

End-of-life Care: Japan and the World

Research Report

International Comparative Study on Terminal Care System

International Comparative Study on Ideal Terminal Care and Death
Surveys with Professionals and Facilities
Interviews with Facility Representatives

(Summary)

For the Ideal End-of Life Care and Death

March 2012

ILC-Japan

International Comparative Study on Ideal End-of-Life Care and Death

Since its foundation in 1990, International Longevity Center (ILC)-Japan, in collaboration with its 14 sister organizations across the globe, has continued its efforts to build a vibrant aged society where not only older people but also all the generations can support each other.

Japan is aging dramatically with fewer children, and the country is expected to have much more deaths (about 1.66 million) than births (about 0.58 million) by 2040. In this context, it will become increasingly essential to build the environment where (1) older people can continue independent living as long as possible, (2) they can fulfill their lives even when they need assistance in daily living, (3) the quality of life (QOL) based on older people's own decisions until the last stage can be ensured, and (4) the conditions can be acceptable to caregivers.

In order to build the environment that enables older people to stay at home, make their own decisions and have decent QOL as well as to clarify the ideal end-of-life care, we have decided to employ the method of international comparison as a starting point so that we can conduct in-depth analyses while revisiting what had been taken for granted in Japan. For this purpose, we formed an "International Comparative Study on Ideal End-of-Life Care and Death" investigation and research committee; consisting of researchers specializing in a various fields such as medicine, welfare and bioethics; and started an interdisciplinary study.

One component of this study "International Comparative Study on Ideal Terminal Care and Death" was completed thanks to the support from various medical and welfare facilities in Japan as well as ILCs and other organizations around the world.

It is the greatest pleasure that we were able to clarify the environmental differences in end-of-life care between Japan and other countries, to point out unique characteristics of Japan, to make policy recommendations, and to present this booklet as a compilation of the study.

We would like to take this opportunity to express our deepest gratitude to the investigation and research committee members as well as those who kindly supported the study.

This booklet summarizes results of the international study in "2011 International Comparative Study on Ideal End-of-Life Care and Death" report, and ILC-Japan is fully responsible for the contents of this booklet. Please also note that this booklet does not include references. Please refer to the full report for more information.

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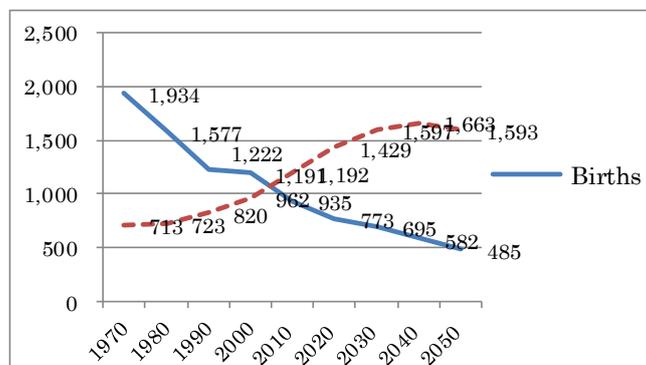
1. Background, Outcome and Recommendations of “International Comparative Study on Ideal Terminal Care and Death”

Kanao Tsuji
President, Life Care System

1. Background

1) Number of births and deaths

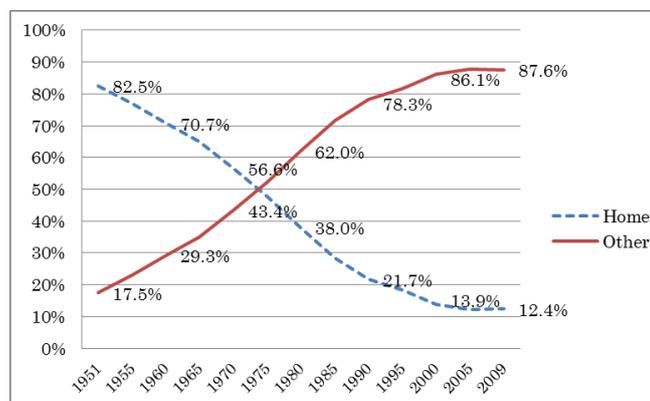
In Japan, the number of births will decrease while that of deaths will increase.



The number of births and deaths (in 1,000s) in Japan (“Vital Statistics” “Population Projection for Japan”)

2) Changes in the place of death

According to data on places of death in Japan, currently 87.6% die in a hospital, while 12.4% die at home (i.e. other than hospital).



Why are there differences in place of death among countries (see the table below) despite the equal level of their medical technology?

Proportions of Hospital Deaths (%)

Year	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009
Japan	76.2	77.1	78.2	78.4	78.6	78.9	79.6	79.8	79.7	79.4	78.6	78.4
USA			50.0	49.2	48.5	47.2	46.1	45.3		43.0		
UK									67.6	66.5	66.1	65.5
France	58.1					56.3	57.5	57.2	57.7	57.2	57.6	57.7
Netherlands						31.0	29.0	29.0	28.0			
South Korea	28.5	32.2	36.0	39.9	43.5	45.1	46.7			54.7		
Australia	35.3							60.4				
Czech										68.9	69.3	69.6

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2. Methodology

Our study started with the following 2 questions.

Question 1: Why have hospital deaths been increasing while deaths at home have been decreasing?

Question 2: What are the factors that determine where we die?

Assuming that the contents of medical treatment are almost the same across the globe, we may be able to explain that differences in national policies are contributing factors to differences in place of death. Another possible explanation is the difference in how the professionals handle “death,” which is strongly influenced by medical care. Then, what are the factors that influence medical professionals’ judgment when making decisions about terminal-stage medical treatment? Are there any differences depending on the elderly patients’ conditions, particularly between the cases of cancer and dementia that are common among older people?

Therefore, we have made the following 3 hypotheses.

Hypothesis 1) Choices of place to die are influenced by relevant legal systems in each country.

Hypothesis 2) Choices of place to die are influenced by relevant medical professional guidelines and judgment by each professional.

Hypothesis 3) Choices of place to die differ between patients with cancer and those with dementia.

In order to test these hypotheses, we conducted the following 4 studies.

A. International Comparative Study on Terminal Care System
(Japan, USA, France, UK, the Netherlands, Israel, Czech, South Korea and Australia)

B. Studies with Professionals and Facilities

a. International Comparative Study on Ideal Terminal Care and Death: Survey with Individual Professionals
(Japan, USA, France, UK, the Netherlands, Israel, Czech, South Korea and Australia)
Hypothetical Cases

- Cancer patient (Mrs. A)
 - Female with terminal cancer. Aged 85. Has 1 month to live.
 - Lives alone. Her son and his wife live close by (15-minute drive).
 - Prefers to continue treatment at home.
- Dementia patient (Mr. B)
 - Male with severe dementia. Aged 80.
 - Repeatedly suffers from aspiration pneumonia. Oral intake is difficult.
 - Lives with spouse only.
 - Wife prefers to take care of him at home despite her limited caregiving capacity.

b. International Comparative Study on Ideal Terminal Care and Death: Facility Survey (Japan and South Korea)

c. International Comparative Study on Ideal Terminal Care and Death: Interviews (Japan, South Korea and Australia)

3. Outcome

As a medical doctor with a 20-year experience in home-based medical care, the author has an impression that people have a high expectation for advanced medicine and hospital medicine even in the terminal phase. In reality, because surgical treatment, including PEG, cannot be provided at home, doctors tend to refer patients to a hospital if requested. In many cases, these patients would be hospitalized. Accordingly, medical professionals who make decisions on medical treatment, including medical doctors, nurses and other professionals, tend to approve this condition.

Consequently, it is very difficult to “discontinue” the treatment they started in a hospital. Therefore, medical treatment would be “continued” until the patient dies, even if the effect of the treatment is not clear. This seems to reflect the large number of hospital deaths in Japan.

What tends to be overlooked in this process is that there is a 100% chance that the time of death will come to each of us and our families. Few doctors and experts point this out.

The following are several characteristics that seem to be unique to Japan based on the survey results.

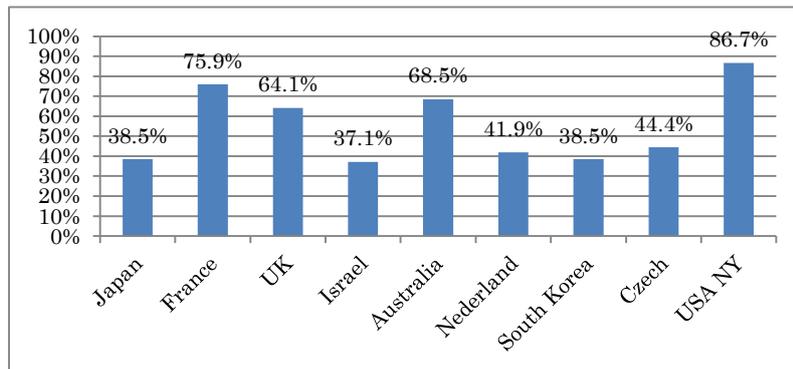
In the hypothetical case A with terminal cancer, 79.2% of the professional respondents in Japan said “the ideal place to support the patient’s final days” would be “home.” However, only 8.2% said “the patient would actually spend the final days at home (see page 13).” The gap between ideal and reality was significantly larger than in other countries. It seems to suggest inadequacy of the medical and care systems that enable people to spend the final days at home and/or care facilities in Japan.

