

End-of-life Care: Japan and the World

International Comparison Study
on
Death and Dying in Place

International Comparative Study on Ideal Terminal Care and Death
International Comparative Study on Terminal Care System

Abbreviated Version

March 2011

International Longevity Center - Japan

International Comparison Study on Death and Dying in Place

International Longevity Center (Japan)

The International Longevity Center was founded in 1990 to perform studies and surveys from an international and interdisciplinary perspective on the various problems accompanying an aging society with fewer children and provide instruction and policy proposals across the globe. Since then, sister centers have sprung up in 12 countries around the world that continue to actively work towards a dynamic life for the elderly.

Japan is moving at an accelerated pace to an elderly society with fewer children and by 2050 more than 35 percent of the population will be ranked as elderly. In this context, it will become increasingly essential that: 1) elderly people should be able to continue an independent life as much as possible, 2) they should be able to lead a full life even if some form of assistance is needed, 3) the QOL for elderly persons in the final stages of life based on their own personal decision should be maintained, and 4) an environment should be formed that caregivers approve of.

We wanted to add our own basic evaluation while reviewing the status taken for granted in Japan up till now, by employing the method of international comparison as a starting point for clarifying the proper stance to take on end-of-life care as well as the elderly person's right to make his own decisions and QOL. To do this we formed an investigation and research committee to make an "International Comparison Study on Death and Dying in Place" by way of research work both at home and abroad in a wide range of specialist fields including medical care, welfare and life ethics. We carried out an "International Comparative Study on Ideal Terminal Care and Death" and "International Comparative Study on Terminal Care System" focusing on 8 countries including Japan as well as separate study efforts by each of the research members.

The aim of this investigation and research was to clarify differences in end-of-life care between Japan and overseas countries as well as special features of such care in Japan and to offer suggestions on overall policy. We were able to provide ethical issues involving end-of-life care and future directions to work towards, and offer important indicators on areas to work towards on issues on the culture, systems and policy positions of Japan as seen from abroad.

This booklet provides a summary of the "International Comparison Study on Death and Dying in place" report of 2010, and International Longevity Center is responsible for the dialog and text of this booklet. Please consult the report for more information.

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The International Comparison Study on Death and Dying in Place

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“International Comparison Study on Death and Dying in Place” Summary

THE PERSON

- The unique qualities of AD persons are concealed rather than lost (Hasegawa)
- Even though his/her bodily functions have declined, the patient can still recognize whether or not someone is paying attention to him/her. (Uchide)

Basic Viewpoints

- Bringing back the “End-of-life culture” (round table talk)
- In dementia care, the concept of autonomy must be redefined as “being able to express their needs and thoughts in relationships with those close to them.” (Minooka)

Family, community, health care, long-term care

- If a 24 hour care system were available then end of life care in home is possible (round table talk)
- “Cure sometimes, Comfort always” (Minooka)
- [satisfaction with end-of-life care] = [satisfaction of person with dementia] + [family satisfaction] + [satisfaction of nursing/caregiver staff] (Minooka)
- Introduce PEG only after it is explained and understood (round table)
- To spend peaceful final days as one wish, the prevalence of Advance Directive and the movement “let’s think about our own end-of-life care” are important (Minooka)
- Health care costs for the 1 year prior to death decrease as the age rises. The future drop in death rates in advanced countries will occur due to a delay in disease outbreaks (Fukawa)
- Education is needed to promote the fact that as one becomes aware that life is limited and death is also a natural process, then one starts to want to get involved in that end-of-life process (Uchide)

Policy Issues

- End-of-life care at home...Medical treatment-care teams
- Standards for gastric fistula...Installation guidelines
- Promoting an understanding of natural death
- Advanced directive legislation for medical treatment
- Legislation for restriction and suspension of medical treatment (Isobe)

• In Japan there is no national consensus so a large gap exists between ideal and actual status on issues such as end-of-life locations, artificial feeding and discussion leadership so there is a great deal of confusion among patients, family and experts. (International comparative study)

• France, Australia, and Israel already have laws, and precedents for terminal stage nursing care, and medical treatment for doctors, nurses and care workers (International system study),

I. General remarks

1. Worldwide issues and outlook on dementia end-of-life care (excerpt)

Kazuo Hasegawa

1. Final stages of dementia

The final stages of dementia are defined as the d, e, f of 7 of FAST classification as stipulated by Reisberg. This period may continue from several months to several years and there are no uniform limitations on this period. In this respect, dementia differs from the final or terminal stages of cancer.

2. Medical treatment issues in the final stages of dementia

These stages have no strictly defined borders and sometimes the patient shows progression or regression while the stages overlap in an overall process from 10 to 15 years. In the light to moderate periods of dementia, behavioral disorders occur in approximately 80% of the time as cognitive functions deteriorate, but these behavior disorders are transient and disappear on reaching serious periods of dementia. This has been pointed out as a major cause of social psychological disorders. It is also a cause of severe stress on the family and care workers. This process is in most cases accompanied by physical complications. The drugs for treatment sometimes induce side effects that lead to a loss of awareness levels accompanied by so-called delusions (impaired consciousness + insecurity + hallucinations) that are extremely difficult to cope with. Old age related physical impairments unrelated to dementia sometimes occur and frequently happen during the end-of-life care so that a closely coordinated effort by specialists such as the medical and nursing staff is required.

3. Issues in end-of-life care of dementia

The principle behind Person Centered Care is the strong adherence to consistent treatment from the light to intense stages of dementia. Namely, one can expect that the end-of-life treatment will remain consistent from the day the dementia patient is first met until the terminal death period. This method doubts the view that a person suffering from a high degree of dementia will not be able to understand anything that is happening and will become merely a human vegetable. The dementia patient may in fact be capable of sensing the presence of someone there with the patient. This method believes that those suffering from Alzheimer type dementia have not lost their individuality but rather it has become concealed.

4. Help for the family and care workers

End-of-life treatment needs to go beyond universality, logic, and objectivity based on known science and one must then strive for understanding by listening to the story of the patient's life. This is treatment that departs from the "third person" approach and is closer to a "you and me" relation that achieves an understanding of the patient's inner

experiences. The mourning of the family must also sometimes be soothed and regret or anxiety on the part of the family must also be alleviated in what amounts to grief care.

5. Cultural background of end-of-life care

Mr. Fukazawa Shichiro wrote a novel called "The Ballad of Narayama" whose theme was the simple abandonment of the elderly. The heroine named "Orin" was a female in a poor region who willingly went to a mountainous place used for abandoning elderly person as the local custom for solving the problem of lack of food. Her attitude was to progress to a far-off different world that transcended death. Though this was a cruel custom, Orin feels content with spending her final time alone because she can truly feel the love of her son, the long-lasting village tradition and the mountainous landscape she grew up in.

Cultural backgrounds behind end-of-life treatment include these deep human thoughts about death, and build links to draw closer to others.

In recent years, terminal (end-of-life) medical treatment and care have become facility-centered, especially hospital-centered care. However home-based end-of-life medical treatment surrounded by a family with warm human bonds is essential for the most important event in life which is the completion of the individual life with dignity.

2. Round table talk: Home nursing, medical and end-of-life care (1 section)

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Hasegawa I feel myself that forming new bonds is essential when caring for someone suffering from dementia. Due to impaired cognitive functions, dementia patients lose their sense of relationship, and peripheral disorders often referred to as problem behavior occur since their own inner experience differs from what is actually possible to do in real life. Care work involves some means to eliminate that difference and I think forming a new relationship with that person is an essential element in care work.

Yamazaki For us human beings, seeing of someone about to depart from this life is an important event and it certainly seems like a waste to entrust hospitals with that kind of thing.

In-home care for terminal patients is becoming a part of daily life and can be a success if daily life is stable and a determined physician and nurses willing to respond 24 hours a day can handle this task. There are now nursing homes for the elderly and similar places where the patients lead their daily lives so if a doctor is willing to help there then I feel there is no need to check in to a regular hospital. To the contrary, if there is a reliable outside visiting doctor or nurse system set up then there is no need to waste effort going to a hospital at the critical moment when nearing death.

Akiyama I strongly feel that we have to return to the end-of-life care culture we once had. In the period around 1975, there was a reversal in hospital death rates versus home deaths and in the 30 years since then the end-of-life care culture has disappeared.

I think we have to work towards passing along that end-of-life care culture by involvement in the care location, knowing the significance of end-of-life care, and the importance of the end of life, and this includes us and our young children becoming familiar with this concept.

Uchide I think eliminating the problem of dying alone requires not only of course someone else being there but also that you must be committed when dealing with the elderly. I believe that a person's identity is not something within that person but rather something that arises from within a relationship with the family doing the nursing and the local area. I think it is interesting that the human side of a person is formed from many relationships. That especially is what we have to seriously work towards, namely forming bonds and relationships.

Yamazaki The medical treatment team provides feeding tubes and PEGs in order to overcome that critical moment, but those treatments should be carried out only after offering a clear explanation about what happens afterwards to patients that received the procedure and obtaining the understanding by the patient.

3. Ethical issues and perspective of end-of-life care for the person with dementia

Masako Minooka

1. How should we view the personhood of the person with dementia?

How people in society and care workers view the people with advanced dementia affect on ethical considerations and the quality of care that is provided.

(1) Overcoming the 'Empty Shell' theory: Rather than viewing dementia sufferers as an empty shell with a damaged personhood, we should respect them as 'individual persons' and recognize their personhood in every aspect.

(2) Accept the identity between now and past: It is essential that the care providers respect the history of the individual.

(3) Ethics of interpretation: We must recognize that we see the people with dementia through our own filter and interpret them in our sense of value.

(4) Concept of autonomy in dementia: In dementia care, the concept of autonomy must be redefined as "being able to express their needs and thoughts in relationships with those close to them."

(5) Ethical stance that respects the dignity of those with dementia

- a. From <ethical stance for those exercise complete personal rights> to <ethical stance for those who are moral subjects based on the relation with the people around them>
- b. From <ethical stance for those having competence> to <ethical stance for supporting those with incomplete capacity>
- c. From <ethical stance for those capable of moral and logical thinking> to <ethical stance for those with rich emotion as a human being>

2. Establishing a system for appropriate end-of-life care for the people with advanced dementia "mitori"

(1) Ethically appropriate end-of-life care

a. "Mitori" means: "Mitori" is "care that support the elderly and their families in a natural process towards death, rather than meaningless life-prolonging treatment."

b. Achieving balance from a medical, ethical and legal standpoint: Elements for achieving a proper balance in 'end-of-life care' include: 1) The patient is medically in the terminal stage and the futility of treatment is obvious, 2) The wish of the patient to refuse life-prolonging treatment, 3) Consent by the family, 4) Procedural justice in the process of decision making, 5) Reaching a social consensus.

a) Medical viewpoint:

- Defining terminal stage: Standardized definition is difficult. Diagnosis must be made by several physicians in each case. If consensus is not made, the advice by the third party (e.g. ethics consultation, ethics committee) is needed.

- Evidence Based Ethics --Tube feeding in patients with advanced dementia--

Some medical research overseas shows that tube feeding for patients with advanced dementia; a. does not prevent aspiration pneumonia, b. does not improve survival rates, c. It did not decrease the rise of decubitus ulcers and infection; so that PEG should not be a standard medical procedure for the patients with advanced dementia, and oral feeding should be the first choice.

b) Legal viewpoint:

- Issue of medical consent: Legally, the patient is protected from intrusive actions by the doctor for medical treatment since consent for medical treatment must be obtained from the patient. However there is recent debate on whether a substitute for medical treatment consent is possible or not since medical treatment consent does not constitute a legal action but rather “consent for violation of personal exclusive interests protected by law”. Therefore, the recent legal view is that consent by the family is no more than a substitute for the consent of the patient and the right to give consent is not something that can be granted to a third party.

c) Ethical viewpoint:

- Is artificial nutrition and hydration in terminal stages of dementia “treatment” or “daily care”? Or is it “ordinary medical treatment” or “extra-ordinary medical treatment”? Moreover, are “withholding” and withdrawing life-prolonging treatment, or “intention to” and “foreseeing” death ethically different? Careful thought is needed on how to deal with these issues.

(2) Process of decision making

<Decision making by the patient>

a. Right to self-determination: All individuals with mental capacity are guaranteed the right to self-determination in the receiving of medical treatment. This is a rule of ethics called respect for autonomy and is based on the legal principle of informed consent. However, adequate communication is essential in this regard in the final stages of dementia.

b. Mental capacity: The person with dementia should not be comprehensively evaluated as incompetent. The evaluation on mental capacity must be carefully made over time and separately for each case.

c. Concept of autonomy in dementia: Even in cases where the rational mental capacity is inadequate, the person with dementia can express the feeling, desire and needs in relation with the people around him. The concept of autonomy in dementia care is not only an individualistic aspect but also relational aspect of decision making. Implementing this wider concept of autonomy facilitates shared decision making.

d. Shared Decision Making: In cases where mental capacity is inadequate, then residual mental capacity should be evaluated per each issue rather than judging it comprehensively incompetent, and a process of sharing and supporting self-decision making is important. If the patient has no mental capacity then the family may act as a substitute for making decisions.

