

# Current conditions of the end-of-life care in France and Europe.

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# Outline

1. Europe
2. France
3. The study : « End-of-life Care : Japan and the World.” Comparison between Japan and Europe

# End of life in Europe: an overview of medical practices

- The circumstances of death have changed over the last years in Europe. Most people die at old or very old ages, often in a hospital or care home after a long chronic illness. A much wider range of medical treatments and palliative care has also become available. Patients, for their part, more often prefer to die peacefully rather than prolong life at all costs
- As a consequence of these changes, health professionals are increasingly faced with medical decisions that might hasten the death of their patients, and a debate on the rights of the terminally ill and on the acceptability of euthanasia and other end-of-life decisions has emerged in several countries.

# End of life in Europe: Current legislation

- The Dutch and Belgian parliaments voted in favour of euthanasia in 2001 and 2002.
- In Switzerland, assisted suicide has been implicitly authorized for many years.
- In Germany, the right to access to specialised palliative care whenever needed, at any time and in all situations was introduced in SGB V (Social Security Code; §§ 37 b and 132 d)
- The Spanish legislation has followed most principles and recommendations made by international organisms, (WHO) (EU).
- EU made the 24th Recommendations (2003).
- In France, the “Leonetti’s Law” was voted in April 2005 and brought into force in February 2006. It authorizes doctors to withhold unnecessary medical treatment or to intensify pain relief, even if this hastens death.

# End of life in Europe : Current legislation

Actually : All countries have general laws about patient rights or advance directives.

Other regulations regarding health care usually concern funding and regulations of specific palliative care settings (Belgium, The Netherlands, UK, France, Germany) or incentives for better coordination of care (Germany) and equal access to palliative care (Spain).

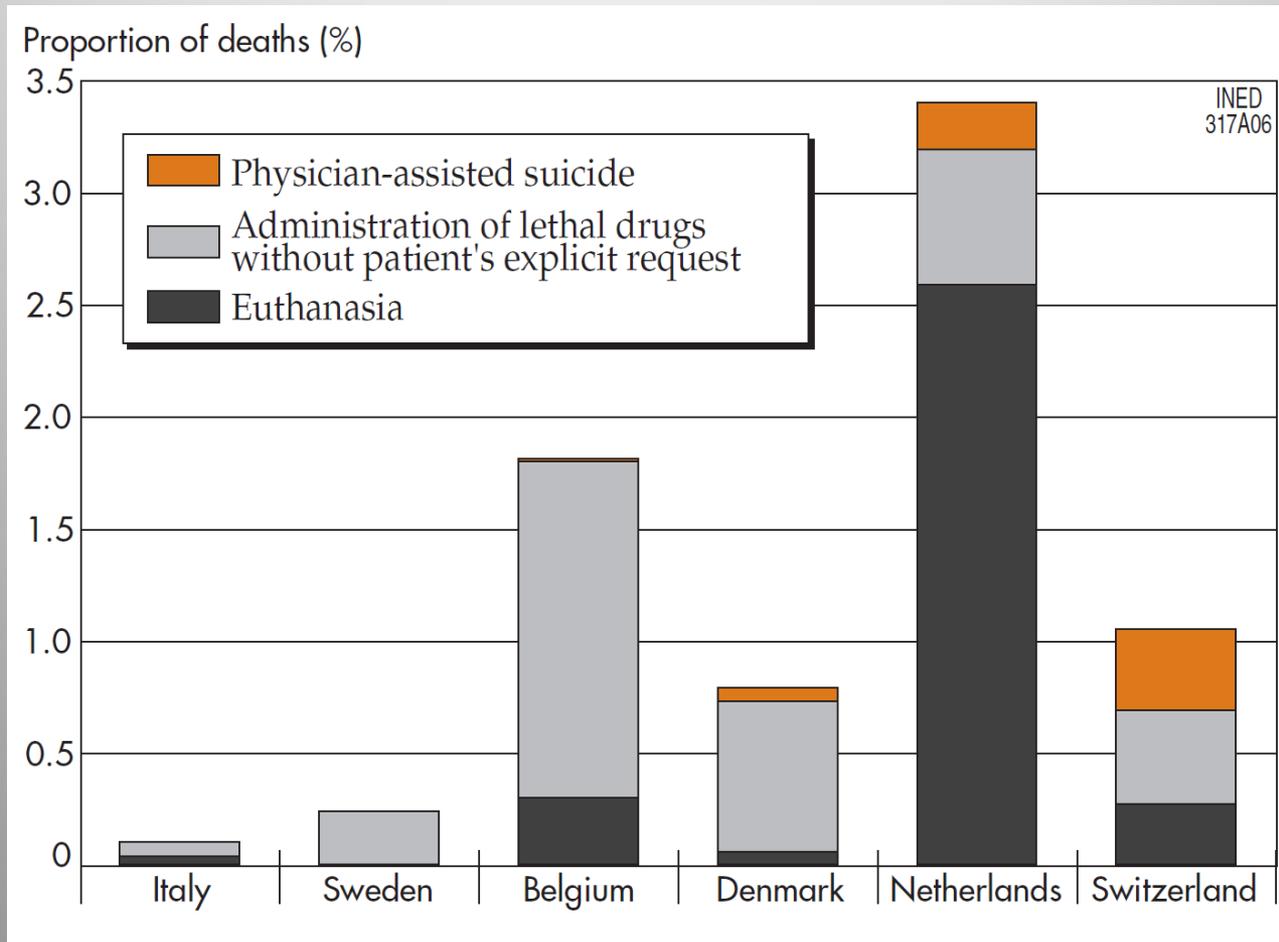
# End of life in Europe : First, Pain relief

