Death with Dignity

By Koichiro Adachi

Every fall, Japanese universities host show-and-tell days featuring a wide range of student activities. Many of the most recent ones, in the fall of 1992, saw poster displays, symposia and other events focused on the theme of "Between Life and Death." Indeed, this has been the trend for the past few years. As a result, I have had the chance to talk with a lot of university students about the Japan Society for Dying with Dignity (JSDD), euthanasia, living wills and all of the legal problems involved. Interest in death with dignity has spread to high-school students as well.

Six groups of students from different high schools in Tokyo recently visited the JSDD offices with a request for information so they could write a report for their social studies class. Of course, they had already read the JSDD's *Dying with Dignity* and *A Dying with Dignity Reader* as well as numerous newspaper and magazine clippings. They had boned up on the subject, and they asked some very good questions.

For example, they wanted to know the difference between death with dignity and euthanasia, the difference between passive euthanasia and active euthanasia, what the JSDD was doing by way of public education programs, how many members the JSDD had, why the membership is growing so fast, why people join the JSDD, and much, much more.

Among them, there was a group that not only asked questions but also borrowed a JSDD videotape on death with dignity so they could show it to the whole class.

I particularly remember a group of five junior high school students who came all the way from Aichi Prefecture with their teacher in May 1992 to see what they could learn. The whole class was visiting Tokyo and planned to go to Tokyo Disneyland the next day, but these kids wanted to find out a little more about death with dignity so they could include it in their report on the outing.

At the time, I was astonished that a group of junior high school students would be dealing with such a life-and-death subject and asking about death with dignity. "It sure is," I thought, "a change from the old days when kids were sheltered or indifferent." So I asked them if they were looked at as the oddballs in the class. And one of them answered, "Not at all. There is a lot of talk at school about death with dignity."

In the fall of 1992, a pair of girls from one of Tokyo's leading junior high schools showed up at the JSDD to say that their class was going to be debating euthanasia and they were on a foraging expedition to gather information and supporting evidence for the "for" side. I did what I could to help them, and on the way out, one of them said, "Thanks for all of the ideas and information. We've got enough here to blow the other side out of the water."

Current buzzword

I wondered out loud how many high school students there were who knew about death with dignity. Their answer was that more and more students have been thinking seriously about life and death since sex education classes started discussing AIDS. And once they start looking death in the eye, they notice that the media seem to deal with it as a three-part package including brain death, organ transplants and death with dignity, so that students everywhere are familiar with the term "death with dignity"—even if they are not really sure about the details.

Death with dignity seems to be one of Japanese society's current buzzwords. With the AIDS threat, young people are more conscious of their own and other people's mortality and have become more interested in death with dignity. While I should be pleased that people are more interested in death with dignity, I am sorry that it has to have such tragic causes.

According to the Ministry of Health and Welfare, there are now 977 people in Japan who have AIDS or are HIV positive (not counting those who were infected by transfusions of contaminated blood). Of this number, 424 were new in 1992. While these numbers are much smaller than in many other countries, they are still large enough to finally move the schools and all of society into high gear on AIDS prevention and treatment.

While the connection between AIDS and death with dignity may seem somewhat strained, there are reports that such a linkage is not limited to Japan and that the AIDS epidemic was one factor behind the November 3 California referendum on whether or not to legalize assisted suicide. Nor is this something that we can write off as peculiar to the United States or California with its large HIV-positive population.

Are adults as interested as young people are in death with dignity? There has been a surge of applications for membership of the JSDD, and membership was over 50,000 as of the end of December 1992. We have been getting between 50 and 100 applications every day.

The JSDD is a nongovernmental organization established in 1976 to defend the people's right to make their own decisions on dying. At first, it was ignored by both the health care establishment and the public at large—and there were even some who termed it "a group of loonies." As might be expected, members were few and the membership did not grow very fast. It was not until 1990 that the membership topped 10,000.

These were a difficult 14 years for the JSDD as it battled public prejudice and scorn. Yet in 1991, the membership was up to 30,000 and the media suddenly latched onto this increase as symbolizing a new social phenomenon.