<Decision making by the family>

- a. Advance Directive: It contains 1) Instructions on medical treatment for prolonging life, etc. (called a living will when it is written), 2) Designating a proxy who decide about the patient's end-of-life care for him/her.
- b. Substituted judgment: In cases where there are no clear and specific advance directives, the surrogate consider the patient's sense of value and views and decide for him/her.
- c. Best Interest judgment: The surrogate makes a decision considered to be in the best interests of the patient. The surrogate considers "Will the benefits of that treatment really exceed the load it places on the patient?" based on the medical facts and the patient's sense of values. Here it is essential that the family, doctor, nurses and care providers mutually discuss this from the patient's point of view and avoid making decision arbitrarily.
- d. Proxy or Surrogate --Who will take the initiative in discussions from hereon in deciding on end-of-life care?

If the patient designated a proxy then that person has number one priority. At this point, guardian for the contracts of the daily life is considered that they can't decide about medical matters. In actual practice, one of the family members has the role of surrogate. To avoid paternalism, those providing the medical treatment should not be the final decision maker.

(3) QOL of the person with end-stage dementia

- a. Rethinking the medical goals, shifting from cure to comfort care: Goals in terminal stage treatment should not be in accordance with the patient's sense of values. Answers to a survey by the Ministry of Health, Labour and Welfare in 2008 revealed that 71% of those facing death within 6 months did not want life-extending treatment. Shifting from complete curing of a disease to comfort care contributes to finding a hope.
- b. The consideration of quality of life VS quantity of life: Life sustaining treatment might contribute to quantity of life, but does not contribute to quality of life in end-stage dementia.
- c. Palliative care in terminal stage dementia
 - a) Ethical difference between "withholding or withdrawing life-prolonging treatment at the patient's request" and "Euthanasia"

Here, "withholding or withdrawing life-prolonging treatment at the patient's request" when it turns out to be futile means practicing comfort care or palliative care, and accepting the natural course of disease. It is completely different concept from euthanasia. This euthanasia on the other hand is mainly an action to intervene directly in the bodily functions of the patient to directly cause death. Active euthanasia is "doing something" to end one's life while passive euthanasia is "doing nothing" to end one's life.

b) Cure sometimes, comfort always

The care with concept of palliative care or hospice care for the patients with end-stage dementia is implemented in foreign countries. Comfort care means to reduce pain, discomfort, dyspnea, etc.

c) Shifting from terminal care to end-of-life care

Essential actions to achieving a peaceful end-of-life are: 1) Recognizing the futility of treatment 2) Promoting communication with those who decide policy 3) Assent on the end-of-life process 4) starting end-of-life comfort care at a timely opportunity.

(5) Issues with family care givers (for supporting them)

a. Role and limits on family caregivers: Family caregivers actually provide care and are also advocates for the people with dementia. But they have burdens physically, mentally and economically. It is important to support family by counseling, advising and utilizing short-stay or respite-care and sometimes placing the patient in a facility should be considered to improve QOL of family members and person with dementia.

b. QOLs (Quality of Lives) and QWL (Quality of Working Life)

a) QOL in the relationship -- From Quality of Life to Quality of Lives

Rather than just the QOL of the person with dementia, achieving a balance with the QOLs of the people involved is also important.

b) QWL (Quality of Working Life; "Active and energetic working life")

The quality of the working life of the care givers/workers is a factor affecting the QOL of both the family and the person with dementia.

c. Degree of satisfaction with end-of-life care (=boosting the quality of end-of-life care):

The 5 factors for boosting end-of-life care are comfort, QOL, dignity, and support for the family and staff. This therefore yields: [satisfaction with end-of-life care] = [satisfaction of person with dementia] + [family satisfaction] + [satisfaction of nursing/caregiving staff].

(6) Importance of Advance Directive and Advance Care Planning

Proper end-of-life care requires respecting the wishes of the person with dementia. The advance directive includes; the wish to reject treatment, where the patient desires to stay in his/her final days, who the patient wants nearby when the time comes, who should decide about the end-of-life care as a proxy, and what is needed to spend one's final days in peace, etc. To spend peaceful final days as one wish, the prevalence of Advance Directive and the movement "let's think about our own end-of-life care" are important.

II. “International Comparative Study on Terminal Care System” “International Comparative Study on Ideal Terminal Care and Death” Report and Analysis

1. Viewpoints of international studies (excerpt)

Kanao Tsuji

French historian, Philippe Ariès reports the following.

Dying in a hospital started happening because the hospital had already become a place where treatment could be given that was not available in the home. The hospital was originally a place to accommodate pilgrims and the sick and needy of society but it gradually evolved into medical centers where one received treatment and the fight with death was carried out. Formerly people died in hospitals because the physician’s treatment was a failure. Nowadays however, hospitals are not places for recovery but have become places to die”. “Death (currently) is now a technical phenomenon in which treatment is stopped. That stoppage of treatment is decided by the physician and the medical team at the hospital. (Essais sur l’histoire de la mort en Occident, 1975)

These comments are undeniable even now and the problems involved are debated from each and every aspect.

However in Japan which is rapidly becoming an elderly society, a review of care for terminal stage patients, which is said to have been a large problem, is now making slow but steady progress.

Nevertheless, not very many international comparative studies of terminal care for the elderly have been carried out so far.

Upon then launching an international investigation and research effort on home nursing care-treatment and end-of-life care, our investigative team embarked on a debate based on the following 2 question points. Question 1 is “Why are hospital deaths increasing while deaths at home are growing fewer?”; and Question 2 “What causes the differences in places where we face death?”.

We considered the following assumption about these 2 questions, namely “the difference in terminal stage treatment is limiting the location of the treatment and therefore the place to die.” Advances in medical technology stem from scientific research so a certain recommended medical treatment is largely common across the world. However due to the difference in rates at death locations, the handling of “death” as something dominated largely by medical treatment is expected to differ according to the specialists in each country.

Namely, the judgment of medical staffs in each country can be amply predicted to have a large impact on deciding the type of medical treatment for terminal cases. That leaves the following question which is: in countries where most treatment is at home what type of systems allow us to “apply the brakes” in what tends to be excessive medical treatment?

We decided that it was necessary to get actual comments from the care staff at end-of-life treatment locations. However, our past experience showed that even making vague queries to the health care staffs in various countries would only lead to ideal answers coming back to us. So we decided on the method of creating typical clinical cases and asking the staffs own opinions and how they dealt with those cases. Specifically we assumed a Case A which was terminal cancer; and Case B which was severe dementia. We then instituted a comparative international study with the cooperation of the International Longevity Centers in France, UK, the Netherlands, Israel and Czech as well as The National Council for Palliative Care in UK, Hammond Care in Australia and the Alzheimer's association in Korea.

This investigative effort consisted of two surveys, one was an International Comparative Study on Terminal Care System involving systems and guidelines on death and end-of-life treatment in each country; and the other was an International Comparative Study on Ideal Terminal Care and Death which included the above two A and B cases.

2. International comparative study on terminal care system (1 section)

Taeko Nakashima

- This study has the goal of clarifying terminal care systems as one type of background for defining replies to the “International Comparative Study on Ideal Terminal Care and Death” to acquire an understanding of laws and guidelines for care and treatment.
- Replies made to this study were obtained from the International Longevity Centers in the alliance countries of France, UK, the Netherlands, Israel, and Czech. The National Council for Palliative Care cooperated with our study requests via the ILC-UK, and Hammond Care in Australia and the Alzheimer’s association in Korea cooperated with us.

1. Existence of Laws, Regulations

<p>i. In your country, are there any laws and/or regulations that set rules on medical and care activities by doctors, nurses and direct care workers specifically targeting the terminal care like Mrs. A’s and Mr. B’s cases? If yes, please also briefly describe these laws/regulations, including their titles.</p>	<ul style="list-style-type: none"> - Laws and regulations have been established in France, Australia, and Israel. - Such laws still have not been established in Japan, the UK, Czech, and the Netherlands. - France enacted Act No. 2005-370 (normally called the “Leonetti Law”) in April 22, 2005 that involves end-of-life treatment and patient’s rights” which eases palliative medical treatment regulations and terminal stage treatment. - Israel enacted the Act of the Dying Patient law in December 2006.
<p>ii. Are there public subsidies (esp. for patient) for terminal care in your country? If yes, please also briefly describe these laws/regulations, including their titles.</p>	<ul style="list-style-type: none"> - Many countries provide assistance based on existing medical and nursing care services, etc. - In France care worker family or relatives can obtain an allowance of 49 euros per day to allow being at home until the death of a patient in the terminal stage.
<p>iii. In your country, are there laws, regulations and/or guidelines that set rules on death with dignity and/or euthanasia (e.g. implementation, prohibition, etc.)? If yes, please also briefly describe them.</p>	<ul style="list-style-type: none"> - Laws clearly prohibit euthanasia: In France, UK, Netherlands, and Israel - In the UK, euthanasia and assisted suicide are seen as violations of the law. However, in 2010, the public prosecutor’s office issued guidelines for law enforcement agencies stating in what situations assisted suicides should be prosecuted and specifying in what circumstance prosecuting a case is not in the public interest. - Israel also prohibits active euthanasia or medical staff assisted suicides under laws regarding terminal care patients. - Even in Czech and Japan that have no laws or regulation regarding euthanasia, the act of euthanasia is basically not allowed. - In Czech, the Czech Medical Chamber) declared that care should not be provided that offers no positive results. - The Netherlands enacted an (“Administrative act for supporting assisted suicides and termination of life based on official request”) euthanasia law. The law covers a physician administering a drug with the goal of ending the patient’s life (euthanasia) or usage by the patient himself from the doctor’s prescription (assisted suicide). This euthanasia law specifies strict conditions for the doctor to end the patient’s life, or the doctor to assist the patient in ending his own life. - Euthanasia is not permitted in any other country except the Netherlands and no statistical information is available.

2. Existence of Guidelines

<p>i. In your country, are there any rules and/or guidelines made by professional organizations that set rules on medical and care activities by doctors, nurses and direct care workers specifically targeting the terminal care like Mrs. A's and Mr. B's cases? If yes, please also briefly describe these rules/guidelines.</p>	<ul style="list-style-type: none"> - There are multiple documents and guidelines on this subject in France, the UK, Australia, Netherlands and Japan - In France there are various documents on this subject regarding cancer and terminal care and various document regarding patient rights based on work of the social problems committee and guidelines from the Palliative Care Society. - In the Netherlands, guidelines on palliative care have been drafted by the Netherlands Physicians Council. These specify the decision-making process including instruction for starting palliative care, conditions for use of painkillers, and communication with the patient and close relatives. It also describes the drugs for use and reports that the physician must provide. - National planning and national strategies for terminal care and palliative care have been established in France, the UK, Australia. - In 2008, France announced its "Development of the Palliative Care Program for 2008-2012 ("Programme de développement des soins palliatif 2008- 2012") as it national plan on a scale of 230 million euros. - The UK Health Ministry announced its "End of life Care Strategy" in 2008.
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3. Death for terminal stage dementia sufferers

<p>i. In your country, are there laws, regulations, rules and/or guidelines that set rules on medical and care activities for older persons who have communication difficulties due to such conditions as dementia? If yes, please briefly describe them.</p>	<ul style="list-style-type: none"> -There are no laws or regulations governing this in any of the countries. - However, in France the Leonetti Law specifies a consultation process: a decision is made based on the patient's advance directive (if present), opinions of close family and relatives, opinion of the doctor, and guardians (if present) and the decision must be preserved for the record. - In the UK, The Mental Capacity Act (2005) for England and Wales and the Adults With Incapacity Act (Scotland) 2000) have been established. <p>The system under the Mental (decision-making) Capacity Act has been extended to support self-determination in the overall life-style including medical treatment in a carry-over from the previous system centered mainly on asset management via Enduring Power of Attorney, etc. This act covers those 16 years of age and over, suffering from learning disabilities, dementia, mental disability, and brain damage (through injury), and cerebral apoplexy, etc.</p> <ul style="list-style-type: none"> - Australia allows the drafting of Advance Care Directives. This document expresses the subject persons wishes for treatment and describes for example whether the subject wishes to receive tube feeding or not or wishes resuscitation performed or not. <p>The subject person can also provide an Enduring Power of Attorney. This person is appointed by a legally binding document specifying who can decide on and handle assets and financial matters even if the subject person for example loses their mental capacity due to severe dementia, etc. The subject person can also specify a guardian (near relative, friend or legal representative) in the same way. If for some reason, the subject person is unable to render consent on carrying out or quitting a treatment or other process, then the guardian can fill the role of that person's representative or proxy.</p>
<p>ii. In Japan, it is common for family members to have conflicts with other family members and/or health care providers when the patient cannot express decisions. Please tell us of any measures or means for mediation in such cases</p>	<ul style="list-style-type: none"> - In the Netherlands and UK there is an organization partially developed for handling such cases. In France and Australia, a family conference is held or physicians or other specialists consult with the family to resolve the matter. - In the UK, the IMCA (Independent Medical Capacity Advocate) was established as an organization to act as a proxy agent working to assist or provide for the maximum benefit of the subject person in case of major medical treatment when that person has lost the capacity for self-determination or has no family or friends to represent him. The IMCA itself does not directly make decisions but finds out and expresses what is the maximum benefit to the subject to the NHS (National Health Service) and other local self-governing bodies. The IMCA can be called even if the subject

