughout a person's whole life seen from biological, psychological and sociological standpoints. To obtain this goal revival of humanity in various fields of society is needed.

(c) We have to create our own bioethics taking into consideration Japan's particular social and cultural background.

The ordinary doctor-patient relations in Japan do not need direct judicial intervention or patient's rights officer, although there are some medical disputes recently. The fact we have special medical insurance system that is not seen in any other country in the world is causing a lot of troubles. But it seldom happens that the medical treatment is the target of civil movement.

Being a doctor is generally considered to be a highly distinguished occupation that requires self-discipline. Doctor-patient relation is full of trust which is particular in Japan. The doctors are supposed to work for the cause of dignity of individuals and nature's order, for which there are two rules that the doctors should follow.

(a) The results of experiments of biological technology on other living things should not be applied to human beings as they are.

(b) We have to make it clear the difference between human beings and other living things.

This idea is based on the thought of Kant, I.'s "absolute value of human beings" and is supported by the philosophical concept that each individual has absolute right and value without exception because he is a human being.

We are now confronted by the propositions like the cause and meaning of life particular with human beings.

Humanistic psychology made its debut 20 years ago as the third psychology after psychoanalysis and behavioral therapy mainly in the United States, and has helped to find the answers to these propositions. The answers can be summarized as follows:

(1) Human beings are not the mere collection of parts.

(2) Human beings have their own will and make a decision within his responsibility. We can not explain human action with only stimulation--reaction relation.

(3) A person should be aware about his psychological condition that is related his physical condition.

(4) A person exists within his limited time and within certain human relation.

(5) A person seeks the meaning of life and also the cause of life.

The above summary has a figure of Orientalism, taking seriously the human beings as a whole, confronting the human existence's reality, (related always with death and surroundings) using

physical technique to regain his existence as a whole person.

Having basics on humanistic psychology helps bioethics to develop into the study of humanity revival.

If a doctor has the knowledge of bioethics, he can approach to the bio-psycho-socio-ethical existence of patients.

4) Terminal care and bioethics

Death is one of the fundamental themes in the study of bioethics.

There are many problems that should be studied concerning death: i.e. the definition of death, truth telling, terminal care, hospice, vegetative condition, applying standards for the use of life-supporting devices, euthanasia, rejection of treatment. Everyone of these is almost impossible to get a definite answer.

It is simply because of the individuality of death, for each person has his own death as he has his own life. Besides to discuss death we have to consider the view of life and death and religion of both the doctor and the patient and the relationship between them.

A. Definition of Death

Life-supporting devices, transplantation of the viscera and brain death raise the need of definition of death. The basics of the discussion are:

- 1) A live person should not be considered as dead
- 2) A dead person should not be treated as alive
- 3) Avoid the confusion of dead and alive and make quick treatment according to circumstances.

These are the human right oriented views seeking the profit of patients as the result of treatment. On July 9, 1981 the Presidential Committee for the Study of Ethical Problem concerning medical, scientific, behavioral study defined the text on the definition of death as,

1) irreversible stoppage of circulatory and respiratory system

or

2) irreversible stoppage of the function of entire brain, including brain stem.

The committee also suggested that the announcement of death should be made according to the medical standard which is accepted in general. This suggestion was prepared by more than 1000 specialists and non-specialists after lots of discussion is supported by many problems from various fields.

The definition of death is still under discussion along with the definition of brain death in Japan and also in various countries.

There is a judicial precedent in the United States admitting the right to die, but we should consider this problem thoroughly, not to jump at a quick conclusion.

Life and death has always been a theme since the dawn of humankind. The answer should be after ample discussion and general agreement. Viscera transplantation is sure to help many lives, but the doctors cannot be too careful in announcing the donor's death. They should seek enough opinions from the specialists and non-specialists in various fields.

At present, the death announcement is usually made after three triad which the doctors in general seem to think it appropriate are recognized.

- a) stoppage of breathing
- b) stoppage of the heart
- c) dilatation of the pupil

B. Terminal Care, Hospice

Terminal care aims physical comfortableness, release from physical pain, psychological release from fear of death, acceptance of the ambivalence to death. The patient is supposed to stay self-conscious of his social existence and try to make use of his remaining time and stay proud of being a human bio-ethically with the help of terminal care.

To tell or not to tell cancer to a cancer patient is no longer the theme of discussion. It is now the time to discuss how to make the telling. That is, the telling should be made considering the patient's bio-psycho-socio-ethical conditions and the doctors should share the information, decision and procedure with patients and take considerate care of them. If no telling of the truth keeps the patient from losing hope, it is acceptable.

Pain has a lot to do with terminal care. The patient try to communicate with the doctors with the word "Ouch", or express the

pain with his movemet. The doctors are expected to understand the various needs of the ptient through his expression of pain. Hospice does not mean the building itself but the care taken in 'a place where a person works hard to be considerate to another person's pain,' as Dr. Hara said.