Moreover, in a hypothetical case B with severe dementia, only 26.2% of Japanese respondents chose “remaining life expectancy” as the explanation given to families in addition to the basic medical information (see page 16).

In the same case B, as a primary reason for actually taking a certain basic principle in working with Mr. B, the most frequent response in Japan was “high possibility for longer life (38.8%),” followed by “more likely to fit family’s wish (31.6%).” These proportions were much higher than most of the other countries. On the other hand, while the proportion of the response “respect for the patient’s dignity” to the same question was quite high in other countries, only 16.7% of Japanese respondents chose this (see page 18).

These results are closely associated with the author’s impression mentioned above, suggesting a lack of consensus regarding end-of-life care in Japan.

Moreover, while there are few differences among countries in principles on end-of-life care for cancer patients (see page 17), it is quite difficult to diagnose the terminal condition for dementia patients. Hence, the treatment will continue if the patient is not considered terminal, while the status quo will be maintained for those considered terminal (see figure below).



Do you think Mr. B is in the terminal phase? (% of "Yes")

Related to this question are that France, UK and the Netherlands have very high proportions of the elderly following Japan (16.8%, 16.6% and 15.3% respectively, United Nations "World Population Prospects 2010") and that these 3 countries have laws, national strategies and/or guidelines on end-of-life care. More specifically, France has "Leonetti Law (2005)" and "Palliative Care Development Program (2008)," UK has "Mental Capacity Act (2005)" and "End of Life Care Strategy (2008)," and the Netherlands has "Euthanasia Act (2001)" and "Palliative Care Plan (2008)" (see page 10). In France, for example, it seemed to take over 20 years to have national discussion before passing Leonetti Law.

The differences among countries shown in the figure above seem to reflect the historical differences between European countries and Japan rather than cultural differences among the countries. While European countries have long history as longevity societies, Japan rapidly became one in recent years. Hence, the amount of discussion among citizens seems to differ between these countries.

In addition, it is clear that the number of dementia cases will increase globally, and so will the number of deaths caused by dementia. There should be global movement, not just at the national level, so that the rights for the quality end-of-life care can be recognized throughout the world. It seems critical to advocate that being treated with dignity and respect until the last minute is one of the basic human rights.

Lastly, the author would like to address the tests of the 3 hypotheses.

Hypothesis 1) Choices of place to die are influenced by relevant legal systems in each country.

Hypothesis 2) Choices of place to die are influenced by relevant medical professional guidelines and judgment by each professional.

The survey results seem to support the hypotheses 1 and 2. However, while the contents of relevant laws and national plans seem to have influence, the process of building national consensus in developing such laws and plans seems to play a fundamental role. This is something our country should learn.

Hypothesis 3) Choices of place to die differ between patients with cancer and those with dementia.

Each country is about to standardize and implement specific end-of-life care for cancer patients, and there is little gap between ideal and reality. However, understanding of dementia is different among countries, and there is a lack of global standards. In this sense, it seems safe to say that there are differences in places of death between cancer and dementia patients. In essence, appropriate standardization on end-of-life care for dementia patients lags behind that for cancer patients.

4. Recommendations for Japanese Policies

In conclusion, the author would like to summarize this chapter with policy recommendations.

1) National discussion is needed on the ideal end-of-life care for dementia patients

While the number of dementia patients increases dramatically in Japan, there is no medical consensus on end-of-life care for dementia patients, particularly on diagnosis of the “terminal phase.” The situation is the same for other care professions. It seems essential to have a wide range of discussions through engagement of citizens.

2) National laws are needed

The end-of-life is an issue shared by citizens and care professionals. Hence, new legal systems on end-of-life care will be needed while considering differences among various conditions, including cancer and dementia. While the Article 13 of Japanese Constitution rules “people’s right to life, liberty and the pursuit of happiness,” the author would also like to propose the idea that “right to be treated with dignity at the end of life” should be the right to pursue happiness in an aging society.

3) Promoting education for home care professionals who provide end-of-life care

There is a lack of education for “professionals” who can provide end-of-life care outside of hospitals. Besides the measures mentioned above, there are urgent needs for development of professional guidelines as well as professional education based on these guidelines. In the meantime, promotion of collaboration among home care professionals (i.e. doctors at clinics, visiting nurses and direct care workers) will solve the problems regarding different opinions and judgment among various care professionals.

2. International Comparative Study on Terminal Care System

Taeko Nakashima

Senior Researcher, Institute for Health Economics and Policy

In this chapter, the author summarizes laws, strategies and guidelines on palliative and end-of-life care as well as on dementia patients. The table below categorizes the laws into “euthanasia” and “end-of-life.” The laws on “euthanasia” include systems regarding active euthanasia, passive euthanasia and assisted suicides in response to wishes “to end life soon” due to a patient’s pain and various sufferings. The laws on “end-of-life” include respect for a patient’s wish to have natural death without life-sustaining treatment when such treatment is considered to bring no benefit. An advance directive is included in many cases as one example to respect the patient’s wish.

	Laws		Strategies	Guidelines
	End-of-life	Euthanasia		
Japan				Guidelines on Terminal Medical Care Decision-Making Process (Ministry of Health, Labour and Welfare)
South Korea				Guidelines on Withdrawal of Life-Sustaining Treatment (Medical Association, etc.)
Czech				Recommendations by Czech Medical Chamber
Israel	The Act of the Dying Patient (2006)			
France	Leonetti Law (2005)		Palliative Care Development Program (2008)	Palliative Care Guidelines (Society of Palliative Care), etc.
UK (Mainly England)	(Mental Capacity Act) (2005)		The End of Life Care Strategy (2008)	Treatment and Care towards the End of Life (General Medical Council), etc.
USA	Patient Self-Determination Act (1990)	3 states (e.g. Oregon Death with Dignity Act, 1991)		Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying, etc.
Australia		Euthanasia Law Act (1997) X Rights of the Terminal Ill Act (1995)	National Palliative Care Strategy (2000)	Guidelines for a Palliative Approach in Residential Aged Care and Community Care (Government), etc.
Netherlands		Euthanasia Act (2001)	Palliative Care Plan (2008)	Guideline for Palliative Care (Dutch Physicians Organization)

3. Results of Interviews on End-of-life Care

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The purposes of the interviews are to understand the current conditions and problems surrounding end-of-life care and to find the factors that contribute to characteristics of and differences in the end-of-life care.

The table below shows the “primary reasons” for taking an actual principle in working with a patient. In Australia, the survey respondents are less likely to choose “high possibility for longer life” and are more likely to choose “respect for a patient’s dignity” and “expected improvement of QOL” particularly in the dementia case. In Japan, the proportion of “more likely to fit family’s wishes” is particularly high.

Reasons for taking an actual principle in working with a dementia patient (Q3-8-2)

	Possible to recover fully	Longer life	QOL	Economic	Respect dignity	Family’s wish	Guideline	Other
Japan (n=209)	6 2.9%	81 38.8%	14 6.7%	1 .5%	35 16.7%	66 31.6%	1 .5%	5 2.4%
South Korea (n=75)	1 1.3%	32 42.7%	13 17.3%	0 .0%	20 26.7%	8 10.7%	0 .0%	1 1.3%
Australia (n=51)	2 3.9%	4 7.8%	12 23.5%	0 .0%	25 49.0%	5 9.8%	1 2.0%	2 3.9%

From the interviews in Australia, several key words emerged that would emphasize the importance of independent living, including “replacement for the lost Ikigai (i.e. meaning of life, life worth living),” “the patient decides his/her own treatment,” “trying not to lower QOL” and “(caregivers’) core identity and meaning of life.”

On the other hand, several unique responses in the Korean interviews include “people want to have the loved ones live as long as possible due to the strong sense of devotion,” “people tend to take care of parents at home and to feel ashamed to come to an institution” and “people still tend to think that children who put their parents in hospital are good ones while those who put their parents in nursing home are the shame.”

In other words, while Australian people tend to place top priority on QOL that focuses on individual approaches to a society, Korean people tend to have Confucian norm, though it is gradually diminishing.