	<p>person has family and friends if they are involved in cases of abuse. The IMCA can also voice official objections when a decision is being carried out that does not conform to the best interests of the subject person.</p> <p>- In Japan no such organization has been established. However the Medical Alternative Dispute Resolution (ADR) arbitration association was established in March, 2010 and related study is underway.</p>
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4. Use of PEG (tube feeding)

<p>i. In your country, how common is it to use feeding tubes for elderly patients who are in the terminal phase?</p>	<ul style="list-style-type: none"> - None of the following replies gives a clear understanding via statistical materials, etc. - The UK, Israel and Japan tend to use surgery for artificial feeding in the terminal stage. However Czech does not use it. In Australia there are comparatively few cases using tube feed in the terminal care stage.
<p>ii. In your country, are there any laws and/or guidelines that set rules on usage of artificial nutrition tube feeding in the terminal phase (e.g. implementation, prohibition, etc.)?</p>	<ul style="list-style-type: none"> - Most countries have no regulations on tube feed in the terminal stage - In Israel, terminal care laws allow the patient's doctor to refrain from tube feeding and fluids based on his/her decision in patients near death. - France has guidelines provided by the French Cancer Center (FNCLCC). These suggest not performing enteral nutrition when patient PS (Performance Status) is 2 (the patient cannot work due to sickness) or greater or remaining life is about 3 months. - In the Netherlands, a medical specialists council has issued treatment Guidelines specifying when tube feeding is needed. Use of artificial Feeding and tube feeding in the case of terminal patients is left up to the physician treating that patient, however, overall patient treatment laws obligate doctors to comply with medical ethics standards. Moreover, the nation-wide nursing home organization in the Netherlands called Arcares has issued multi-occupational guidelines in 2001 regarding nutrition and fluid replacement in incoming patients. These guidelines specify what measures to take regarding all types of circumstances.

3. International comparative study on ideal terminal care and death

(1 section)

Kanao Tsuji, Daisuke Watanabe, Taeko Nakashima

This study was made by the theoretical question method in a document question format targeting 8 countries (Japan, France, United Kingdom, Netherlands, Israel, Czech, Australia and Korea). It assumes the following two theoretical terminal cases of: (Case A: Terminal cancer, Case B: Dementia) and investigated the ideal judgment an expert would make as well as a practical judgment the expert might make under actual circumstances. Moreover, in order to analyze the difference between ideal and practical judgments the study also examined the awareness regarding medical treatment and nursing experience, end-of-life care experience, ideal death and ideal end-of-life care.

The investigation was made by the International Longevity Center-Japan, as well as by ILC Centers in the overseas countries of France, UK, the Netherlands, Israel and Czech. The investigation in the UK was made with the cooperation of The National Council for Palliative Care. The investigation in Korea was made by the Korean Alzheimer's association and in Australia with the cooperation of two institutes (Hammond Care and Ramsay Health).

The investigation in Japan centered on 12 facilities (7 nursing homes, 2 group homes, 1 complex facility (a combination of nursing home, long-term senior health care facility, small scale multipurpose home-care nursing, group home, clinic), 1 home-visit nursing care station and 1 hospital as well as on 10 physicians.

Investigation period was from October to December 2010.

In this study, strict ethical control was exercised to ensure personal information privacy and the investigation was implemented anonymously following the judgment on ethics by the ethics committee at the Foundation of Social Development for Senior Citizens.

Number of Respondents by Country

	Medical doctor	Nurse	Direct care worker	Social worker	Other (PT,OT, etc.)	N.A.	Total
Japan	20 9.0%	59 26.7%	102 46.2%	21 9.5%	18 8.1%	1 0.5%	221 100.0%
France	12 70.6%	3 17.6%	0 0.0%	0 0.0%	2 11.8%	0 0.0%	17 100.0%
U.K.	5 50.0%	1 10.0%	0 0.0%	4 40.0%	0 0.0%	0 0.0%	10 100.0%
Israel	25 39.7%	17 27.0%	0 0.0%	15 23.8%	6 9.5%	0 0.0%	63 100.0%
Australia	11 19.3%	20 35.1%	8 14.0%	11 19.3%	7 12.3%	0 0.0%	57 100.0%
Netherland	10 35.7%	14 50.0%	0 0.0%	4 14.3%	0 0.0%	0 0.0%	28 100.0%
South Korea	16 20.0%	44 55.0%	2 2.5%	18 22.5%	0 0.0%	0 0.0%	80 100.0%
Czech	16 28.6%	17 30.4%	4 7.1%	12 21.4%	4 7.1%	3 5.4%	56 100.0%
Total	115 21.6%	175 32.9%	116 21.8%	85 16.0%	37 7.0%	4 0.8%	532 100.0%

International Comparative Study Summary

- Japanese often think about the subject of death. (P23)
- In Japan, a comparatively small percentage wish for “end-of-life care that allows spending as much time as possible together even for example if no longer able to speak” or for “end-of-life care in a system that allows receiving as much treatment and nursing as possible”. Moreover, they tend to take formal religion rather lightly. (p24, p25)
- In Japan, there is no nation-wide consensus so there is a large gap between ideal and actual circumstances on issues such as “location for terminal stage treatment,” “artificial feeding” and “discussion leadership,” leading to a great deal of confusion among the patient, family and specialists. (p26, p27, p30, p31, p34)
- Japanese specialists in many cases place comparatively heavy emphasis on “family opinions” and “length of remaining life” when setting treatment guidelines. (p28 - p30)
- The lengthy waiting period for space at senior citizens home and long-term care clinics is a fact of life in Japan and is probably due to the large percentage of elderly in society. (p33)
- There are clearly established laws and guidelines for end-of-life care in France, the UK and Australia where a large number of responses diagnosed Mr. B’s case as terminal and at the same time did not select artificial feeding. Whether this large number of cases is due to the law functioning effectively or is a national trait is something that should be further investigated. (p35)
- Though among specialists, doctors tend to attach importance to “a prepared death surrounded by one’s family,” nurses tend to stress “death within a short period that does not stress or inconvenience others” which implies that nurses attach importance to the lifestyle of the patient and family. (p36)

【Case A: Terminal cancer】

Mrs. A (85 yrs. old) is a terminal cancer patient and has 1 month to live. She is currently hospitalized and needs medicine to control pain on a daily basis. She sometimes becomes semi-conscious, but she can communicate verbally and has sufficient memory retention to lead daily life without problems. However, her physical capacity is declining, and she needs assistance in toileting. Her husband has already passed away, and her son and his wife live close by (15 minute drive). Yet, both the son and his wife work outside and do not have much time on weekdays. Mrs. A's primary income is her pension, and it is difficult for her to pay for renovating her house (e.g. bathroom). Mrs. A prefers to spend her final days at home, where she has memories with her husband, but she says "I shouldn't ask for too much."

【Case B: Severe dementia】

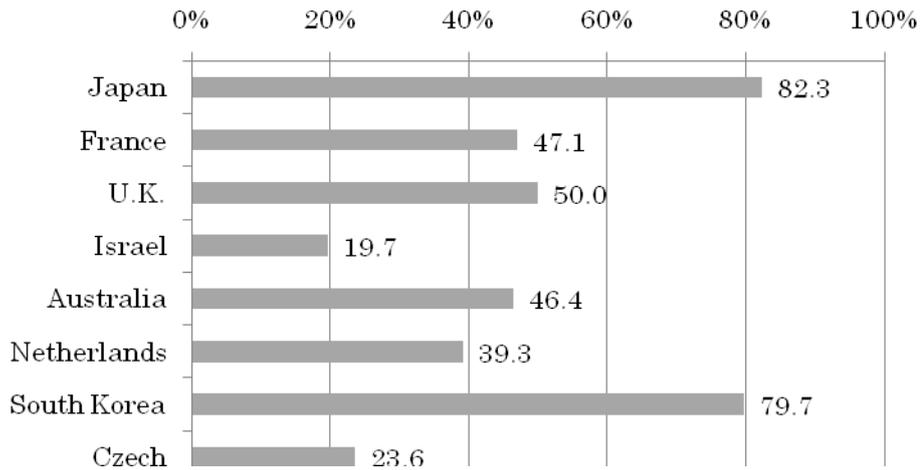
Mr. B (80 yrs. old) lives with his wife at home. It has been 10 years since he was diagnosed with dementia. Although his consciousness is not impaired, he can only respond to families and direct care workers with eye movements. In general, it is extremely difficult for him to communicate with others. About a half month ago, he had high fever and cough, so he went to hospital and was diagnosed with pneumonia. Currently, he is unable to swallow foods, and he takes medicine and nutrition through IV. Because he cannot receive nutrition by mouth, he may soon need artificial nutrition (ex. tube feeding). However, he is not expected to live long even with this treatment. His wife (80 yrs. old) hopes to have him stay and spend last days at home. She also hopes to spend as long a time with him as possible. Yet, her caregiving capacity is low, and there are no relatives nearby.

<AWARENESS OF DEATH AND END-OF-LIFE CARE>

Japanese rate was highest for both “I think often about death” and “I feel anxiety about death”. Next highest after Japan is Korea. Both Israel and Czech had a low percentage for this question as shown below.

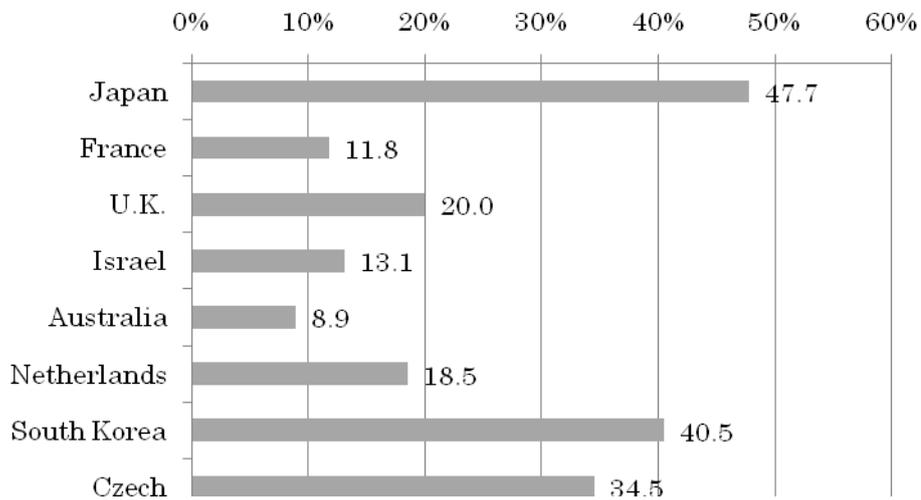
How often do you think about death? (Q4-1)

(The total percentage of those answering “Very often” and “Often” is shown below.)



Do you usually feel anxiety about and/or fear of death? (Q 4-2)

(The total percentage of those answering “Very much” and “Somewhat” is shown below.)

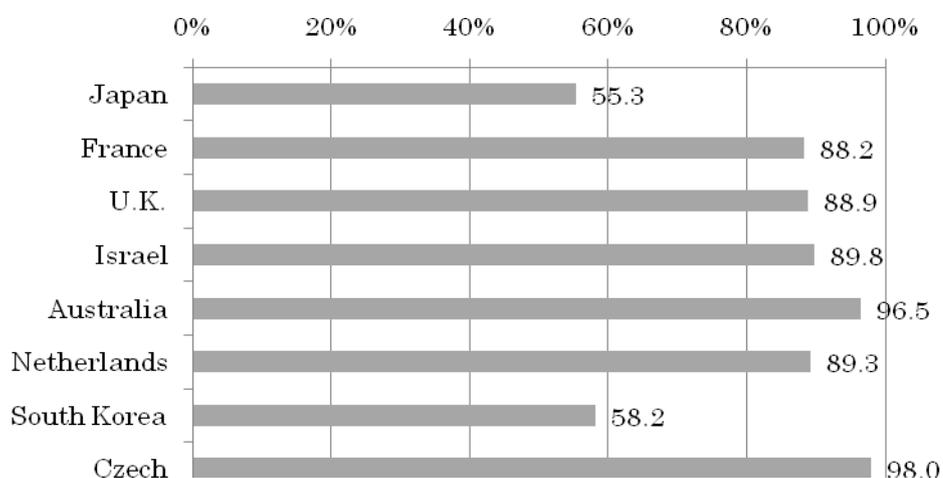


Japan had a comparatively low percentage of positive replies to questions about one's spouse or close relative such as: "Want to spend as much time as possible together even if unable to have a conversation" , "Want environment with as much medical care and service as possible" , "Want to shorten the patient's final suffering period" and "Want treatment to follow the patient's religious or cultural rituals". Moreover, Japanese tend to take formal religion rather lightly.