Today, 70% of the members are 65 or over, and the average age is on a declining trend. Another recent trend is for husband and wife to both join together.

How are we to account for the JSDD's

sudden popularity after its long years in the wilderness? There are a number of direct contributing factors and some indirect supporting factors.

In 1989, the Emperor Showa passed away after a very long illness. While he was fighting for his life, the media carried daily reports on his condition. They gave his blood pressure, pulse, the amount of blood discharged, the amount of blood he received in transfusions, and much more. Death was a constant companion for all of Japan, and it was brought right into the living room. As a result—and especially among older people—there was a greater immediacy about death and willingness to talk about it. The old taboos had been broken, and death was something that could be discussed.

The following year, 1990, former ambassador and Japanologist Edwin O. Reischauer died, reminding people again of death's sad inevitability. In addition, the media reported that Reischauer had refused extreme measures to prolong his life and had instead opted for death with dignity.

Media furor

Then in 1991 there was a media furor over the case of a doctor charged with homicide for helping a patient die at the Tokai University Hospital. In this case, the doctor administered potassium chloride to a patient with terminal cancer to enable him to die with dignity.

And last year, 1992, the Japan Medical Association did a volte-face and decided that it would condone death with dignity. This represented a 180° turnaround for a medical establishment that had long claimed that medical practitioners had exclusive authority to deal with matters of life and death and that lay interference was unwelcome.

The same year, a potter in Tochigi Prefecture was attacked by a swarm of bees, went into shock, and died—and was allowed to die with dignity in accordance with her wishes. Because she had also indicated that she wanted to be an organ donor, a respirator was used to keep her body functioning, even though her brain was dead, until the organs could be harvested. This incident was widely reported as a classic case of the possible linkage between death with dignity and organ transplants.

Coinciding with this heightened public interest, the World Federation of the Right to Die Societies held its four-day Ninth International Conference in Kyoto starting on October 23. Including 29 organizations from 18 countries, this federation is quietly campaigning to have death with dignity recognized worldwide. There were reports on the situations in the member countries as well as medical and other advances that are relevant to death with dignity. These educational programs were open to the public, and the hall drew over 800 interested participants every day.

Every time there is a public event such as this, more people become aware of the JSDD's work and want to find out about death with dignity. The movement for recognition of the individual's right to die with dignity has finally been accepted by society at large. In addition to these direct reasons for the movement's acceptance, there are at least half a dozen indirect supporting factors.

First is that Japan has passed Sweden and Switzerland and holds the world's longevity record. The average Japanese lifespan is now 76.11 for males and 82.11 for females. Historically, Japanese have lived in extended families with several generations under a single roof, but the pattern now is for just the married couple and their younger children to live together.

As a result, there are more and more homes with just one or two old people living alone. And as a further result, more old people have decided that they want to be allowed to die with dignity and without creating a lot of fuss for other people. The old feeling of wanting to live as long as possible—even an extra second, no matter how painful—is slowly giving way to a new concern for the quality of life and the quality of death.