These differences seem to provide a partial explanation for the survey results that Australian respondents are less likely to choose “high possibility for longer life” but more likely to choose “respect for the patient’s dignity” and “expected improvement of QOL.” Moreover, since Japanese people tend not to have such norms, there is no definite criterion for decision-making. Consequently, Japanese people seem to focus on the wishes of families, who are the central players at the moment.

In addition, it seems noteworthy that palliative care teams in Australia are committed to end-of-life care in a wide range of settings, including hospitals, nursing homes and communities, and that they have a great impact on the whole society.

4. International Comparative Study on Ideal Terminal Care and Death

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Taeko Nakashima: Senior Researcher, Institute for Health Economics and Policy

9-Country Survey: Respondents' Professions

	Medical doctor	Nurse	Direct care worker	Social worker	Other	PT · OT (recoded)	Total
Japan	20	59	103	23	8	7	220
South Korea	16	44	2	18	0	0	80
Israel	25	18	2	15	3	0	63
Australia	11	20	8	11	2	5	57
Czech	17	17	2	12	5	0	53
Netherlands	15	15	0	1	2	0	33
France	17	7	0	2	3	0	29
UK	35	14	0	18	0	0	67
USA (NY)*	15	15	0	0	0	0	30
Total	171	209	117	100	23	12	632

* Note on USA: Due to its federal system and lack of public health insurance, the situation varies from one state to another. Moreover, this sample does not represent USA as a whole because (1) the research collaborator (ILC-USA) is located in a metropolitan area (New York), (2) there is no respondent who is a direct care worker since the survey was conducted in medical facilities, and (3) the survey was conducted in facilities where PEG is actively provided. In this report, the author put "USA (NY)" in order to stress that the sample is not the US representative.

9-Country Survey: Implementing Agencies and Subject Facilities

Country	Implementing Agencies and Subject Facilities
Japan	ILC-Japan; 12 facilities (7 nursing homes, 2 group homes, 1 multiple facility, 1 visiting nurse service agency and 1 hospital) and 10 individual doctors.
South Korea	Korean Alzheimer's Association
Israel	ILC-Israel
Australia	2 medical and long-term care facilities (HammondCare and Ramsay Health)
Czech	ILC-Czech
Netherlands	ILC-Netherlands
France	ILC-France
UK	ILC-UK
USA (NY)	ILC-USA

*Unless otherwise specified, the survey was conducted in October-December, 2010 (October-December in 2011 in USA).

Contents

【Characteristics】

Sex / Year of birth and age / Current workplace / Qualification / Working condition / Type of job / Years of practice experience / Years of practice experience in home-based care / Experiences in witnessing death(s) during the last year

【Cancer Case】

The ideal place to support the end of life / The actual place to face the end of life / Availability of institutions and hospitals / The ideal person whose opinion should be the highest priority in setting a direction for the future / The actual person whose opinion would be the highest priority based on the previous experience / Priorities in setting a direction on the future treatment and terminal care / Explanations given to families (son and his wife) in addition to the basic medical information / The ideal basic principle in working with a patient and its reason / The actual basic principle in working with a patient and its reason / The ideal direction for a patient towards the death and its reason

【Dementia Case】

Is this patient "terminal"? Why? / (Other questions are the same as the cancer case)

【Attitudes toward Death】

Frequency of thinking about death / Anxiety about and/or fear of death / Opinions on death / Ideal death for self / Ideal place of death for self / Ideal death for spouse and family / Ideal place of death for family

Places to spend the final days: Ideal and reality

The ideal place to spend the final days is “home” for both terminal cancer and dementia cases in each country. In reality, however, such is not the case. The gap between ideal and reality is the biggest in Japan.

The “best” place to spend the final days (ideal, cancer case, %) Q2-1-1

	Home	Assisted living	Group home	Old people's home	LTC hospital	Hospital, clinic	Hospice (institution)	Other
Japan	79.2	1.8	.5	1.4	1.8	2.7	12.2	.5
France	51.7	41.4	.0	.0	.0	.0	6.9	.0
UK	79.7	1.6	1.6	.0	3.1	3.1	3.1	7.8
Israel	79.4	.0	.0	1.6	3.2	1.6	12.7	1.6
Australia	62.5	10.7	.0	5.4	5.4	1.8	12.5	1.8
Netherlands	67.7	.0	.0	.0	.0	.0	32.3	.0
South Korea	59.5	7.6	1.3	.0	7.6	.0	24.1	.0
Czech	50.9	3.6	.0	1.8	1.8	.0	41.8	.0
USA (NY)	93.3	.0	.0	.0	.0	.0	3.3	3.3

The “actual” place to spend the final days (reality, cancer case, %) Q2-1-2 SQ

Japan	8.2	.9	.0	7.7	11.8	59.5	11.4	.5
France	7.1	17.9	.0	.0	25.0	32.1	17.9	.0
UK	20.6	.0	30.9	16.2	14.7	10.3	4.4	2.9
Israel	33.3	1.6	.0	3.2	34.9	11.1	14.3	1.6
Australia	8.9	7.1	.0	16.1	7.1	14.3	46.4	.0
Netherlands	33.3	.0	.0	.0	3.0	12.1	51.5	.0
South Korea	35.4	8.9	.0	.0	21.5	1.3	32.9	.0
Czech	12.5	.0	.0	.0	42.9	17.9	26.8	.0
USA (NY)	.0	.0	.0	46.7	.0	40.0	.0	13.3

The “best” place to spend the final days (ideal, dementia case, %) Q3-2-1

	Home	Assisted living	Group home	Old people's home	LTC hospital	Hospital, clinic	Hospice (institution)	Other
Japan	76.0	4.1	1.8	11.3	5.0	.5	.9	.5
France	44.8	17.2	.0	.0	13.8	3.4	17.2	3.4
UK	66.2	1.5	16.9	4.6	3.1	.0	.0	7.7
Israel	52.4	4.8	.0	7.9	31.7	.0	1.6	1.6
Australia	46.4	12.5	.0	17.9	14.3	1.8	7.1	.0
Netherlands	68.8	.0	.0	.0	28.1	.0	3.1	.0
South Korea	25.3	20.3	.0	3.8	43.0	2.5	3.8	1.3
Czech	35.2	7.4	.0	3.7	24.1	7.4	20.4	1.9
USA (NY)	96.7	.0	.0	.0	.0	.0	3.3	.0

The “actual” place to spend the final days (reality, dementia case, %) Q3-2-2

Japan	22.7	1.8	2.3	23.6	21.8	26.4	1.4	.0
France	11.1	18.5	.0	.0	22.2	40.7	7.4	.0
UK	13.4	1.5	43.3	29.9	1.5	1.5	1.5	7.5
Israel	24.2	.0	1.6	9.7	54.8	3.2	1.6	4.8
Australia	8.9	7.1	.0	32.1	16.1	23.2	8.9	3.6
Netherlands	24.2	.0	.0	.0	66.7	6.1	3.0	.0
South Korea	15.2	17.7	.0	7.6	49.4	5.1	5.1	.0
Czech	3.7	.0	.0	.0	40.7	46.3	5.6	3.7
USA (NY)	33.3	.0	.0	.0	6.7	53.3	.0	6.7

Decision-makers on treatment and terminal care: Ideal and reality

In setting a direction of treatment and terminal care, the respondents in each country selected the patient herself in a cancer case and the patient's wife in a dementia case as the persons whose opinions should be put the highest priority. In reality, however, such is not the case. The gap between ideal and reality is the biggest in Japan.

The "ideal" person whose opinion should be put the highest priority when setting a direction of treatment and terminal care (ideal, cancer case, %) Q2-3-1

	Patient	Son	Primary care doctor	Specialist physician	Nurse, direct care worker w/ daily contact	Social worker	Other
Japan	75.6	15.4	3.6	.9	1.8	2.3	.5
France	65.5	.0	17.2	6.9	3.4	6.9	.0
UK	85.7	1.6	4.8	3.2	4.8	.0	.0
Israel	90.5	3.2	.0	1.6	4.8	.0	.0
Australia	83.6	9.1	3.6	.0	1.8	.0	1.8
Netherlands	100.0	.0	.0	.0	.0	.0	.0
South Korea	79.7	11.4	.0	1.3	6.3	1.3	.0
Czech	23.6	20.0	12.7	34.5	3.6	5.5	.0
USA (NY)	100.0	.0	.0	.0	.0	.0	.0

The "actual" person whose opinion would be put the highest priority when setting a direction of treatment and terminal care (reality, cancer case, %) Q2-3-2 SQ

Japan	14.0	64.3	12.2	3.6	2.3	3.6	.0
France	32.1	32.1	14.3	17.9	.0	.0	3.6
UK	38.2	23.5	16.2	19.1	1.5	.0	1.5
Israel	30.2	47.6	3.2	9.5	3.2	1.6	4.8
Australia	34.0	32.1	15.1	18.9	.0	.0	.0
Netherlands	39.4	21.2	6.1	15.2	12.1	3.0	3.0
South Korea	26.6	64.6	3.8	1.3	3.8	.0	.0
Czech	73.2	1.8	3.6	16.1	5.4	.0	.0
USA (NY)	100.0	.0	.0	.0	.0	.0	.0