Considering "ideal terminal care" for your spouse and family (parents and children), what do you think of the following statements? (Q5-1)

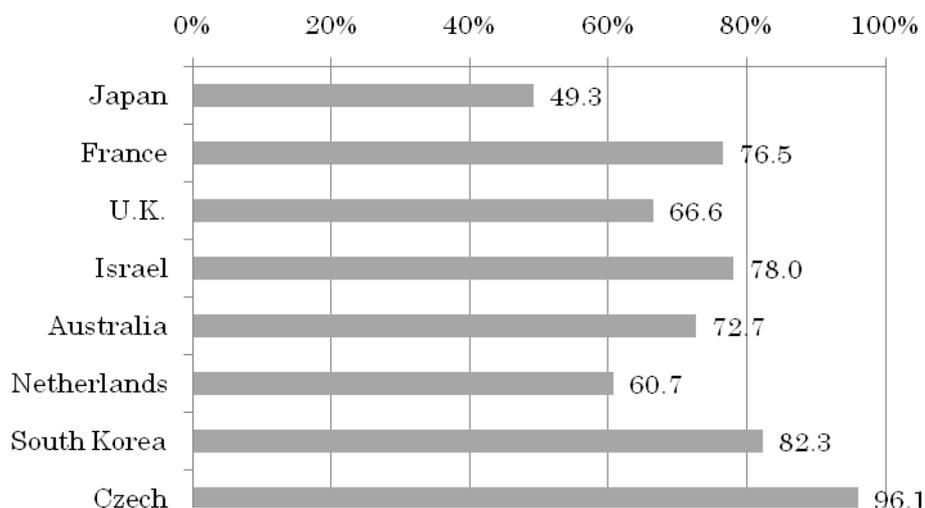
Want to spend as much time as possible together, even if unable to have conversation

(Total percentage of people replying "Strongly agree" and "Agree somewhat")



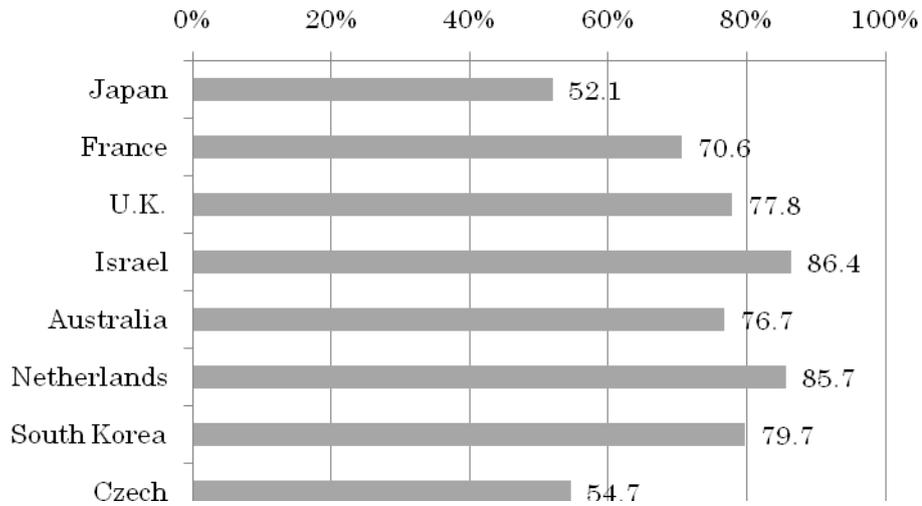
Want environment prepared so as to receive as much medical and care service as possible

(Total percentage replying "Strongly agree" and "Agree somewhat")



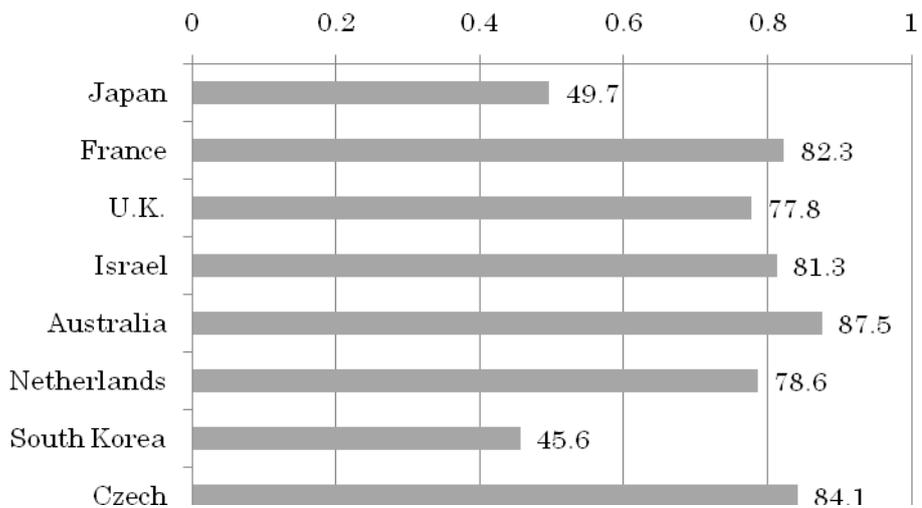
Want to shorten the patient's final suffering period

(Total percentage replying "Strongly agree" and "Agree somewhat")



Want treatment to follow the patient's religious or cultural rituals

(Total percentage replying "Strongly agree" and "Agree somewhat")



<THOSE DECIDING END-OF-LIFE CARE>

In Japan and Korea, judgments were different with a large percentage believing that “Mrs. A herself” should ideally have decision-making rights yet a large percentage believing that her “son” should have actual rights. In Czech, the UK and Netherlands there was no difference in judgments with a large percentage believing that Mrs. A herself should have actual rights.

Mrs. A’s Case: Whose opinion do you think “should be given the highest priority” in discussions that decide medical treatment and terminal care policies? (Q2-3)

	Mrs.A	Mrs. A's son	Primary care doctor	Specialist physician	Nurse or Direct care worker who has daily contact	Social worker	Other	Total
Japan	167 75.6%	34 15.4%	8 3.6%	2 .9%	4 1.8%	5 2.3%	1 .5%	221 100.0%
France	12 70.6%	0 .0%	1 5.9%	2 11.8%	1 5.9%	1 5.9%	0 .0%	17 100.0%
U.K.	9 100.0%	0 .0%	0 .0%	0 .0%	0 .0%	0 .0%	0 .0%	9 100.0%
Israel	57 90.5%	2 3.2%	0 .0%	1 1.6%	3 4.8%	0 .0%	0 .0%	63 100.0%
Australia	46 83.6%	5 9.1%	2 3.6%	0 .0%	1 1.8%	0 .0%	1 1.8%	55 100.0%
Netherlands	28 100.0%	0 .0%	0 .0%	0 .0%	0 .0%	0 .0%	0 .0%	28 100.0%
South Korea	63 79.7%	9 11.4%	0 .0%	1 1.3%	5 6.3%	1 1.3%	0 .0%	79 100.0%
Czech	13 23.6%	11 20.0%	7 12.7%	19 34.5%	2 3.6%	3 5.5%	0 .0%	55 100.0%
Total	395 75.0%	61 11.6%	18 3.4%	25 4.7%	16 3.0%	10 1.9%	2 .4%	527 100.0%

Mrs. A’s Case: Based on your previous experience, whose opinion do you think should get actual priority in discussions that decide medical treatment and terminal care policies? (Q2-3sq)

	Mrs.A	Mrs. A's son	Primary care doctor	Specialist physician	Nurse or Direct care worker who has daily contact	Social worker	Other	Total
Japan	31 14.0%	142 64.3%	27 12.2%	8 3.6%	5 2.3%	8 3.6%	0 .0%	221 100.0%
France	5 29.4%	5 29.4%	2 11.8%	4 23.5%	0 .0%	0 .0%	1 5.9%	17 100.0%
U.K.	6 66.7%	0 .0%	0 .0%	3 33.3%	0 .0%	0 .0%	0 .0%	9 100.0%
Israel	19 30.2%	30 47.6%	2 3.2%	6 9.5%	2 3.2%	1 1.6%	3 4.8%	63 100.0%
Australia	18 34.0%	17 32.1%	8 15.1%	10 18.9%	0 .0%	0 .0%	0 .0%	53 100.0%
Netherlands	12 42.9%	6 21.4%	2 7.1%	4 14.3%	2 7.1%	1 3.6%	1 3.6%	28 100.0%
South Korea	21 26.6%	51 64.6%	3 3.8%	1 1.3%	3 3.8%	0 .0%	0 .0%	79 100.0%
Czech	41 73.2%	1 1.8%	2 3.6%	9 16.1%	3 5.4%	0 .0%	0 .0%	56 100.0%
Total	153 29.1%	252 47.9%	46 8.7%	45 8.6%	15 2.9%	10 1.9%	5 1.0%	526 100.0%

The majority believed that the “Wife” should ideally have decision-making rights on end-of-life care for Mr. B but there was an increasing trend in each country toward actual rights going to the “Physician”.

Mr. B’s Case: Whose opinion do you think “should be given the highest priority” in discussions that decide medical treatment and terminal care policies? (Q3-4)

	Mr.B	Mr.B's wife	Primary care doctor	Specialist physician	Nurse or Direct care worker who has daily contact	Social worker	Other	Total
Japan	20 9.0%	177 80.1%	7 3.2%	1 .5%	2 .9%	12 5.4%	2 .9%	221 100.0%
France	0 .0%	16 94.1%	0 .0%	1 5.9%	0 .0%	0 .0%	0 .0%	17 100.0%
U.K.	2 20.0%	7 70.0%	0 .0%	0 .0%	0 .0%	0 .0%	1 10.0%	10 100.0%
Israel	5 7.9%	45 71.4%	2 3.2%	5 7.9%	1 1.6%	0 .0%	5 7.9%	63 100.0%
Australia	11 20.0%	30 54.5%	6 10.9%	2 3.6%	3 5.5%	1 1.8%	2 3.6%	55 100.0%
Netherlands	4 14.3%	23 82.1%	0 .0%	1 3.6%	0 .0%	0 .0%	0 .0%	28 100.0%
South Korea	14 17.9%	53 67.9%	2 2.6%	1 1.3%	6 7.7%	1 1.3%	1 1.3%	78 100.0%
Czech	1 1.9%	20 37.0%	7 13.0%	23 42.6%	2 3.7%	1 1.9%	0 .0%	54 100.0%
Total	57 10.8%	371 70.5%	24 4.6%	34 6.5%	14 2.7%	15 2.9%	11 2.1%	526 100.0%

Mr. B’s Case: Based on your previous experiences, whose opinion do you think should get actual priority in discussions that decide medical treatment and terminal care policies? (Q3-4sq)

	Mr.B	Mr.B's wife	Primary care doctor	Specialist physician	Nurse or Direct care worker who has daily contact	Social worker	Other	Total
Japan	2 .9%	130 59.4%	42 19.2%	7 3.2%	14 6.4%	21 9.6%	3 1.4%	219 100.0%
France	1 5.9%	9 52.9%	3 17.6%	3 17.6%	0 .0%	1 5.9%	0 .0%	17 100.0%
U.K.	1 11.1%	4 44.4%	1 11.1%	1 11.1%	1 11.1%	0 .0%	1 11.1%	9 100.0%
Israel	3 4.8%	37 58.7%	7 11.1%	11 17.5%	1 1.6%	0 .0%	4 6.3%	63 100.0%
Australia	3 5.4%	32 57.1%	10 17.9%	5 8.9%	4 7.1%	1 1.8%	1 1.8%	56 100.0%
Netherlands	0 .0%	16 57.1%	2 7.1%	8 28.6%	0 .0%	1 3.6%	1 3.6%	28 100.0%
South Korea	5 6.5%	54 70.1%	9 11.7%	1 1.3%	8 10.4%	0 .0%	0 .0%	77 100.0%
Czech	7 13.0%	21 38.9%	4 7.4%	19 35.2%	1 1.9%	1 1.9%	1 1.9%	54 100.0%
Total	22 4.2%	303 57.9%	78 14.9%	55 10.5%	29 5.5%	25 4.8%	11 2.1%	523 100.0%

<POLICY GOALS FOR NURSING & MEDICAL TREATMENT>

As their reason for selecting a “best choice” policy for Mrs. A, the response from many Japanese was to “More likely to fit family’s wish” and few answered “Expected improvement of QOL”.