Second is that the amazing advances in modern medical technology have blurred

Membership of Japan Society for Dying with Dignity

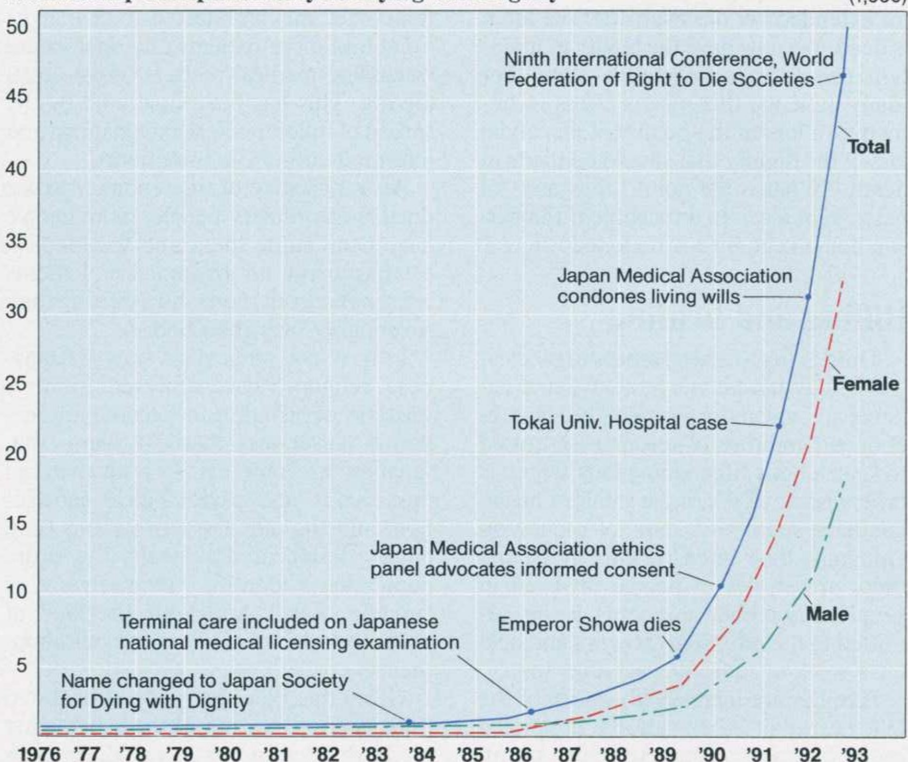

Photo: Kyodo News Service

Waiting area in a hospital. Prolonged fruitless efforts to keep terminal patients alive have prompted a feeling that medical care is more concerned with billing than with healing.

the lines between life and death and made it possible to keep the body functional much longer than before. Illnesses that were once fatal can now be cured. The other side of this, of course, is that doctors can now decide not to let a person die when he or she otherwise might do so.

In the past, people were considered dead when their hearts stopped. Today, heart-lung machines can be used to keep the heart beating and the lungs working for extended periods even after the brain is dead. We now have the ability to maintain people in a vegetative state. For many patients, this means a loss of humanity, a loss of the quality of life, and a loss of the dignity that should be theirs in death. "What is the point," they ask, "of being kept alive on a machine if the person being kept alive is no longer there?"

Billing and healing

Third is that these advances in medical technology have come at a cost, and patients are now more aware of the tremendous expenditure of resources required to keep a body functioning long after it is otherwise dead. Even the smallest hospitals have spent vast sums of money on equipping their intensive care units, and there are stories of people involved in simple automobile accidents being admitted to the intensive care unit and held for a week or more for test after test.

Families are increasingly aware of the bill that awaits them after a prolonged round of fruitless efforts to keep a terminal patient alive, and the patients themselves are starting to question whether that is the way they want to be remembered. Many of the letters received by the JSDD specifically mention dissatisfaction with medical care that seems to be more concerned with billing than with healing.

Fourth is that patients are being more assertive. Doctors have traditionally been accorded special respect and looked up to as healers. As a result, some doctors fell into the habit of looking down on their patients. Yet this has started to change as more and more patients and doctors are discussing medical matters on an equal footing. This has been furthered by the spread of fuller medical explanations and informed-consent requirements.

Also indicative of the tendency to see doctors as ordinary people, more people have been suing them and the medical establishment for malpractice. Patients are speaking out more and asserting their sovereignty over their bodies.

Fifth is the miraculous way the Japanese economy has recovered from its wartime devastation to become an economic power less than 50 years later. Japanese are now rich in both material possessions and psychological satisfaction, and the old class distinctions have largely disappeared as nearly the entire population identify themselves as "middle class." And with the land at peace, people are also less anxious about their everyday lives.

Given this, older people have begun to think about preparing for the inevitability of death. Bookstores have whole racks filled with best-selling books about life and death—silent testimony to the idea that quality of death is an integral part of quality of life. People have begun to think of life and death as the two sides of the same coin. And as a result, more and more of them are deciding how they want to die and then deciding to live their lives appropriately.

Sixth is the change in personal values. Japan adopted Western institutions and embarked on rationalistic mass production for over a century. Even after the war, people considered it a virtue to work hard to increase production. Yet there has recently been a change in this pattern as people's values have shifted from emphasizing quantity to emphasizing quality.