The "ideal" person whose opinion should be put the highest priority when setting a direction of treatment and terminal care (ideal, dementia case, %) Q3-4-1

	Patient	wife	Primary care doctor	Specialist physician	Nurse, direct care worker w/ daily contact	Social worker	Other
Japan	9.0	80.1	3.2	.5	.9	5.4	.9
France	.0	93.1	3.4	3.4	.0	.0	.0
UK	15.3	69.5	3.4	3.4	3.4	.0	5.1
Israel	7.9	71.4	3.2	7.9	1.6	.0	7.9
Australia	20.0	54.5	10.9	3.6	5.5	1.8	3.6
Netherlands	12.1	84.8	.0	3.0	.0	.0	.0
South Korea	17.9	67.9	2.6	1.3	7.7	1.3	1.3
Czech	1.9	37.0	13.0	42.6	3.7	1.9	.0
USA (NY)	6.7	93.3	.0	.0	.0	.0	.0

The "actual" person whose opinion would be put the highest priority when setting a direction of treatment and terminal care (reality, dementia case, %) Q3-4-2 SQ

Japan	.9	59.4	19.2	3.2	6.4	9.6	1.4
France	3.6	53.6	17.9	21.4	.0	3.6	.0
UK	5.9	47.1	8.8	20.6	8.8	5.9	2.9
Israel	4.8	58.7	11.1	17.5	1.6	.0	6.3
Australia	5.4	57.1	17.9	8.9	7.1	1.8	1.8
Netherlands	.0	54.5	9.1	27.3	.0	6.1	3.0
South Korea	6.5	70.1	11.7	1.3	10.4	.0	.0
Czech	13.0	38.9	7.4	35.2	1.9	1.9	1.9
USA (NY)	.0	100.0	.0	.0	.0	.0	.0

Priorities in setting a direction on treatment and terminal care

For the cancer case, the most frequent response is “relieving patient’s pain” in each country. For the dementia case, “the patient’s wife’s wish” tends to be the highest priority. In Japan, the proportion of the response “easing the family burden” is relatively high.

(With consideration for the patient’s wishes,) the highest priority that should be placed
(cancer case, %) Q2-4

	Son’s wish	The longest life possible	Relieving the patient’s pain	Continuation of the patient’s lifestyle	Easing the family burden	Other
Japan	6.3	.0	57.9	31.7	2.7	1.4
France	.0	.0	69.0	27.6	.0	3.4
UK	3.2	.0	61.9	31.7	.0	3.2
Israel	3.2	.0	69.8	25.4	.0	1.6
Australia	3.6	.0	76.4	14.5	.0	5.5
Netherlands	3.0	.0	57.6	39.4	.0	.0
South Korea	3.8	.0	53.2	31.6	10.1	1.3
Czech	3.6	5.4	78.6	7.1	1.8	3.6
USA (NY)	3.3	.0	90.0	.0	6.7	.0

(With consideration for the patient’s wishes,) the highest priority that should be placed
(dementia case, %) Q3-5

	Wife’s wish	Relative’s wishes	The longest life possible	Relieving the patient’s pain	Continuation of the patient’s lifestyle	Easing the family burden	Other
Japan	56.6	.9	.5	10.9	15.4	14.9	.9
France	51.7	3.4	6.9	24.1	3.4	10.3	.0
UK	36.4	6.1	1.5	30.3	13.6	1.5	10.6
Israel	46.0	11.1	3.2	28.6	7.9	1.6	1.6
Australia	41.1	.0	.0	42.9	5.4	8.9	1.8
Netherlands	51.5	3.0	.0	33.3	6.1	6.1	.0
South Korea	57.7	2.6	.0	19.2	15.4	5.1	.0
Czech	32.1	7.5	1.9	18.9	20.8	7.5	11.3
USA (NY)	100.0	.0	.0	.0	.0	.0	.0

What to explain to families

When giving explanations to families, Japanese respondents tend to make consideration to family caregivers, putting relative importance on “family care burden” and “financial cost.” “Remaining life expectancy” is less likely to be provided in Japan and France. In France, there tends to be less explanation for families in general.

Explanations to families besides medical information (cancer case, %, MA) Q2-5

	Remaining life expectancy	Living will	Alternative therapy	Patient's suffering and pain	Available medical/LTC system	Moment of death	Financial cost	Family care burden	Grief after death
Japan	48.6	25.0	22.3	72.3	75.9	31.8	42.3	50.0	10.5
France	11.4	5.1	1.3	35.4	39.2	16.5	5.1	11.4	1.3
UK	66.1	45.2	19.4	72.6	71.0	40.3	17.7	41.9	29.0
Israel	60.0	34.5	18.2	74.5	63.6	34.5	23.6	32.7	41.8
Australia	50.0	21.4	23.2	75.0	78.6	39.3	12.5	23.2	26.8
Netherlands	75.8	18.2	6.1	72.7	72.7	.0	6.1	51.5	9.1
South Korea	53.6	57.1	39.3	85.7	50.0	14.3	32.1	46.4	10.7
Czech	69.6	55.1	33.3	79.7	75.4	43.5	18.8	29.0	47.8
USA (NY)	53.3	46.7	36.7	100.0	80.0	3.3	.0	.0	13.3

Explanations to families besides medical information (dementia case, %, MA) Q3-6

	Remaining life expectancy	Living will	Alternative therapy	Patient's suffering and pain	Available medical/LTC system	Moment of death	Financial cost	Family care burden	Grief after death
Japan	26.2	19.5	23.5	42.1	82.4	22.6	34.4	75.6	10.0
France	14.1	3.8	.0	17.9	50.0	12.8	2.6	20.5	1.3
UK	61.3	25.8	17.7	50.0	83.9	24.2	29.0	48.4	17.7
Israel	66.1	33.9	14.3	51.8	67.9	28.6	26.8	44.6	42.9
Australia	40.4	5.8	11.5	50.0	86.5	32.7	13.5	38.5	26.9
Netherlands	57.6	9.1	6.1	54.5	75.8	.0	9.1	69.7	6.1
South Korea	57.1	35.7	28.6	53.6	60.7	14.3	46.4	64.3	7.1
Czech	68.1	46.4	23.2	69.6	73.9	47.8	29.0	43.5	50.7
USA (NY)	56.7	46.7	13.3	100.0	76.7	.0	.0	10.0	16.7

Basic principles in working with patients: Ideal and reality

For the cancer case, in all the countries, “pain control” is the most frequent choice as the basic principle in both the ideal and actual situations. The most frequent reason is “respect dignity.” The relatively popular choice in the actual situation is “family’s wish” in Japan and “guideline” in UK and Australia.

The “best” basic principle in working with a patient (ideal, cancer case, %) Q2-6

	Anticancer drug	High level medical services	Alternative medicine	Pain control	Do nothing special	Other
Japan	.9	.5	1.8	91.9	.0	5.0
France	2.5	7.6	6.3	79.7	1.3	2.5
UK	.0	3.2	.0	87.3	4.8	4.8
Israel	1.8	.0	.0	90.9	.0	7.3
Australia	.0	3.8	.0	90.6	.0	5.7
Netherlands	.0	.0	.0	81.8	.0	18.2
South Korea	.0	.0	.0	96.4	.0	3.6
Czech	.0	4.7	.0	68.8	.0	26.6
USA (NY)	.0	.0	.0	100.0	.0	.0

Reason for choosing the principle selected above (ideal, cancer case, %) Q2-6-2

	Possible to recover fully	Longer life	QOL	Economical	Respect dignity	Family’s wish	Guideline	Other
Japan	.0	1.4	21.4	1.4	64.1	7.7	.0	.0
France	1.3	.0	29.5	.0	56.4	6.4	.0	1.3
UK	.0	1.6	59.7	.0	33.9	.0	1.6	.0
Israel	.0	1.8	40.0	1.8	52.7	.0	.0	.0
Australia	1.8	1.8	34.5	1.8	60.0	.0	.0	1.8
Netherlands	.0	.0	42.4	.0	54.5	.0	.0	.0
South Korea	.0	.0	55.2	.0	41.4	.0	3.4	.0
Czech	.0	3.2	32.3	1.6	53.2	1.6	1.6	.0
USA (NY)	.0	.0	6.7	.0	83.3	10.0	.0	.0

The “actual” basic principle in working with a patient (reality, cancer case, %) Q2-7