As a professional, which of the following do think is “the best choice” as a basic principle for working with Mrs. A? (Q2-6)

	Aggressive treatment with anticancer drug	Aggressive treatment with high level medical services	Aggressive treatment with alternative medicine	Pain control only (without aggressive treatment)	Do nothing special	Other	total
Japan	.9%	.5%	1.8%	91.9%	.0%	5.0%	100.0%
France	.0%	.0%	.0%	94.1%	.0%	5.9%	100.0%
U.K.	.0%	.0%	.0%	50.0%	.0%	50.0%	100.0%
Israel	.0%	3.2%	.0%	87.3%	4.8%	4.8%	100.0%
Australia	1.8%	.0%	.0%	90.9%	.0%	7.3%	100.0%
Netherlands	.0%	.0%	.0%	82.1%	.0%	17.9%	100.0%
Korea	2.5%	7.6%	6.3%	79.7%	1.3%	2.5%	100.0%
Czech	.0%	3.8%	.0%	90.6%	.0%	5.7%	100.0%
Total	1.0%	2.1%	1.7%	88.2%	.8%	6.3%	100.0%

Why did you choose the response in the previous question? Please choose the reason that you think is “most important.” (Q2-6sq)

	Possible to recover fully	High possibility for longer life	Expected improvement of QOL	Economical	Respect for Mrs. A's dignity	More likely to fit family's wish	Set by national/facility guideline	Other	Total
Japan	.0%	1.4%	21.4%	1.4%	64.1%	7.7%	.0%	4.1%	100.0%
France	.0%	.0%	52.9%	.0%	41.2%	.0%	5.9%	.0%	100.0%
U.K.	.0%	.0%	62.5%	.0%	25.0%	.0%	12.5%	.0%	100.0%
Israel	.0%	1.6%	59.7%	.0%	33.9%	.0%	1.6%	3.2%	100.0%
Australia	.0%	1.8%	40.0%	1.8%	52.7%	.0%	.0%	3.6%	100.0%
Netherlands	.0%	.0%	39.3%	.0%	57.1%	.0%	.0%	3.6%	100.0%
Korea	1.3%	.0%	29.5%	.0%	56.4%	6.4%	.0%	6.4%	100.0%
Czech	1.8%	1.8%	34.5%	1.8%	60.0%	.0%	.0%	.0%	100.0%
Total	.4%	1.1%	33.1%	1.0%	56.0%	4.2%	.6%	3.6%	100.0%

When responding with a reason in the case of actual treatment of Mrs. A, few of those in Japan responded with “Expected improvement of QOL.” (Q2-7-2)

Which of the following do you think should actually be taken as a basic principle for working with Mrs. A? Please choose the most likely response based on your experience. (Q2-7)

	Aggressive treatment with anticancer drug	Aggressive treatment with high level medical services	Aggressive treatment with alternative medicine	Pain control only (without aggressive treatment)	Do nothing special	Other	total
Japan	5.9%	.9%	3.2%	83.1%	2.3%	4.6%	100.0%
France	.0%	.0%	5.9%	82.4%	5.9%	5.9%	100.0%
U.K.	.0%	14.3%	.0%	71.4%	.0%	14.3%	100.0%
Israel	6.5%	11.3%	.0%	72.6%	3.2%	6.5%	100.0%
Australia	3.5%	5.3%	.0%	82.5%	.0%	8.8%	100.0%
Netherlands	3.6%	.0%	.0%	78.6%	3.6%	14.3%	100.0%
Korea	5.2%	5.2%	3.9%	85.7%	.0%	.0%	100.0%
Czech	13.2%	15.1%	.0%	66.0%	1.9%	3.8%	100.0%
Total	6.0%	4.8%	2.1%	80.0%	1.9%	5.2%	100.0%

Why did you choose the response in the previous question? Please choose the reason that you think is “the most important”. (Q2-7sq)

	Possible to recover fully	High possibility for longer life	Expected improvement of QOL	Economical	Respect for Mrs. A's dignity	More likely to fit family's wish	Set by national/facility guideline	Other	Total
Japan	.0%	5.5%	15.6%	2.3%	54.1%	16.1%	.5%	6.0%	100.0%
France	.0%	6.3%	43.8%	.0%	31.3%	.0%	12.5%	6.3%	100.0%
U.K.	.0%	12.5%	50.0%	.0%	37.5%	.0%	.0%	.0%	100.0%
Israel	.0%	3.3%	36.1%	3.3%	19.7%	6.6%	23.0%	8.2%	100.0%
Australia	.0%	1.8%	40.4%	1.8%	42.1%	7.0%	.0%	7.0%	100.0%
Netherlands	.0%	3.6%	32.1%	.0%	57.1%	3.6%	3.6%	.0%	100.0%
Korea	.0%	3.9%	22.1%	1.3%	58.4%	9.1%	.0%	5.2%	100.0%
Czech	5.5%	3.6%	34.5%	.0%	38.2%	1.8%	16.4%	.0%	100.0%
Total	.6%	4.4%	26.0%	1.7%	46.9%	10.0%	5.2%	5.2%	100.0%

When selecting a reason for their “best choice” of treatment policy for Mr. B, many in the UK, Australia, and the Netherlands responded with “Respect for Mr. B's dignity” while in Japan most responses were “More likely to fit family’s wish.”

As a professional, which of the following do you think is “the best choice” as a basic principle for working with Mr. B? (Q3-7)

	Artificial nutrition	Aggressive treatment with alternative medicine	Rehabilitation	Keep the current treatment	Do nothing special	Other	Total
Japan	46.2%	.9%	16.7%	27.1%	2.7%	6.3%	100.0%
France	17.6%	.0%	23.5%	35.3%	11.8%	11.8%	100.0%
U.K.	22.2%	.0%	11.1%	22.2%	.0%	44.4%	100.0%
Israel	50.8%	.0%	7.9%	25.4%	7.9%	7.9%	100.0%
Australia	15.1%	.0%	9.4%	45.3%	11.3%	18.9%	100.0%
Netherlands	29.6%	.0%	11.1%	25.9%	14.8%	18.5%	100.0%
Korea	59.7%	2.6%	6.5%	22.1%	2.6%	6.5%	100.0%
Czech	45.5%	2.3%	6.8%	38.6%	.0%	6.8%	100.0%
Total	43.2%	1.0%	12.3%	29.2%	4.9%	9.4%	100.0%

Why did you choose the response in the previous question? Please choose the reason that you think is “most important”. (Q3-7sq)

	Possible to recover fully	High possibility for longer life	Expected improvement of QOL	Economical	Respect for Mr. B's dignity	More likely to fit family's wish	Set by national or facility guideline	other	Total
Japan	2.3%	20.5%	11.0%	.0%	26.5%	35.6%	.0%	4.1%	100.0%
France	.0%	11.8%	35.3%	.0%	35.3%	17.6%	.0%	.0%	100.0%
U.K.	14.3%	.0%	14.3%	.0%	71.4%	.0%	.0%	.0%	100.0%
Israel	1.6%	6.5%	38.7%	.0%	30.6%	9.7%	8.1%	4.8%	100.0%
Australia	5.7%	1.9%	22.6%	1.9%	54.7%	5.7%	.0%	7.5%	100.0%
Netherlands	11.1%	3.7%	22.2%	.0%	40.7%	7.4%	3.7%	11.1%	100.0%
Korea	2.6%	32.1%	16.7%	1.3%	34.6%	10.3%	.0%	2.6%	100.0%
Czech	3.9%	3.9%	49.0%	2.0%	35.3%	2.0%	3.9%	.0%	100.0%
Total	3.3%	15.6%	21.6%	.6%	33.7%	19.6%	1.6%	4.1%	100.0%

In France and the UK, the “Artificial nutrition” as the actual treatment policy for Mr. B had a low percentage of replies. In Japan, Israel, Korea and Czech many respondents were in the “Artificial nutrition” group. This “Artificial nutrition” showed a particularly large gap between ideal goal and actual goals. This also had the largest percentage of actual use.

The most often given reason for actual use of this in Mr. B’s case in Japan is that it “High possibility for longer life” and “More likely to fit family's wish.”

Which of the following do you think should be actually taken as a basic principle in working with Mr. B? Please choose the most likely response based on your experience. (Q3-8)

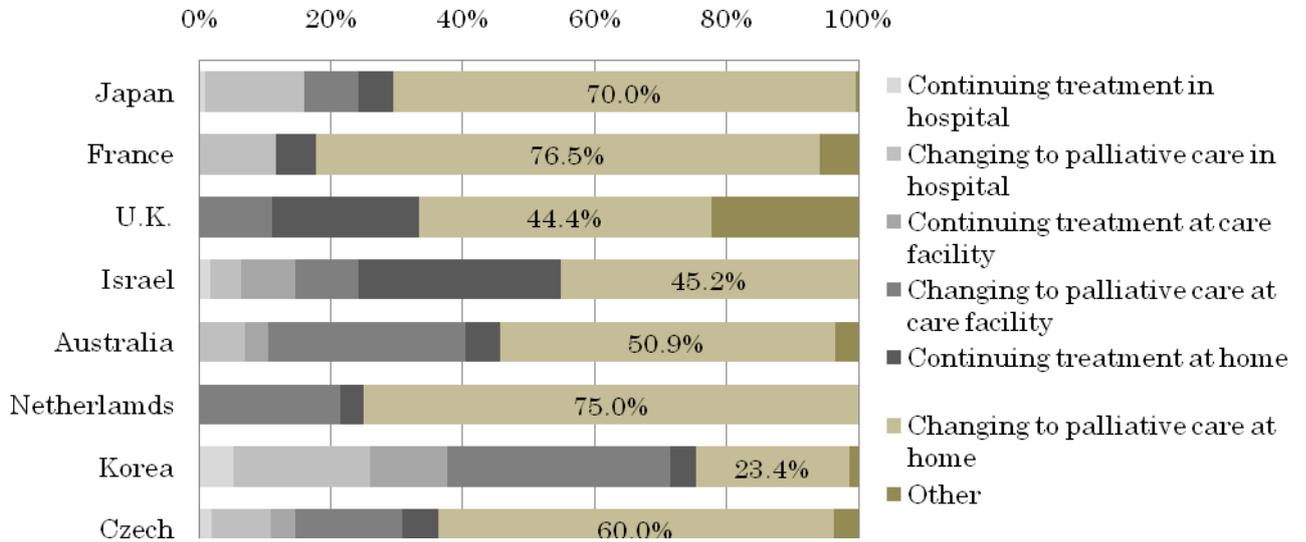
	Artificial nutrition	Aggressive treatment with alternative medicine	Rehabilitation	Keep the current treatment	Do nothing special	Other	Total
Japan	71.6%	.0%	6.0%	18.8%	1.4%	2.3%	100.0%
France	17.6%	.0%	5.9%	52.9%	17.6%	5.9%	100.0%
U.K.	33.3%	.0%	.0%	50.0%	.0%	16.7%	100.0%
Israel	70.5%	.0%	3.3%	18.0%	6.6%	1.6%	100.0%
Australia	41.2%	.0%	9.8%	35.3%	2.0%	11.8%	100.0%
Netherlands	44.4%	.0%	3.7%	33.3%	11.1%	7.4%	100.0%
Korea	69.6%	2.5%	3.8%	20.3%	.0%	3.8%	100.0%
Czech	63.8%	.0%	4.3%	21.3%	4.3%	6.4%	100.0%
Total	63.6%	.4%	5.3%	23.1%	3.2%	4.3%	100.0%

Why did you choose the response in the previous question? Please choose the reason you think is “most important.” (Q3-8sq)

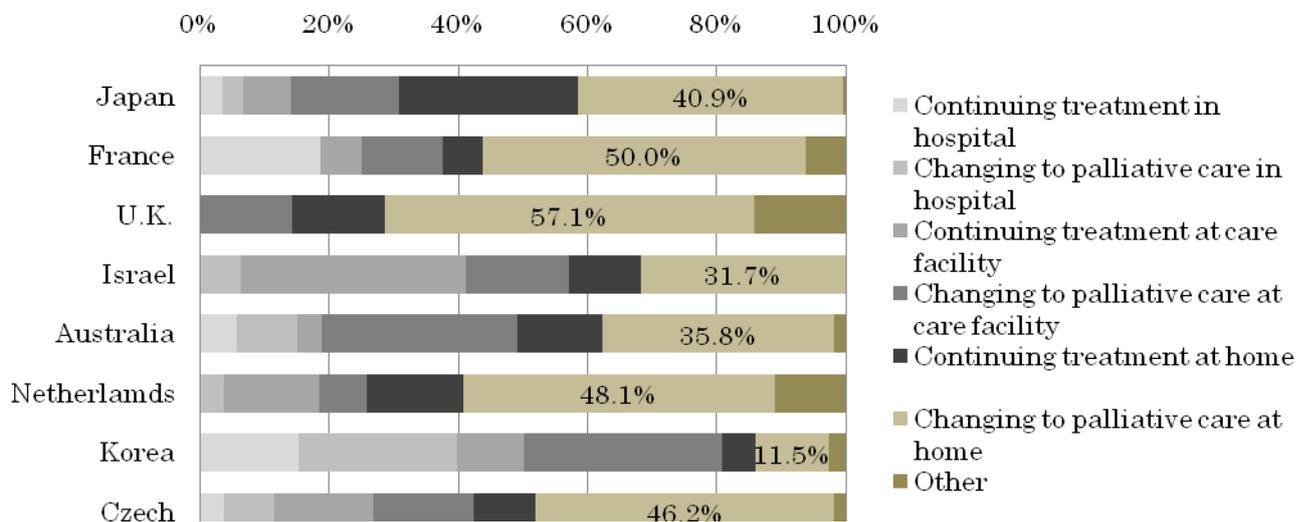
	Possible to recover fully	High possibility for longer life	Expected improvement of QOL	Economical	Respect for Mrs. A's dignity	More likely to fit family's wish	Set by national or facility guideline	other	Total
Japan	2.9%	38.8%	6.7%	.5%	16.7%	31.6%	.5%	2.4%	100.0%
France	5.9%	17.6%	5.9%	.0%	35.3%	29.4%	5.9%	.0%	100.0%
U.K.	.0%	14.3%	28.6%	.0%	57.1%	.0%	.0%	.0%	100.0%
Israel	.0%	8.6%	29.3%	.0%	20.7%	10.3%	24.1%	6.9%	100.0%
Australia	3.9%	7.8%	23.5%	.0%	49.0%	9.8%	2.0%	3.9%	100.0%
Netherlands	18.2%	4.5%	18.2%	.0%	31.8%	9.1%	.0%	18.2%	100.0%
Korea	1.3%	42.7%	17.3%	.0%	26.7%	10.7%	.0%	1.3%	100.0%
Czech	.0%	7.3%	41.5%	.0%	31.7%	4.9%	14.6%	.0%	100.0%
Total	2.9%	27.1%	16.7%	.2%	25.4%	19.6%	4.8%	3.3%	100.0%