To take even such a very everyday example as rice, people now have basically enough and farmers are vying to produce and sell specialty brands selected for their quality. Even rice is subject to marketing trends and their emphasis on brand names. Nor is this only rice. In almost everything, people whose basic needs have been satisfied are wanting to move up to better quality.

This is also true of the quality of life—the core of our existence—as people who no longer have to struggle to stay alive are now paying more attention to the quality of their lives. It is not enough to live a long time. The more important consideration is how fully the person has lived—how well he or she has lived. And in the process, people are rethinking the old assumptions and asking themselves if they want to be kept alive if they are in a vegetative state, if they have advanced Alzheimer's disease, or if they are otherwise incapacitated.

They are starting to see death as an integral part of life and death with dignity as the culmination of life with dignity. Not coincidentally, there are more and more continuing education programs for adults around the country focusing on the quality of life.

For all of these reasons and more, people are increasingly opting for death with dignity.

In May 1992, the *Yomiuri Shimbun*, a leading national newspaper, conducted a nationwide survey of attitudes toward

cancer and death with dignity. Some 79% of the respondents said they were interested in death with dignity, and 86% said that an incurable or terminal patient's desire for death with dignity should be respected. As the *Yomiuri* pointed out, a surprising number of people want to be allowed to die quietly and naturally.

Living will

The JSDD accepts members who have signed and sent in the standard living will of their own volition. This living will was drawn up by legal specialists, medical professionals, and other expert consultants referring to other living wills around the world and modifying them to take account of conditions in Japan (see the box).

Under the JSDD's living will, the individual affirms that he or she is of sound mind, desires that no extraordinary measures be taken to artificially prolong his or her life in the event of irreversible or incurable illness, and requests that appropriate pain relief be provided. The living will also contains thanks all who respect these wishes and absolves them of responsibility for the consequences. It is a simple statement of the individual's desires, and it is expected that it will be entered into freely and voluntarily.

Once a member files this living will with the JSDD, the JSDD holds it in custody in a large fireproof safe and issues the member two copies of the living will and a membership card. Members are encouraged to show the membership card to their doctors and to make sure that both their family and their doctors are aware of their desire to die with dignity.

Unlike in the United States, the living will does not have the force of a legal document in Japan. As a consequence, there are some members who fear that their doctors may refuse to treat them or refuse to respect the terms of the living will if they show it to them.

While the Japanese medical establishment is gradually becoming more aware of the importance of terminal care, many doctors still believe that the purpose of medicine is to prolong the patient's life as long as possible and that death is defeat for the profession.

It was this that prompted the JSDD in November 1991 to survey the families of 296 members who had died within the past two years and to ask them if the attending physician had provided terminal care in keeping with the terms of the living will.

About half of the people said that their loved ones had died peacefully without having to invoke the living will. These people died of many causes, including cerebral infarction, myocardial infarction, and old age. There were even two traffic fatalities.

Of the cases where the living will was invoked, 93.54% said that their loved ones had been able to die with dignity in keeping with the terms of the living will. I am hopeful that this indicates an increasing awareness of and respect for the death with dignity concept.

The JSDD is working hard for both quality of life and quality of death—living with dignity and dying with dignity—and we see this as the ultimate civil rights struggle. Being able to die well is, after all, the last right in a free and democratic society.

Dying with Dignity Declaration
(Living Will)

To my family, my friends, and my medical attendants:

In preparation for a time when I face an incurable illness and death is near, I declare that my wishes are as follows.

This declaration is made by me at a time when I am of sound mind. Therefore, this is effective in full force unless I revoke or withdraw this declaration in writing when I am mentally sound.

1. I request that medical technology should not be used to artificially prolong my life, if modern medicine concludes that my disease is irreversible or incurable and my life is certified to be terminal.

2. I request, however, that effective pain reduction should be fully achieved by methods such as use of narcotics etc., even though such treatment may shorten my life.

3. I request that all life-sustaining procedures should be withdrawn, if I lie for several months in a condition known as a persistent vegetative state.

I express my heartfelt thanks to all those concerned who faithfully realized my requests.

I further declare that I hereby absolve these people from any civil liability arising from action taken in response to and in terms of this declaration.

Signature: ____________________

Date: ____________

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