	Anticancer drug	High level medical services	Alternative medicine	Pain control	Do nothing special	Other
Japan	5.9	.9	3.2	83.1	2.3	4.6
France	5.2	5.2	3.9	85.7	.0	.0
UK	6.5	11.3	.0	72.6	3.2	6.5
Israel	3.5	5.3	.0	82.5	.0	8.8
Australia	13.2	15.1	.0	66.0	1.9	3.8
Netherlands	3.0	.0	.0	81.8	3.0	12.1
South Korea	.0	.0	3.6	89.3	3.6	3.6
Czech	1.6	12.5	1.6	73.4	4.7	6.3
USA (NY)	.0	.0	.0	90.0	.0	10.0

Reason for choosing the principle selected above (reality, cancer case, %) Q2-7-2

	Possible to recover fully	Longer life	QOL	Economical	Respect dignity	Family’s wish	Guideline	Other
Japan	.0	5.5	15.6	2.3	54.1	16.1	.5	6.0
France	.0	3.9	22.1	1.3	58.4	9.1	.0	5.2
UK	.0	3.3	36.1	3.3	19.7	6.6	23.0	8.2
Israel	.0	1.8	40.4	1.8	42.1	7.0	.0	7.0
Australia	5.5	3.6	34.5	.0	38.2	1.8	16.4	.0
Netherlands	.0	3.0	39.4	.0	51.5	3.0	3.0	.0
South Korea	.0	3.6	39.3	.0	46.4	.0	7.1	3.6
Czech	.0	4.8	25.8	6.5	43.5	3.2	3.2	12.9
USA (NY)	.0	.0	7.1	.0	67.9	25.0	.0	.0

For the dementia case, in all the countries, “artificial nutrition” is the most frequent choice as the basic principle in both the ideal and actual situations. The most frequent reason is “respect dignity.” As the reasons for choosing the response in the actual situation, Japanese respondents are less likely to choose “respect dignity” and “QOL” while they are more likely to choose “family’s wish” and “longer life.” “Guideline” is more likely to be chosen in UK and Australia.

The “best” basic principle in working with a patient (ideal, dementia case, %) Q3-7

	Artificial nutrition	Alternative medicine	Rehabilitation	Keep the current treatment	Do nothing special	Other
Japan	46.2	.9	16.7	27.1	2.7	6.3
France	59.7	2.6	6.5	22.1	2.6	6.5
UK	50.8	.0	7.9	25.4	7.9	7.9
Israel	15.1	.0	9.4	45.3	11.3	18.9
Australia	45.5	2.3	6.8	38.6	.0	6.8
Netherlands	34.4	.0	9.4	25.0	12.5	18.8
South Korea	10.7	.0	14.3	35.7	14.3	25.0
Czech	23.9	1.5	11.9	25.4	4.5	32.8
USA (NY)	6.7	.0	23.3	60.0	.0	10.0

Reason for choosing the principle selected above (ideal, dementia case, %) Q3-7-2

	Possible to recover fully	Longer life	QOL	Economic	Respect dignity	Family’s wish	Guideline	Other
Japan	2.3	20.5	11.0	.0	26.5	35.6	.0	4.1
France	2.6	32.1	16.7	1.3	34.6	10.3	.0	2.6
UK	1.6	6.5	38.7	.0	30.6	9.7	8.1	4.8
Israel	5.7	1.9	22.6	1.9	54.7	5.7	.0	7.5
Australia	3.9	3.9	49.0	2.0	35.3	2.0	3.9	.0
Netherlands	9.4	3.1	28.1	.0	40.6	6.3	3.1	9.4
South Korea	.0	6.9	37.9	.0	37.9	10.3	6.9	.0
Czech	6.6	4.9	21.3	.0	57.4	3.3	1.6	4.9
USA (NY)	.0	.0	33.3	.0	36.7	26.7	.0	3.3

The “actual” basic principle in working with a patient (reality, dementia case, %) Q3-8

	Artificial nutrition	Alternative medicine	Rehabilitation	Keep the current treatment	Do nothing special	Other
Japan	71.6	.0	6.0	18.8	1.4	2.3
France	69.6	2.5	3.8	20.3	.0	3.8
UK	70.5	.0	3.3	18.0	6.6	1.6
Israel	41.2	.0	9.8	35.3	2.0	11.8
Australia	63.8	.0	4.3	21.3	4.3	6.4
Netherlands	46.9	.0	3.1	34.4	9.4	6.3
South Korea	17.9	.0	7.1	46.4	14.3	14.3
Czech	40.0	.0	9.2	33.8	3.1	13.8
USA (NY)	73.3	.0	.0	26.7	.0	.0

Reason for choosing the principle selected above (reality, dementia case, %) Q3-8-2

	Possible to recover fully	Longer life	QOL	Economic	Respect dignity	Family’s wish	Guideline	Other
Japan	2.9	38.8	6.7	.5	16.7	31.6	.5	2.4
France	1.3	42.7	17.3	.0	26.7	10.7	.0	1.3
UK	.0	8.6	29.3	.0	20.7	10.3	24.1	6.9
Israel	3.9	7.8	23.5	.0	49.0	9.8	2.0	3.9
Australia	.0	7.3	41.5	.0	31.7	4.9	14.6	.0
Netherlands	19.2	3.8	26.9	.0	26.9	7.7	.0	15.4
South Korea	6.9	10.3	13.8	.0	41.4	20.7	6.9	.0
Czech	3.7	16.7	18.5	.0	38.9	9.3	1.9	11.1
USA (NY)	.0	3.3	23.3	6.7	30.0	30.0	.0	6.7

The ideal direction towards the death

For the cancer case, the most frequent response is “changing to palliative care at home” in each country. Japan is one of the countries where respondents are less likely to choose “changing to palliative care at care facility.” Japanese respondents are also less likely to choose “expected improvement of QOL” as the reason for choosing a particular direction.

For the dementia case, the relatively frequent response in Japan is “changing to palliative care at home.” When combining treatment and palliative care, usage of “care facility” is relatively rare. As the reason for choosing a particular direction, Japanese respondents are less likely to choose “expected improvement of QOL.”

The best direction towards the death (cancer case, %) Q2-8

	Treatment in hospital	Palliative care in hospital	Treatment at care facility	Palliative care at care facility	Treatment at home	Palliative care at home	Other
Japan	.9	15.0	.0	8.2	5.5	70.0	.5
France	5.2	20.8	11.7	33.8	3.9	23.4	1.3
UK	1.6	4.8	8.1	9.7	30.6	45.2	.0
Israel	.0	7.0	3.5	29.8	5.3	50.9	3.5
Australia	1.8	9.1	3.6	16.4	5.5	60.0	3.6
Netherlands	.0	.0	.0	18.2	3.0	78.8	.0
South Korea	.0	7.1	.0	.0	7.1	82.1	3.6
Czech	1.5	2.9	2.9	13.2	19.1	55.9	4.4
USA (NY)	.0	.0	.0	.0	.0	100.0	.0

Reasons for choosing the direction selected above (cancer case, %, MA) Q2-8-2

	Possible to recover fully	Longer life	QOL	Economical	Respect dignity	Family's wish	Guideline	Other
Japan	0.5	4.1	25.5	4.5	82.7	19.1	0.5	4.1
France	0.0	0.0	51.7	0.0	82.8	6.9	0.0	3.4
UK	0.0	8.8	44.1	2.9	89.7	22.1	11.8	7.4
Israel	0.0	0.0	36.1	1.6	65.6	3.3	3.3	3.3
Australia	0.0	1.8	35.1	1.8	63.2	12.3	5.3	8.8
Netherlands	0.0	0.0	30.3	0.0	84.8	9.1	0.0	9.1
South Korea	1.3	2.6	44.2	7.8	64.9	16.9	1.3	0.0
Czech	1.8	7.3	47.3	9.1	78.2	21.8	7.3	1.8
USA (NY)	0.0	0.0	13.3	0.0	83.3	33.3	0.0	0.0