Except for Korea, the most often given response as the best policy for helping Mrs. A and Mr. B face death was “Changing to palliative care at home” (Q2-8, 3-9)

As a professional which of the following do you think is the “best” policy for helping Mrs. A face death? (Q2-8)



As a professional which of the following do you think is the “best” policy for helping Mr. B face death? (Q3-9)



<AT HOME : AT A FACILITY>

Japanese typically have a long waiting period before they can move into a “Old people’s home” or “Hospital/ clinic” (Q2-2)

If Mrs. A was to use an institution listed below, would she need to wait before moving in? (Q2-2) (Average value, month)

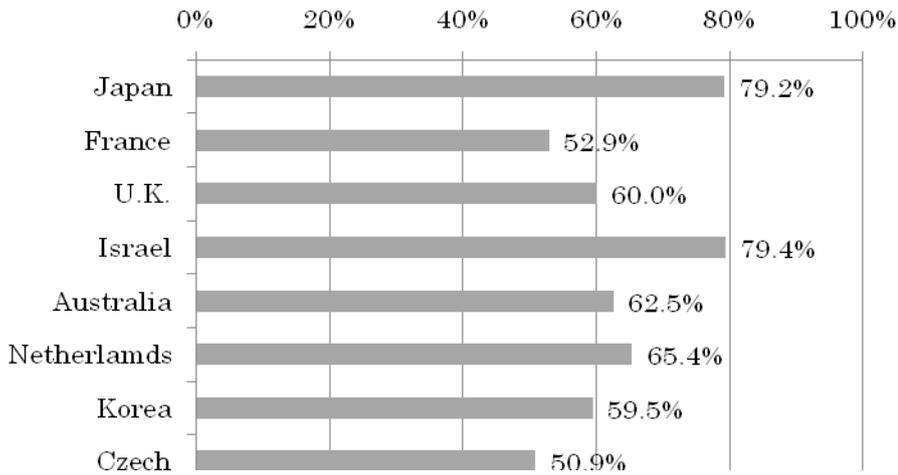
	Assisted living	Group home	Old people's home	Long term care hospital	Hospital/ clinic	Hospice (institution)
Japan	2.50	5.06	10.19	4.58	1.31	2.76
France	1.31	2.25	2.63	1.86	1.25	1.79
U.K.	2.25	2.55	1.49	1.00	1.00	0.54
Israel	8.35	11.05	6.09	1.44	2.00	1.64
Australia	1.93	3.50	1.77	1.19	1.17	0.82
Netherlands	9.50	9.25	4.59	1.97	1.13	0.54
Korea	4.50	4.00	2.33	1.50	2.32	2.71
Czech	14.03	3.00	32.35	1.31	1.33	2.03
Total	6.58	5.05	9.64	2.47	1.49	1.99

If Mr. B was to use an institution listed below, would he need to wait before moving in? (Q3-3) (Average value, month)

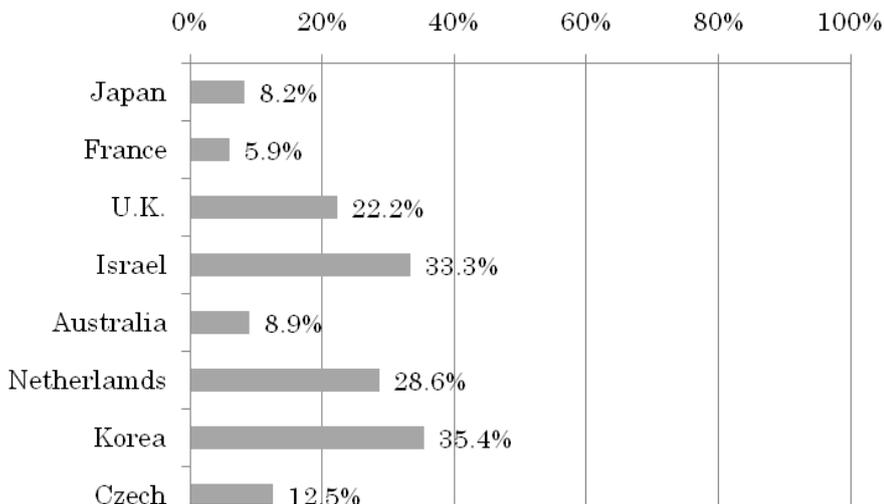
	Assisted living	Group home	Old people's home	Long term care hospital	Hospital/ clinic	Hospice (institution)
Japan	4.13	4.44	8.86	5.34	3.46	3.44
France	1.29	2.75	2.6	2.09	0.67	1.95
U.K.	3.33	2.50	1.30	1.17	1.00	0.75
Israel	11.86	22.00	4.07	1.60	1.00	1.27
Australia	2.82	3.00	1.93	2.25	1.00	1.00
Netherlands	12.00	12.00	5.03	2.08	1.75	0.68
Korea	4.50	6.00	1.50	1.75	2.20	3.22
Czech	11.75	.	34.60	1.26	0.00	2.65
Total	7.09	6.77	9.77	2.73	2.34	2.16

Japanese responded that the suitable place for Mrs. A and Mr. B to spend their final days was “at home” but actually this period is in many cases not spent at home. The gap between the suitable place and the actual place was larger in Japan than any of the other countries in the survey.

Which of the following places do you think is the “best” place for Mrs. A to spend her final days? (Q2-1) (Percentage of respondents that answered “Mrs. A’s home”)



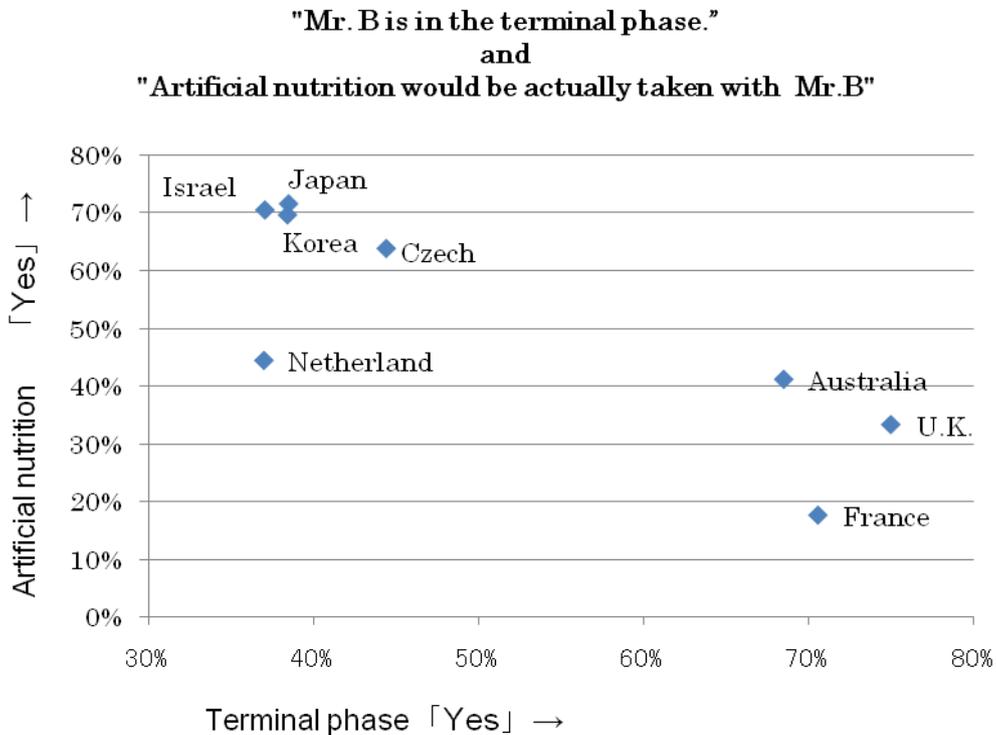
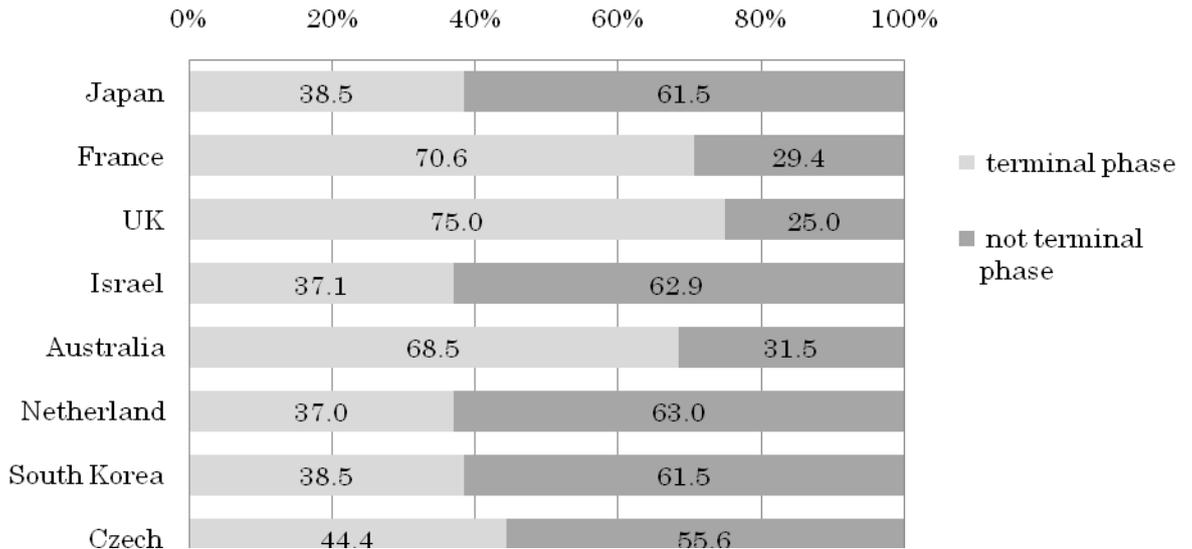
Based on your previous experiences, where do you think Mrs. A would actually spend her final days? (Q2-1sq) (Percentage of respondents that answered “Mrs. A’s home”)



<Judging Terminal Phase and Use of PEG>

Many respondents in the UK, France, and Australia think that “Mr. B is in the terminal phase” however many in Japan, Korea, Israel, the Netherlands and Czech think that Mr. B “is not in the terminal phase”.

Do you think Mr. B is in “the terminal phase”? (Q3-1)



4. International comparative analysis in awareness on ideal terminal care and death (1 section)

Daisuke Watanabe

Comparative analysis by occupation using factor scores

To develop a scale for measuring ideal death and ideal end-of-life care awareness, we made a factor analysis of respective investigative items for ideal death and ideal end-of-life care utilizing data from the 5 countries of Japan, Korea, Israel, Australia, and Czech. We consequently extracted “Death in a short time that causes no problems” and “Prepared death surrounded by family” as latent factors for ideal death and “End-of-life care spending as much time as possible together” and “Short term and low cost end-of-life care” and “End-of-life care allowing communication” as latent factors in ideal end-of-life care.

Next, we made a comparison (one-way analysis of variance) of average values taking the respective factor scores for ideal death and ideal end-of-life care and using occupations (doctors, nurses, care workers) as explanatory variables.

Table 1: One-way analysis of variance of factor scores for ideal death and ideal end-of-life care

	Ideal death		Ideal end-of-life care		
	Death in a short time that causes no problems	Prepared death surrounded by family	End-of-life care spending as much time as possible together	Short term and low cost end-of-life care	End-of-life care allowing communication
Medical doctor (n=79)	-0.21±0.99	-0.05±0.77	0.09±0.77	-0.24±0.91	-0.04±0.85
Nurse (n=146)	0.15±0.79	0.06±0.84	-0.07±0.89	0.30±0.86	-0.01±0.88
Direct care worker (n=219)	-0.02±0.90	-0.03±0.76	0.00±0.83	-0.11±0.96	0.03±0.74
F value	4.59*	0.78	0.99	11.96***	0.23

* p<.05, ** p<.01, *** p<.001

Analyzing results by occupation showed a significant difference among factor scores for ideal death per “Death in a short time causing no problems to others” and ideal end-of-life care in “Short term and low cost end-of-life care”. Both of these tended to be emphasized highly by nurses but not favored at all by doctors. This allows assuming that nurses are more prone to favor death over a short term in end-of-life care. Care workers averaged nearly 0 in “Death in a short time causing no problems to others” and tended not to highly emphasize “Short term and low cost end-of-life care”. Results from making a multiple comparison of these answers by utilizing Tukey b showed that in the prior case there was a significant difference level of 1% between nurses and doctors. Namely, nurses tended to emphasize “Death in a short time causing no problems to others” more than doctors. Moreover, in the latter case a significant difference between nurses, doctors and care

workers (all on a significance level of 1%). Namely, nurses regarded “Short term and low cost end-of-life care” as significant. This is thought due to the fact that nurses emphasize the resultant burden and the financial situation of the patient and family.