C. A philosophy of life and death

One of the scriptures of the ancient Buddhism is written in poetry titled 'HOKKUKYO'

We are now nearing the boundary of death
Those who are on other side, do not know the truth
Those who know the truth
Will never fight again

Buddhism is the basis of the Japanese way of thinking, and we are ethically Oriental. The Japanese have been the farming people who feel th natre and the people as one body and all the people are connected in some way or another. All the Japanese people grieve for the dead when they find the Japanese name on the passenger list when an airplain crashes overseas.

We and our society are within an ecological system. We are living under nature's order as well as social order. We are leading a social life within the nature's living world. "Death territory" is where all the living things will go eventually, and if we find it inevitable, we start to take 'here and now' seriously, doing our best every moment of our lives.

The only difference between the patient and the non-patient is

the comparative knowledge of the time of death. This view gets along well with the existence of the human beings. This is the essential philosophy of life and death for the doctors either in terminal care or in daily common clinic care. This is the very basic of whole person (holistic) treatment and a must for the establishment of therapeutic-self.

Bioethics connects the realistic part of medical treatment like medical science and technology with the ideal, abstract part of it like ethics and philosophy. They are inter-related but independent.

Bioethics is not universal but circumstantial ethics. When we see bioethics in this way, we inevitably find the philosophy of life and death at its bottom.

We now try to find procedures to establish our life and death philosophy.

a) the knowledge of inability

If we know our own inability, it means we know our own limitations and this knowledge makes us modest. We should not be conceited and have to always ask ourselves what we can do when we see the patients, and this attitude help us have wisdom. As the proverb goes, 'Discretion makes one sincere.'

To share the tears with the patients is 'Hi' (sadness) in Buddhism. It can be said the life and death philosophy is the ethics of 'Hi'

b) One dies as one lived

We often have a standard view of death, but each death is different from another. How one dies is just like how one lives.

We doctors are quite often too accustomed to death and often try not to see the death of other person. In order to face death, we

have to get rid of our conventional view, see the patient's individuality, and treasure that individuality.

c) When one's relative dies, it is a time to think over death

Basically, a hospital is a place for work and a patient is an object of the occupation for us doctors. A patient's death is not our own. But when one of our relatives dies, it is no longer remote but close. We remember when we played with him and that makes us full of grief. A relative's death is emotional. That emotion can help us understand the death of a patient. The understanding is made when the doctor sees the patient warmly as a human being as well as scientifically.

d) Think one's own death

A man is lonely even at his birth and stays so until his inevitable death.

Death is always 'Asuwa wagami.' (meaning ^ttomorrow it's my fate.) We are usually optimistic and seldom think of our own death, thinking ourselves an exception. Death is generally thought to be impure and we usually see only the negative side of it. But we have to see the positive side of it, too. People grow because they are mortal.

To think death as impure makes us fear the death. But what we have to do is not to fear, but to live a rich life positively. When one says he is ready to die, he feels his job in this world is to be done. His readiness for death makes his life beautiful for the first time in his life. This state is what Kukai, the famous priest in the Japanese old era, called 'Sokushinjobutsu' (meaning to have a rank near Buddha right after one's death, for him living and dying have the same meaning). 'Here and now' is not the same as

what the opportunist means. It means a full, rich life, positive attitude toward life, within the limit of time and his relative existence.

e) A person who does not learn, will grow old like a cow. He gains weight but does not gain wisdom (old Buddhism poem).

Aging, disease, and death are abominable but inevitable. We have to face death and while dealing with it, try to live a better life.

We have to keep learning ^{by day} day and try to be wiser. For this we cannot afford to waste even a moment of our time.

5) Conclusion

Bioethics has developed from the encyclopedic study on life to a study to seek the essence of human existence on the basis of humanistic psychology. Bioethics is sure to be the main cause of holistic treatment from now on.

For the development of this study in the medical treatment of Japan the following conditions are necessary.

(a) Bioethics in the future should not hinder the development of science and technology, but should be used to evaluate the development and help the effective use of it.

(b) Bioethics should not stay as idealism. It has to be studied among the various views on medical treatment to bio-psycho-socio-ethical(existential) medical model. It should not be only a theme of academic discussion. The realistic realm of science and technology and the idealistic abstract realm of ethics

should be related and unified in the whole person medicine.

(c) Oriental, especially Japanese way of approach means a lot for us to keep bioethics under preceding conditions. "Ishinhou" (doctor's manual) written in the Heian era (982), "Youjoukun" (life style medicine) by Kaibara, Ekiken (1913), "Seitai no zenkisei" (holistic naturality of human being) by Hashida Kunihiro and the recent "Whole person medicine from psychosomatic medicine" by Ikemi, Yujiro (1982): these literatures and many more are already in Japan to help the development of bioethics.

It is our responsibility to create bioethics that suits the Japanese with the help of good work of our predecessors. This is not for the Japanese only but also for whole human beings toward 21st century.