The best direction towards the death (dementia case, %) Q3-9

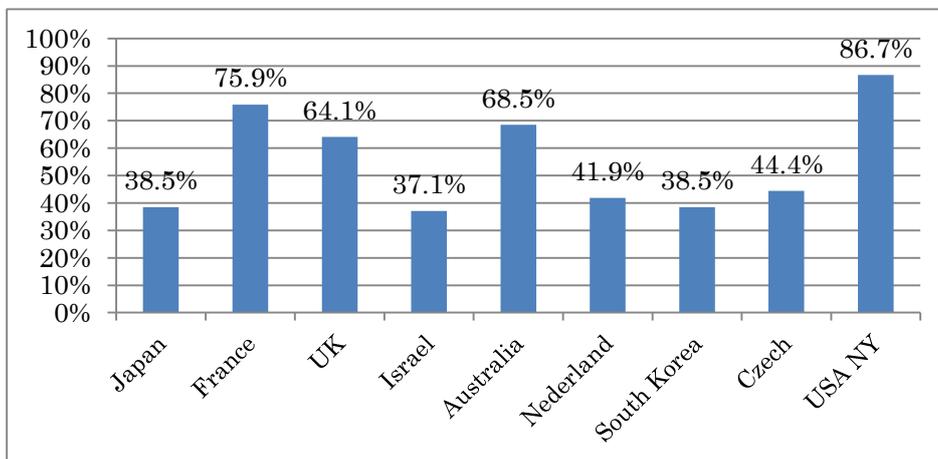
	Treatment in hospital	Palliative care in hospital	Treatment at care facility	Palliative care at care facility	Treatment at home	Palliative care at home	Other
Japan	3.6	3.2	7.3	16.8	27.7	40.9	.5
France	15.4	24.4	10.3	30.8	5.1	11.5	2.6
UK	.0	6.3	34.9	15.9	11.1	31.7	.0
Israel	5.7	9.4	3.8	30.2	13.2	35.8	1.9
Australia	3.8	7.7	15.4	15.4	9.6	46.2	1.9
Netherlands	.0	3.2	12.9	9.7	19.4	45.2	9.7
South Korea	18.5	3.7	3.7	11.1	7.4	51.9	3.7
Czech	9.1	7.6	6.1	21.2	12.1	39.4	4.5
USA (NY)	.0	.0	.0	.0	13.3	86.7	.0

Reasons for choosing the direction selected above (dementia case, %, MA) Q3-9-2

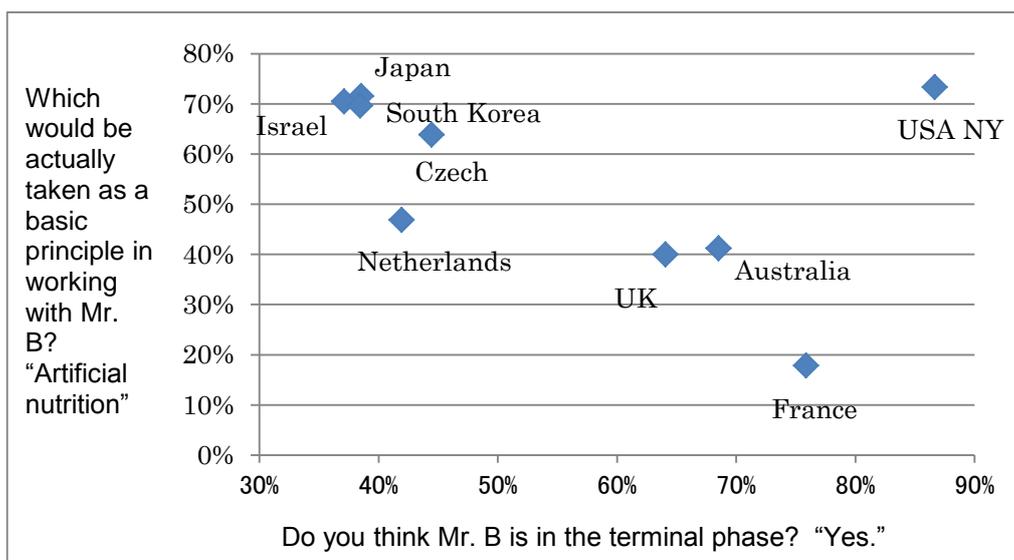
	Possible to recover fully	Longer life	QOL	Economic al	Respect dignity	Family's wish	Guideline	Other
Japan	2.7	15.9	18.2	2.7	42.7	61.4	.9	1.4
France	2.6	33.3	26.9	9.0	46.2	24.4	.0	1.3
UK	.0	1.6	33.9	.0	38.7	30.6	16.1	9.7
Israel	1.9	1.9	28.8	1.9	50.0	26.9	3.8	9.6
Australia	.0	13.2	56.6	7.5	64.2	30.2	3.8	5.7
Netherlands	3.3	.0	16.7	.0	43.3	63.3	3.3	3.3
South Korea	3.4	10.3	41.4	.0	69.0	51.7	10.3	3.4
Czech	8.8	14.7	42.6	2.9	77.9	42.6	11.8	11.8
USA (NY)	.0	.0	3.3	3.3	60.0	43.3	3.3	.0

Is the dementia case considered “terminal”?

Japan is one of the countries (Japan, Israel, South Korea and Gzech) where the dementia patient is less likely to be diagnosed as the terminal condition and is more likely to receive artificial nutrition. In Australia, France and UK, the patient is more likely to be considered terminal and is less likely to receive artificial nutrition.



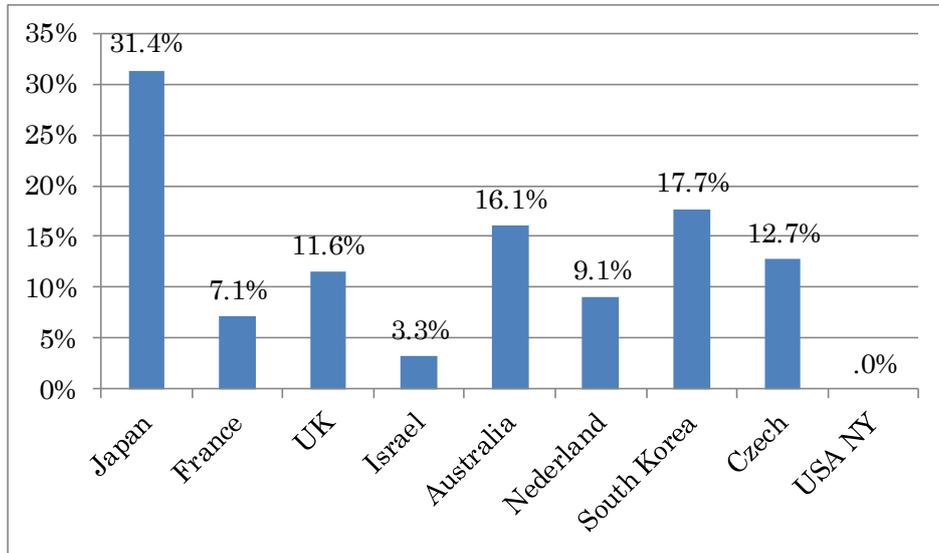
Is the dementia patient considered “terminal”? (% of “Yes”) Q3-1



% of “The dementia patient is considered terminal” (Q3-1) and “artificial nutrition would be provided”

Frequency of thinking about death

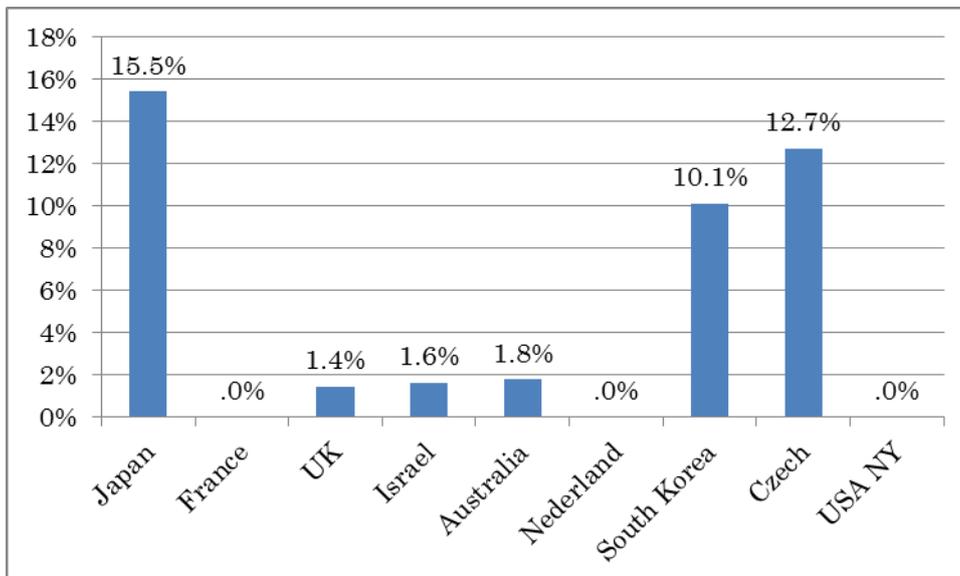
Japanese respondents tend to think about death more frequently.



How often do you think about death? (% of "very often") Q4-1

Anxiety about and/or fear of death

Japanese respondents are more likely to have anxiety about and/or fear of death.



Do you feel anxiety about/or fear of death? (% of "very much") Q4-2

The ideal death and end-of-life care

“Death with little pain and fear” and “death without long struggling days” are frequent responses in each country. The proportions of the responses “death without spending so much money” and “death after the maximum efforts to prolong life” differ among the countries. In France and the Netherlands, relatively fewer respondents choose “death without spending so much money.” In France, the Netherlands and USA, relatively fewer respondents choose “death after the maximum efforts to prolong life.”