Factor scoring by occupation and by country

Table 2: Factor score average ± S.D. for ideal death/ideal end-of-life care by occupation in Japan

	Ideal death		Ideal end-of-life care		
	Death in a short time that causes no problems	Prepared death surrounded by family	Death in a short time that causes no problems	Prepared death surrounded by family	Death in a short time that causes no problems
Medical doctor (n=79)	-0.25±0.83	0.16±0.57	-0.24±0.95	-0.36±1.00	0.24±0.59
Nurse (n=146)	0.13±0.83	-0.10±0.83	-0.41±0.79	0.18±0.83	-0.28±1.08
Direct care worker (n=219)	0.02±0.84	-0.11±0.75	-0.23±0.78	-0.32±0.95	-0.05±0.78

Japan differed significantly from the remaining 4 other countries in its view of ideal death. Specifically there was a large difference in views between nurses and doctors with doctors emphasizing “prepared death surrounded by family” while nurses tended to emphasize, “death in a short time causing no problems to others”. Care workers tended not to favor “Prepared death surrounded by family” very highly. These trends also tended to mirror those for end-of-life care where none of the occupations emphasized “End-of-life care spending as much time together as possible” yet nurses favored “short term and low cost end-of-life care” but doctors to the contrary favored “end-of-life care allowing communication”.

At first glance, these results appear to contradict our first instinctive impression that nurses emphasize the family while doctors emphasize the body. However if viewed from the aspect that nurses emphasize the “burden”, then one can understand that rather than just the body, they favor reducing the load placed on both the patient himself, and his surroundings. The results of this current study allow understanding not only differences among experts in this field but also of how “quality” is viewed.

III. Actual status in overseas countries and analysis

1. Issues for end-of-life care (terminal care) of elderly dementia subjects in Japan —Learning from challenges faced in Italy and Australia—(excerpt)

Yukimi Uchide

I. Introduction

National awareness of dementia among the elderly prior to the 1990's was that medical care and treatment were given in a one-sided manner. However, person centered care has gradually seeped into the consciousness of experts in the field, and values have started to shift from care to reciprocity in that respect that there are more opportunities to care for patients living as members of community and to mutually recognize and support the fact that individuals are irreplaceable. The idea that the end-of-life period of elderly dementia patients is an ordinary part of life has also become widespread. This signifies that the death of that individual is meaningful not only to that person but also to the family, close friends, and the community.

II. End of life care in Italy

<Italian Alzheimer's Disease Association, Cremona palliative care research laboratory>

1. Welfare for the elderly in Italy

Italy has no public health care insurance system that functions on a nation-wide level. Cash allotments rather than benefits are the mainly used medium for care. By the 1980's a monthly sum of 450.78 euros was allocated as a care provider subsidy to families as the most major step in dealing with increased number of elderly requiring care. The actual assistance allotted varies greatly by region. According to a white paper of welfare issued in 2003, "the family has and will continue to hold an important place as a powerful cushion to the social system and as a protective system during major events in the lifecycle such as the birth of children, unemployment and major illness," and the family is placed within the care system for the elderly. However this subsidized care system centering on the family is showing signs of strain due to women's advance into society and the sudden aging of current society. In particular, migrant workers began to take up care-giving jobs in the latter half of the 1990's. In recent years, the mass media has taken up the problem of solitary death, and in the city of Milan for example about 1/3rd of the 270,000 elderly live alone and a further 1/3rd of them die alone at home.

2. Work and end-of-life care by the Italian Alzheimer's Disease Association (AIMA)

Services (all free of charge) provided by AIMA include: a) Promote understanding of family illness, b) Alzheimer's Café, c) Telephone consultations, d) Social and legal consultants, e) Family group meetings, f) Support of volunteer groups, g) Mental health care support for individuals, h) Orienting manuals for care workers, i) Specialist instruction

for paid care work helpers (many are foreign workers), j) Information campaigns (issue of group bulletins), k) Providing information on illnesses and services, l) Other positive activities (fund raising, etc.)

The Alzheimer's Café was founded on a hint from people in the Netherlands. It has been operating since 2006 and plans outings where the patient and family go to movies, dance or listen to music, and play, etc. Activities are monitored by trained volunteer backed up by psychologists and others. These activities are also carried out at the end-of-life stage.

Moreover, 10 percent of the phone consultations involved end-of-life issues. Most numerous are inquiries about who decides matters such as use of PEG or tube feeding or drips for fluid replacement.

3. End-of-life care issues in Italy

(1) Nation-wide citizen's consensus -- understanding of palliative care

Use of PEG, drips and life extending drugs in final stage care is extensive compared to US and other European countries. One reason for this is that more than 90 percent of the population is Roman Catholic so they have a religious tradition of respecting human life. This requires instructing people that life-extending treatments may possibly prolong pain and legal groundwork must also be prepared for advanced directives.

(2) Support for family nursing care

Some 85% of elderly people with dementia live at home and their families reach the point of exhaustion and are abandoned by society. "People with dementia don't want anything and so don't need anything" seems to be the perception by the general public. Needs of family care persons include the following: a) Temporary acceptance of patient at facilities, b) Timely support, c) Useful counseling, support & information on networks, d) Care service activity and evaluations, e) Organization & training for care of the elderly, f) Alleviating the sense of family responsibility, g) Knowledge of nursing care.

(3) Measures for handling care workers from overseas

Specialists have spent a great deal of time learning palliative care but the actual care given in the homes is usually provided by care workers from overseas of whom most have received no education. Improvement of their education and compensation has now become an urgent issue.

4. Challenge of ideal life-end-care in Italy

At the Palliative Research Laboratory they are stating quite strongly that the doctors must shift over from searching for scientific cures to the life ethic approach of pursuing a better life for elderly dementia sufferers.

Taking the standpoint of the family on the other hand, the Alzheimer's Disease Association emphasizes the following points. A first point is that the ideal state between family and patient is to create an environment that can offer specialist care. The family must become aware of the need to obtain information, and financial resources that allows hiring a trained staff as well. A second point is that a legal groundwork must be prepared

for utilizing the advanced directive. A third point is achieving a re-awareness of the significance of home care. One says, “the people in the neighborhood came by our home while mom was in bed and everyone did something. We were not alone. There is no public service assistance but we realized that dying is a natural part of life”. Another comment is that, “in Japan you can choose nursing care by the family or you can entrust it to the long-term care insurance system. It is really great that you can choose from these options”.

5. Comparisons with Italy

Both countries face the common problem of becoming aging societies with few children. The traditional role of the family was also a common point in the past. Italy is recently taking a new look at the role of the family, and the Japanese trend is to cover problems via the entire region instead of leaving it to the families, assuming the breakup of the family just as seen in its own care insurance system. A vital point for both countries is a change in attitude and doing groundbreaking work to shift from scientific cures to life ethics.

III. End-of-life care in Australia

<Results from hearings held with families, visiting nurses, gerontology physicians and day care center directors>

1. End-of-life care for elderly dementia patients

In 1997 a basic strategy called “aging in place” (spending one’s elderly period in a familiar place) was introduced. The National Palliative Care Strategy introduced by the government in the year 2000, started to take shape for providing needed palliative care various measures were taken centering on the community. Moreover in 2004, Guidelines for a Palliative Approach were established that were oriented towards care facilities for the elderly and regional services.

In addition, “evidence based implementation projects” are continually being carried out. Through great amounts of studies and research these projects eliminate attempts to extend life by meaningless care of elderly patients with severe dementia, and support an individual care approach based on alleviating the patient’s symptoms.

2. Advanced directive users

When first moving into a care facility for the elderly, the representative usually works along with the facility manager to write up an “Advanced Directive (AD).” This advanced directive may or may not have legal significance depending on the judgment of the state and local governing bodies.

3. Long- term care at home

Dementia care aid packages for long-term care at home are provided for severe dementia sufferers and their families, that can offer nursing home level care at the patient’s home. This system provides comprehensive services in an organized approach, but the increasing cases of an elderly person caring for an elderly patient amount to a greater burden and the assistance to provide to such families is becoming a large issue.

4. Collaborative approach to care

The NSW health department has issued its Guidelines for End-of-life Care and one of the 8 principles within these guidelines is “a collaborative approach to care.”

Home services that are provided in the northern district of Sydney for families of patients with severe dementia include all types of support such as: a dementia advice center, a telephone consultation service, daycare, and respite care, etc. If in the first stage, then the guardian is given assistance with procedures and an introduction made at a family meeting and constant collaboration is maintained including social exchange with the community. The family can utilize regional-based palliative care team. Moreover, engaging in activities deeply rooted in the patient’s life (such as favorite cuisine, golf, or music appreciation) can be continued each day to gently ease the decline of physical and mental functions.

5. Comparisons with Australia

The background of care in Australia is rooted in a national consensus on end-of-life care and meticulous technical training and principles as shown in the palliative care guidelines. In the case of Japan, the situation tends to focus only on the load imposed on the family but there is also a need to pile up a record of home care success cases and obtain a national consensus by making successive detailed analysis.

Getting everyone to talk openly is important. When inquiring about making the grandchildren do end-of-life care, the trend is to separate the grandchildren from these types of issues. The reason for this being that death is a negative topic and something hateful. In Japan however the custom of the entire family helping in end-of-life care is still alive.

IV. Conclusion

1. Creating a spirit of mutual collaboration that prizes family bonds

Devoting oneself to caring for relatives can cut into your own life and privacy and block out other relationships as well as one’s time. This type of situation can be saved by the relationship in which the patient and the caregiver mutually recognize each other as human beings. Even though his bodily functions have declined, the patient can still recognize whether or not someone is paying attention to him/her.

2. Shifting the elderly dementia patient’s end of life view from a negative to a positive image

By living at home with people who can understand the patient, help the patient remember past events, and by respecting the care workers, the specialist staff can maintain a feeling that what they are doing is worthwhile and switch the situation over to a positive image.

3. Education on end-of-life care”

We should work to create a trend that educates a person from childhood to allow participating along with those close to him in the life process from birth to end-of-life care.

2. Issues and current status of welfare for the elderly and home and institutional long-term care services in Taiwan (excerpt)

Mari Tsuruwaka

1. Current status of low birth rate --rapid aging in Taiwan

As of 2009, the percentage of elderly in Taiwan was 10.63%. The average life expectancy of males was 76.03 years and for women was 82.34 years. The total specific birth rate was 1.03. The percentage of elderly is expected to reach 23.8% by 2030 and 36.7% by 2050. Taiwan has many elderly males due to their sudden influx after losing the civil war in China.

2. Living status of the elderly

In 1976 some 83.7% of the elderly lived with their children but in 2007 this rate had decreased to 60.4%. On the other hand, those living alone or just with their spouses increased approximately 30%

3. National Health Insurance (NHI) system and public pension system

Taiwan's social security system consists of public assistance, social insurance, social welfare, public health and hygiene, public employment, and public housing. The largest point of difference from Japan is welfare policies for the elderly that includes policies in areas such as social assistance and a medical insurance system.

The National Health Insurance Law of 1994 provides health insurance coverage for all citizens. The insurance cost and premium rating of the insurance premium vary with the individual social position and 30% to 60% of the total fee is paid by the citizens, and the difference is paid by the employer or by government subsidy. The government pays health insurance fees for the military, ex-military, those with low income, and 65 and older citizens in Taipei and Kaohsiung.

A pension system covering basic living needs is limited to those who retired at mandatory age among the military, public employees and teachers. Those working in private companies may receive a retirement lump sum grants after a certain amount of years at work but that is not enough for a stable retirement in old age. Retired elderly persons must depend on their children and supported by them.

4. Elderly Welfare Law

The Elderly Welfare Law was established in 1980. This law was first amended in 1997. The legislative intent was to add the principle of protecting the rights of the elderly. It specified the legal duty to those responsible to provide compulsory support for the elderly and changed coverage from 70 and over, to 65 years of age and over, gave rental priority in public-managed housing to three generation families living together, granted a living allowance to low-income elderly persons not residing in facilities, and newly established protective acts for the elderly.

Feature of these legal amendments were described as assuming family support, stressing cash allowances, and having a lack of protective principles.

5. System for providing long-term care services for the elderly

Social welfare systems and medical health systems are available. The social welfare system provided by the Ministry of the Interior delivers mainly home services and facility services for the physically disabled and low-income elderly with taxes as the funding source and is based on the Elderly Welfare Law and Physically Disabled Persons Protection Law (1980). The health system provided by the Department of Health provides home visit nursing care services based on subsidies from the NHI system. These services can be utilized by anyone judged by a physician as needing them regardless of income level.

Welfare policies for the elderly mainly provide, based on the Elderly Welfare Law 1) health measures, 2) economic security allowances, 3) educational and recreational activities, and 4) long-term care services.