The ideal death for self (% of “strongly agree” and “somewhat agree”) Q4-3

	Death w/o burden on family & friends	Death w/ little pain & fear	Death w/o long struggling days	Death w/ enough preparation	Death surrounded by family & friends	Death w/o spending much money	Death w/ self determination (e.g. death w/ dignity)	Death after the maximum efforts to prolong life
Japan	84.0	91.7	86.9	67.1	73.2	72.7	69.5	17.3
France	78.6	66.7	92.9	64.3	89.3	28.6	74.1	3.6
UK	80.9	87.9	82.4	35.4	79.1	57.6	86.6	34.3
Israel	83.3	89.8	89.8	76.3	78.0	70.2	62.7	27.1
Australia	76.8	94.5	91.1	83.9	85.7	56.4	91.1	19.6
Netherlands	57.6	96.9	97.0	75.8	93.9	21.9	87.9	9.1
South Korea	92.4	96.2	96.2	86.1	83.5	77.2	83.5	44.3
Czech	65.3	82.0	83.7	46.8	60.4	38.3	92.3	33.3
USA (NY)	100.0	100.0	96.7	70.0	76.7	66.7	100.0	.0

“Having discussion on preferred treatments with the patient beforehand” and “allowing families and friends to meet with the patient before death” are frequent responses in each country. Japanese respondents are less likely to choose “spending as much time as possible together even if unable to have conversation,” “preparing environment so as to receive as much medical and care service as possible,” “making the patient’s suffering last short” and “following the patient’s religious or cultural ritual.”

The ideal end-of-life care for family (% of “strongly agree” and “somewhat agree”) Q5-1

	Spending as much time as possible together, even if unable to have conversation	Preparing environment so as to receive as much medical and care service as possible	Having discussion on preferred treatment w/ the patient beforehand	Being able to have conversation until the last moment	Allowing families & friends to meet w/ the patient before death	Economical terminal care	Making the patient’s suffering last short	Following the patient’s religious or cultural ritual
Japan	55.3	49.3	86.6	64.1	86.6	31.5	52.1	49.8
France	88.9	74.1	96.3	70.4	84.6	25.9	77.8	77.8
UK	90.9	50.0	96.9	75.4	92.2	29.2	89.2	92.3
Israel	89.8	75.8	89.8	89.8	89.8	34.5	86.4	81.4
Australia	96.4	78.0	92.9	67.9	89.3	45.5	76.8	87.5
Netherlands	84.8	72.7	93.8	57.6	93.9	13.8	87.9	75.8
South Korea	58.2	60.6	77.2	92.4	91.1	64.6	79.7	45.6
Czech	98.0	82.3	94.0	82.4	88.2	23.4	54.8	84.1
USA (NY)	63.3	96.2	100.0	96.7	100.0	70.0	100.0	100.0

The ideal place of death

The most frequent choice as the ideal place of death for self is “home” in each country. The proportions of “hospice (institution)” are different among the countries: the respondents in France, Australia and South Korea are more likely to choose this option.

The ideal place of death for self (%) Q4-4

	Home	Assisted living	Group home	Old people's home	LTC hospital	Hospital, clinic	Hospice (institution)	Other
Japan	71.7	3.7	1.4	2.3	1.4	3.7	6.4	9.6
France	67.9	3.6	.0	.0	.0	7.1	14.3	7.1
UK	82.6	1.4	.0	.0	.0	.0	4.3	11.6
Israel	95.0	.0	.0	.0	.0	3.3	.0	1.7
Australia	78.6	3.6	.0	.0	.0	7.1	10.7	.0
Netherlands	93.9	.0	.0	.0	.0	.0	6.1	.0
South Korea	60.8	7.6	.0	3.8	7.6	1.3	19.0	.0
Czech	84.3	.0	.0	.0	.0	2.0	3.9	9.8
USA (NY)	100.0	.0	.0	.0	.0	.0	.0	.0

The most frequent choice as the ideal place for families to spend their final days is also “home” in each country. In South Korea, respondents are relatively more likely to choose “long-term care hospital,” “hospital, clinic” and “hospice (institution).”

The ideal place for families to spend their final days (%) Q5-2

	Home	Assisted living	Group home	Old people's home	LTC hospital	Hospital, clinic	Hospice (institution)	Other
Japan	67.8	2.8	.9	5.1	1.9	7.9	7.0	6.5
France	80.8	3.8	.0	.0	.0	7.7	3.8	3.8
UK	79.1	3.0	1.5	.0	.0	1.5	3.0	11.9
Israel	95.1	.0	.0	.0	1.6	1.6	.0	1.6
Australia	87.3	3.6	.0	.0	.0	1.8	3.6	3.6
Netherlands	100.0	.0	.0	.0	.0	.0	.0	.0
South Korea	43.0	7.6	.0	3.8	12.7	12.7	17.7	2.5
Czech	90.7	3.7	.0	.0	.0	1.9	.0	3.7
USA (NY)	86.7	.0	.0	.0	.0	.0	.0	13.3

The ideal persons to be present at your death

In each country, the frequent responses are “spouse” and “children.” Japanese respondents are less likely to choose “clergy.” The proportion of “doctor” is relatively high in South Korea, UK and USA.

The ideal persons to be present at your death (%) Q5-3

	Spouse	Parents	Children	Grandchildren	Primary care doctor	Specialist physician	Nurse	Direct care worker	Facility staff	Friends	Neighbors	Clergy	Brother/sister	Other
Japan	68.1	15.7	70.8	20.8	10.2	2.8	8.3	5.1	3.7	18.1	3.2	1.9	3.2	9.7
France	70.6	11.8	58.8	29.4	5.9	.0	.0	5.9	.0	23.5	.0	5.9	.0	.0
UK	80.0	40.0	40.0	10.0	10.0	10.0	10.0	.0	.0	.0	.0	10.0	.0	20.0
Israel	83.6	21.3	75.4	32.8	6.6	4.9	4.9	9.8	4.9	18.0	1.6	13.1	1.6	3.3
Australia	85.2	18.5	79.6	35.2	5.6	1.9	5.6	1.9	.0	33.3	.0	13.0	3.7	7.4
Netherlands	97.0	39.4	84.8	24.2	.0	.0	6.1	3.0	.0	33.3	.0	.0	9.1	.0
South Korea	70.9	2.5	38.0	2.5	19.0	7.6	10.1	11.4	8.9	5.1	.0	17.7	.0	6.3
Czech	77.4	28.3	75.5	17.0	.0	.0	5.7	.0	.0	17.0	1.9	15.1	.0	5.7
USA (NY)	100.0	33.3	96.3	14.8	11.1	7.4	3.7	.0	.0	29.6	.0	14.8	.0	.0

5. 2010 International Comparative Study on Terminal Care: Comments by Collaborating Countries

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1. Purpose

The 2010 International Comparative Study on Terminal Care showed several differences among the participating countries. The purpose of this chapter is to understand the context (systems, national character, culture, etc.) behind these results by obtaining interpretations of the study results from each country.

2. Methodology

The 2010 survey results were sent to the participating countries (Israel, South Korea, Czech, the Netherlands, Australia, UK and France) as well as to USA, which joined the study in 2011, along with the following questions. The respondents are ILC Alliance Centers in Israel, Czech, UK, France and USA; HammondCare in Australia; and Korean Alzheimer's Association.

Q1) There is a significant gap between the ideal (home) and actual (hospital) places at the end of life. In your country, what kind of measures are mainly taken to fill this gap (e.g. housing policies; developing guidelines on the end-of-life care; improving visiting nurses and home care services; and education (particularly on death) for medical doctors, nurses and direct care workers)?

Q2) From the data on "Mr. B is in the terminal phase" and "Artificial nutrition would be actually taken with Mr. B," it seems that the responses can be categorized into 2 groups: (1) Japan, Israel, South Korea, Czech and the Netherlands; and (2) Australia, UK and France. What do you think are the reasons for this difference (e.g. national character, development of laws and guidelines regarding the end-of-life care)?

3. Results

1) Places at the end of life: Gap between "ideal" and "reality"

This gap also exists in Israel. As the arrangements to decrease this gap, the Israeli respondent mentioned a) the Law for the Dying Patient and b) specific services for patients who stay at home at the end of life. In Israel, there are 4 Health Maintenance Organizations (HMOs). Each of them has developed some arrangements for home care. The largest HMO (Haklalit) has developed the service of Home Hospice. Under this service, care is provided on a regional basis by teams comprised of a doctor, nurse and social worker who are trained in palliative care. They are available 24 hours a day, providing such services as regular visits and visits according to needs. However, this service does not cover all the settlements in Israel.