1) Allows the elderly to periodically receive free medical exams from a regional government facility based on article 20 of the Elderly Welfare Law. Whether they actually receive the exam or not is left up to the elderly person.

2) Provides “living assistance subsidies for low income elderly persons” and covers low-income elderly not living in public facilities. The “mid-to-low income elderly persons statute” gives direct economic assistance to those elderly 65 years and older not living in public facilities in distressed circumstances or whose children cannot support them. Allowance is 6,000 Yuan (1 Yuan = 2.8 yen) per month per person for those whose average total family income divided by number of family members is 1.5 times or lower than the minimum standard of living level, and 3,000 Yuan for those with incomes of 1.5 to 2.5 times that level. Those receiving this allowance numbered 156,446 people by the end of 2004.

The Elderly Agricultural Worker Welfare Statute covers elderly farm people. The “Elderly Livelihood Protection Statute” grants 3,000 Yuan per month to average income elderly people. Approximately 690,000 people received benefits as of fiscal 2004, and the total amount dispensed was 24.19 billion Yuan.

3) By 2005, there were 266 “life-long learning institutions” which are equivalent to the universities for seniors in Japan.

4) The cash allowance grants 5,000 Yuan (per eligible person) to families as intended by the Ministry of the Interior to foster home nursing care supplement income that was lost due to nursing care. It covers low to middle income family care givers of whom 8,517 people received the allowance in fiscal 2004 and the total amount dispensed was 39.71 million Yuan. The actual subsidized home services provided are “home visit nursing care”, “home visit nursery”, “home renovation” and “emergency reporting systems”. Regional services are: “day services”, “daycare care”, “short stay” and “meal delivery services.” Facility services include “pay nursing homes,” “special nursing home for elderly,” “recuperative health care facilities,” “elderly clinic wards” “health care facilities for the

elderly” and “retired veterans facilities.”

6. Home care services

The Ministry of the Interior promotes establishment of day care centers and recommends that elderly people living alone and elderly people with working families make use of their services during the day and at night spend time at home with their families. In terms of nursing type day care cash subsidies, the highest sum allotted to low income elderly is 5,000 Yuan per month per person, and 3,000 Yuan for middle income elderly, 1,500 Yuan for commuting expenses and a maximum of 90 Yuan for use of facility equipment. Cash subsidies for meal delivery services are 50 Yuan per meal for mid to low income elderly, and a daily amount of 100 Yuan per person is provided to meet commuting needs for volunteers for meal delivery. To help expand private organizations that provide community services, cash subsidies are also paid for office facilities and equipment, specialized service expenses and office rental fees, etc. Meal service operations not only solve food related problems by providing meals at specified locations or deliver to the home but are also seen as venues for contact with outer society and social mixing. In fiscal 2004, a total of 22,179 people utilized this service and 1,533,203 meals were served.

7. Facility care services

There are a total of 40 pay nursing homes, 845 special nursing homes for elderly, and 31 recuperative health care facilities. Recuperative health care facilities and pay nursing homes comprise 54,233 beds, health care facilities for the elderly comprise 24,777 beds, and retired veteran's facilities comprise 11,513 beds. Together these amount to a total of 90,513 beds. Among these, the recuperative health care facilities and pay nursing homes are utilized by some 54,223 people for a usage rate of 72.6% (as of Sept. 2009). The total demand for beds by elderly in Taiwan is thought to be 70,860 so some 30% of the beds are unused. This is said to be due to the fact that the elderly do not like staying in facilities and prefer to live with their families. Another problem is the cost of living in such facilities since Taiwan has no nursing-care insurance system.

9. Conclusion --Elderly home residents, occupational care workers

Taiwan's welfare policies for the elderly tend to deal with low to middle income elderly people. All other elderly people are driven to seek family care or purchase nursing care services out of their own pocket. Some 30% of the beds remain unused in facilities for the elderly and how to make use of them is an important issue. Most elderly people here want to live with their families in a place they are accustomed to and so the urgent need is for comprehensive home care rather than increasing the available facilities. Currently in the city of Taipei, there are 11 social welfare organizations providing home care, and approximately 2,000 people receiving services. There are approximately 128,000 home care workers residing in Taiwan and almost all of them are employed in households. Many of these home care workers are from Vietnam and the Philippines.

3. Healthcare and long-term care expenditures at terminal stage (excerpt)

Tetsuo Fukawa

1. Introduction

The issue of healthcare expenditure in the period prior to death is complicated. Besides aspects such as end-of-life care, palliative care, and tube feeding (gastric fistula), it also involves ethical issues such as life-support treatment and death with dignity and euthanasia, etc.

2. Healthcare and long-term care expenditures for the elderly aged 65 or over

National healthcare expenditure in Japan climbed to approximately 35 trillion yen in fiscal 2008. Among them, healthcare expenditure for the elderly was 19 trillion yen, or 55% of the total. In fiscal 2008, per capita healthcare expenditure for the elderly declined to 3/4ths of those in fiscal 1999, therefore so-called social hospitalization (use of hospital beds for non-medical reasons) should be decreased considerably (partly due to a shift to long-term care expenditure). For the elderly (65+) as a whole, long-term care expenditure was about one-third of healthcare expenditure. However, for the elderly aged 90 or over, long-term care expenditure was greater than healthcare expenditure.

3. Healthcare expenditure before death: Some previous results

(1) Results from medical claim data for the elderly in the 1990s

Healthcare expenditure for the deceased in Japan varied greatly depending on the use of inpatient services, which turned out to be the main factor of increase in healthcare expenditure per deceased elderly as the month of death approached.

On average, healthcare expenditure per deceased elderly for one year prior to death was 4.3 times than annual healthcare expenditure per surviving elderly. However, the former drastically dropped with age increase, thus the rise in healthcare expenditure at the terminal stage did not greatly affect the overall healthcare expenditure for the elderly.

This has also been reported from overseas. Setting the healthcare expenditure per deceased elderly aged 65-69 for one year prior to death as 100%, then in the case of deceased elderly aged 85 or over, the per capita healthcare expenditure was 50% in Japan and the Netherlands, 63% in Germany, 66% in the US, and 71% in Switzerland. It may be a common phenomenon that healthcare expenditure per deceased elderly for one year prior to death decreases with age increase, regardless of healthcare system for the elderly in each country.

(2) Results from outpatient medical claim data in 12 municipalities for the elderly in National Health Insurance from April to September 1999

Healthcare expenditure per day for deceased outpatients was approximately 1.9 times than that of whole outpatient consultations. Healthcare expenditure per day for deceased outpatients peaked at age group 80-84, and rapidly declined afterwards, compared with gradual decline for survivors outpatients although peak age is the same.

4. Healthcare expenditure before death: Trial use of national database on medical claim data in 2010

Using the national database on medical claim data, we intend to clarify the age pattern of per capita healthcare expenditure, paying special attention to very old age group. Healthcare expenditure for deceased elderly in comparison with that for surviving elderly of same age group is also quite interesting.

5. Discussion

It is possible that a decline in the mortality rate among advanced countries in the future is caused by postponement of cancer and circulatory diseases, not by elimination of these diseases. Moreover, the rise in mortality rates with age increase differ by diseases, there is a greater need to analyze mortality and morbidity of the elderly according to diseases.

4. Outlook and administrative issues on end-of-life care (excerpt)

Fumio Isobe

1. Defining end-of-life care; Focusing on terminal stage medical treatment

In this section, the term “end-of-life care” is used basically to signify terminal stage care. Hospitals are beyond the scope in this section.

2. Current status in Japan

1) What is currently being done

a. End-of-life care at home

Currently approximately 13% of these deaths are in the home

b. End-of-life care in facilities, etc.

Currently, approximately 3% of these deaths occur in facilities. One study shows that in 2006, among special elderly nursing homes, approximately 30% died in facilities, while 44% died in hospitals. Long-term care fees were revised that same year to create “supplemental sum for intensive care” and “supplemental sum for end-of-life care” categories for intensive care work in special elderly nursing homes, and from here onwards it is estimated that end-of-life care will increase in intensive care work in special elderly nursing homes.

c. Problem of feeding tube (PEG) at home & facilities

In recent years, many elderly people are returning to homes or care facilities after receiving PEG or tube implant surgery in hospitals. This creates a problem in terms of welfare for those who are unable to express their will. Moreover maintaining PEG is deemed as medical treatment and the care staff outside the family have been restricted to handle this task, so this create the problem that if a PEG or feeding tube was added for end-of-life care then that patient found difficulty in returning return to his own facility.

2) Legal system

a. Terminal stage medical treatment

In May 2007, the Ministry of Health, Labour and Welfare for the first time instituted “Guidelines on the Decision-Making Process for Terminal Stage Medical Treatment”. These guidelines were meant for hospital medical care but also regarded as suitable for living at home after hospitalization. In the opinion of physicians and others, these guidelines are inadequate in that they do not clearly state what type of medical treatment incurs legal liability and what you can skip and still avoid that liability in terminal stage treatment. At incurable patients group meetings some worry that if taken too far, a doctor can do anything as far as he just obeys the guidelines, and this might open the door to mercy killing contrary to the will of the patient.

b. Draft of outline of Basic Bill on Ending Life Support Measures in Cases of Brain Death

This outline bill was publicly announced by a Diet Member Alliance for Death with Dignity Legislation consisting of non-partisan diet members on the same month that the

above guidelines in a. above were issued. Its content included items such as “doctors shall be able to shut off life support equipment if patients of 15 years of age or more express such intent in writing and the family does not object” and “patient shall be judged as clinically dead upon the judgment of 2 or more physicians”, etc. This is different from a. above in that it establishes the exemption from legal liability that was inadequate in a. above. However arguments opposing this legislation state that there is great danger of infringement of patient rights under the current legal status which provides no guarantees of rights to obtain proper medical care or informed consent, etc.

3. Administrative issues in Japan

1) What the government administration should do under current legislation

a. End-of-life care at home

The government should start providing end-of-life care for home patients by forming “medical-care teams” as described in the guidelines whose members are mainly home support care clinic staff, visiting nurses, visiting care workers, and care managers. This would require thorough utilization of regional resource. First of all, the “eager and efficient care persons” needed for end-of-life care in the home must be identified. In order to provide end-of-life care especially to the increased numbers of people living alone at home, will the Community Comprehensive Support Centers and care managers be able to fill in the role of someone who is capable of functioning as “eager and efficient care person”? Also how to cover the remuneration for the care giving must be debated.

Next, required are doctors that can be dispatched from home care support clinics or hospitals, 24 hour home visit nurses and care worker staff. Also necessary to consider is how to form a system that gives 24 hour service anywhere and secure a fund to cover ample pay for this work. This is truly a “home hospital” situation, and the municipality or Community Comprehensive Support Centers will need to plan and delegate tasks for end-of-life care among homes. Currently in France, Regional Medical Plannings stipulate the number of home hospital admissions.

b. End-of-life care in care facilities, etc.

The government should also evaluate extracting subsidy funds from medical and long-term care insurance for making Regional Support Hospitals as an end-of-life support hospitals. Placing an End-of-life Care Guideline at social welfare facilities will lead to increased end-of-life care in facilities, and help cut down on traffic carrying patients to the hospital. Rewarding the preparation of such guidelines and taking related action will help roll out the system.

c. Standards for PEG (tube feeding)

The government should have the Ministry of Health, Labour and Welfare or related academic councils create guidelines for installing PEG and standards for stopping its usage.

d. Promote understanding of natural death

We must promote an understanding of natural death among medical staff including physicians to achieve superior end-of-life care.

2) The administration's role in showing choices in future legislation

The administration has the role of planning a series of choices to allow the people to choose the end-of-life treatment that they want.

a. Plans should be made for end-of-life care (home hospital) by the municipality or Regional Comprehensive Support Centers plan and allocate require care work to contractors. To make that happen, the most effective method will be to revise long-term care insurance systems to allow municipalities to conclude exclusive contract with a business that will be exempted from Antitrust Law.

b. Legal planning for advanced directives covering medical treatment is a priority.

France, Germany and the Netherlands already have such laws. The contents of such a law would designate procedures mainly for verifying the validity of the instructions of patients.

c. Next, laws to limit or stop medical treatment should be instituted. We must respect the views and opinions that aggressive medical treatment can impose a large burden and drastically lower the quality of his life (QOL) of the patient facing death as well as the fact that excessive life support measures can add to patient suffering and place a huge economic and spiritual burden on the family.

4. Prospects

1) Legal planning for the advanced directive

Results from a survey made in March 2008 have appeared in the informal report of a committee of the Ministry of Health, Labour and Welfare on the approach to end-of-life care (October 2010). In regards to establishing legislation for a Living Will some 62% of the general public disapproves while 54% of physicians are in favor of it. Some type of corroborative evidence obtained from daily work tasks is required here. These opinions must be fully absorbed before moving forward to establishing an effective law.

2) Laws to limit or stop medical treatment

More than 80% of the people in the above report felt troubled or insecure on terminal stage medical care. The Basic Bill on Ending Life Support Measures in Cases of Brain Death introduced as a bill sponsored by a non-partisan group of diet members is one type of such needed draft legislation. And evaluating each content while debating on provisions will truly prove productive for those facing death and their families.