In France, some of the reasons for difficulties in end of life at home include a) a lack of interdisciplinary palliative care networks in communities and b) cultural difficulties for families to accept the end of life at home. In order to respond to the first reason, a new

program 2008-2012 of development of palliative care was announced by the President of the Republic in June 2008 (see Table 1). As for Alzheimer's disease, 100,000 people die each year, but their conditions of death are poorly known. In order to increase the support for caregivers, the Alzheimer Plan 2008-2012 provides various measures to develop and diversify the structures of respite, responding to patients' needs and caregivers' expectations in each region. It also provides the intervention of specialized personnel to strengthen home support. The plan advocates the creation, between 2009 and 2012, of 500 specialized teams.

USA, Czech, Australia and South Korea did not mention the efforts or measures to fill the gap. However, each country reported the background behind the difficult situations to provide end-of-life care "at home."

In USA, although hospice services are often provided in institutional settings, the respondent points out that the possibility of receiving hospice services at home helps to facilitate the goal of end-of-life care at home. For example, the Respecting Choices program, started in 1991 by the Gundersen Lutheran Health System in Wisconsin is an innovative and internationally recognized program that helps to ensure that individual preferences with regard to end of life care are respected. The goal is not necessarily to help people die at home (because this may not be something that everyone wants), but it is designed to make sure that the preferences of patients are not ignored. This program focuses on the process of advance care planning rather than placing emphasis on the completion of living wills or other legal documents, and it involves multiple institutions in an entire community.

Czech has the lowest proportion of the respondents who think that the best place for Mrs. A is her home (50.2 %). It means that half of the respondents would prefer professional care outside the patient's home. The respondent identified (1) service delivery systems and (2) administration of the systems as the influencing factors. Regarding (1) service delivery systems, the country has very well developed institutional care systems both in health and social care sectors. Health care is provided in hospitals (acute care and acute complications) and in long-term care hospitals (after care and sometimes also long-term care and nursing care). This care is completely free for patients with the exception of so called "registration fee (3 USD per day)." There are also hospices which provide specialist palliative care and other necessary services for the terminally sick. On the other hand, the system of home care services is not so well developed, and there are some very important barriers in home care provision. As for (2) administration of the systems, general practitioners are reimbursed for their care (including home visits) according to the number of their registered patients and their age. Besides these payments, they also have "virtual budgets" that they are supposed to spend for so called "induced care," meaning the care (specialist, nursing), nursing aids and drugs which they prescribe. There are restrictions of these virtual budgets imposed by insurance companies, which do not allow GPs to prescribe all necessary care and aids if they have among their patients more severely dependent or dying patients. The respondent points out that these are the possible factors for people to think of institutional end-of-life care as suitable as end-of-life care at home.

In Australia, relatively few people chose “home” as the place at the end of life both in the ideal (46.4%) and actual (8.9%) situations compared with other countries. As a primary reason for these results, the Australian respondent points out a lack of the end-of-life care funding for people who live at home alone. However, the respondent also mentions that if the patient had a family caregiver then it would be quite feasible for her to die at home if her symptoms were reasonably well controlled with the support of her GP, community nurses and specialist palliative care if required.

In South Korea, the respondent mentions individual situations and cultural factors that influence the place. Confucian philosophy has been passed down for generations in Korean society, and the nation has chosen to prioritize families over welfare. Most people had spent their final days at home, but the proportions of hospitals and home as the place to provide end-of-life care started changing around 2002. It is pointed out that the contributing factors include social ones, such as a trend toward the nuclear family, concentrated apartments, social advancement of women and discontinuation of the system of home visit doctors, as well as a lack of 24-hour home care services under the welfare system for the elderly. Another possible factor is that everyone has easy access to hospitals. Under these circumstances, the respondent mentions the needs for home renovation and removing barriers in order to ensure the space for older people to remain at home, enhancement of visiting nurse services, diversification of home care services, adjustment of end-of-life care reimbursement and improvement of palliative care education for family caregivers.

Table 1: Palliative Care Program in France

<ul style="list-style-type: none"> • This program is a set of coordinated measures around three axes. <ul style="list-style-type: none"> • Axis 1: continuation of the development of palliative care units in hospitals and institutions. • Axis 2: development of training and research policy. • Axis 3: support offered to relatives. • Some measures are put forward. The government will spend 230 M€ for the implementation of this program. <ul style="list-style-type: none"> • Opening of the palliative care services in non-hospital structures (particularly in social and medico-social institutions for the elderly and development of home palliative care networks). • Improvement of the quality of support (esp. pediatric palliative care). • Dissemination of palliative culture through a campaign of communication to health professionals and the general public. • The axis 3 for the relatives and the general public includes the following measures. <ul style="list-style-type: none"> XIV - Support for relatives and caregivers, including palliative care training (2 M€ per year). XV - Development of temporary accommodation (creation of 100 places in nursing homes. Cost: 1.3 M€ over 5 years). XVI - Training for volunteers to facilitate the implementation of home palliative care with a goal of 7,000 volunteers trained per year (1.5 M€ per year over 5 years). XVII - Palliative care information for health professionals through the dissemination of the Leonetti law (700 000€). Campaign of information on palliative care and support services for the general public (5 M€). XVIII - Regional organization of an annual day of information on palliative care and support. The hospital Medical Commission will have to prepare an annual report on implementation of the palliative care.

2) Relationships between diagnosis of terminal stage and artificial nutrition

In Czech, despite the fact that palliative care has been often discussed recently, these discussions are mostly limited to cancer patients and not dementia. Therefore, the respondent points out that the professionals in Czech do not estimate the status of Mr. B as a terminal stage of dementia. Moreover, the respondent stresses that the professionals are educated mainly in acute medical specialties and proportion of education in palliative care and long-term care is far less robust than it would be necessary, considering the demographic situation and increase in the number of chronic diseases.

The Israeli respondent mentions (1) the Law for the Dying Patient and (2) Jewish cultural value that life is sacred. According to the Law for the Dying Patient, life sustaining treatment and other futile medical treatment can be withheld only if the patient's death is close and the patient wants or has left advance directives to limit treatment. Even then, fluids and food should not be withheld. Currently, this Law is not absorbed, neither among physicians nor among patients and families. However, another possible interpretation of the result is that the Israeli survey respondents tended to choose artificial nutrition in Mr. B's condition even if he was not considered terminal because the Law prohibits withholding of treatment even at the terminal stage unless the patient clearly expresses his/her will. In addition, dementia is a degenerative disease which can last for years. Therefore, quite often it is difficult to know/evaluate when life will end. This causes a problem in decisions regarding end-of-life care and raises the question of quality of life versus the prolongation of life. It is pointed out that "Life is sacred" is a basic value in Jewish culture as well as the guiding rule for practice among physicians in Israel.

The South Korean respondent points out that provision of artificial nutrition is largely influenced by cultural differences, the patient's decision-making and families' wishes. Confucian philosophy remains deeply rooted among caregivers in their 50s and 60s. In particular, the number of artificial nutrition cases seems to be increasing if patients are spouses because their caregivers tend to have a strong attachment to "life." Moreover, in South Korea, most of the patients who are not certified as needing care (levels 1-3) end up in geriatric hospitals, where IVH is easily administered. Hence, the respondent mentions that oral feeding becomes more difficult, leading to artificial nutrition in the end. (Artificial nutrition is particularly common among patients with vascular dementia because they tend to have dysphasia as well as aphasia.) It is also pointed out that South Korea would need to develop national guidelines like other countries in order to respond to such situations.

According to the Australian respondent, it would be very unlikely for a patient with advanced dementia to be started on IV nutrition in Australia in a hospital setting as there is recognition that advanced dementia is a terminal illness. Regarding the evidence based medicine and practice, there is no evidence in Australia that artificial nutrition or PEG tubes prolongs survival in the setting of advanced dementia due to risk of aspiration. The Australian respondent also mentions that similar results in UK may reflect established palliative care in this country – similar to Australia.

The French respondent states that the reasons for the group difference may be (1) cultural reasons regarding the role and meaning of artificial nutrition at the end of life, (2) existence or not of guidelines regarding the indication of artificial nutrition, and (3) experience of artificial nutrition in end of life situations. In particular, when a patient is in palliative care for a terminal illness, obstinacy in treatment and nutrition are discouraged by the Leonetti Law. Furthermore, practitioners have to follow the guidelines set by the FNCLCC (National Federation of Cancer Centers). Hence, artificial nutrition would not be actually recommended for Mr. B.

4. Discussion

While the interpretations of the survey results vary among the countries, they also suggest the relationships between rules and practice in Israel and France, which have laws and guidelines on end-of-life care. In addition, service delivery systems seem to be associated with the choice of place at the end of life. Yet, there is also a situation, as in Australia, that funding restrictions make end-of-life care at home difficult.