- The painkillers administered are generally strong opioids (from 76% of cases in Italy, to 96% in the Netherlands), and their mode of administration vary considerably from one country to another.
- The doses administered in the last 24 hours of life also vary, but are generally below 300 mg of morphine oral equivalent (83% of cases in Belgium to 93% in Sweden).

# End of life in Europe : For one non-sudden death in three, a possibly life-shortening medical decision is made

- Life-shortening alleviation of pain and symptoms : 19% of all deaths in Italy, 26% in Denmark.
- Withhold or withdraw treatment : 4% of deaths in Italy, 14% of deaths in Sweden, Denmark and Belgium, 20% in the Netherlands and 28% in Switzerland.
- Physician-assisted death, with the administration of a drug explicitly intended to hasten the patient's death, was much less frequent, although it exists in all countries : 0.1% of deaths in Italy, 1.8% in Belgium and 3.4% in the Netherlands, even though these latter two countries had not yet legalized euthanasia at the time of the survey.

# End of life in Europe : Euthanasia is rare





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# EUROPAL : On going study making comparison of 7 European countries

Funding : European Public Health Executive Agency

## Defining best practices in palliative care in Europe :

- To improve the quality of life for patients in palliative care
- To evaluate the quality of palliative care
- To establish indicators for the quality of palliative care in Europe

<http://www.europall.eu/project-group-members/malteser-krankenhaus-palliativ-medicin-bonn/birgit-jaspers> - [europal@anes.umcn.nl](mailto:europal@anes.umcn.nl) - [k.vissers@anes.umcn.nl](mailto:k.vissers@anes.umcn.nl)

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# EUROPAL : Questionnaire - Content

- 1. Health systems with regard to provision and funding of PC**
- 2. Systems to measure PC needs of the population**
- 3. Place of death**
- 4. National and/or regional policies on PC**
- 5. Laws on PC**
- 6. Health plans regarding palliative care and their implementation**
- 7. National/regional PC associations**
- 8. Numbers and description of PC resources**
- 9. Barriers or incentives to provide or receive PC**
- 10. Education and specialisation in PC**
- 11. Role of volunteers in PC organisations and training of volunteers**
- 12. Research (national/regional research plans, funding)**

# EUROPAL : An international set of 51 quality indicators has been developed and validated, defining best practices across European countries.

- **DEFINITION OF A PALLIATIVE CARE SERVICE**

- **ACCESS TO PALLIATIVE CARE**

- *Access and availability*

- *Out of hours*

- *Continuity of care*

- **INFRASTRUCTURE**

- *Infrastructure*

- *Information about care*

- *IT systems*

- **ASSESSMENT TOOLS**

- **PERSONNEL**

- *Team*

- *Education and training of staff*

- *Info sharing*

- *Organisation of care*

- *Support systems*

- **DOCUMENTATION OF CLINICAL DATA**

- *Clinical record*

- *Timely documentation*

- **QUALITY AND SAFETY ISSUES**

- *Quality policies*

- *Reporting adverse events*

- *Complaints procedure*

- **REPORTING CLINICAL ACTIVITY**

- **NATIONAL/INTERNATIONAL**

- *National palliative care policy*

- *Guidelines*

- *Healthinsurance policy*

- *Palliative care networks*

- **RESEARCH IN PALLIATIVE CARE**

- **EDUCATION IN PALLIATIVE CARE**

# End-of-life in Europe : Barriers to the development of Palliative Care

- 1) Lack of financial and material resources;
- 2) Problems related to opioid prescriptions : restrictive procedures and negative cultural stereotypes. Prohibitive cost in some country.
- 3) Lack of public awareness and government recognition of palliative care as a field of specialization seen to a more disease-oriented model of “cure” rather than patient-oriented “care.”
- 4) Lack of palliative care education and training programs in the medical students and nurses curriculum.

End-of-life in France :  
the Leonetti's law was voted in  
April 2005 by the parliament and  
was brought into force in February  
2006

# Leonetti's law : law on the end-of-life rights of patients

- The law meets the expectations of French people who have expressed fears towards the end of life:
  - Fear of suffering
  - Fear of not being able to express their will
  - Fear to undergo aggressive treatment
  - Fear of being abandoned and left to die alone
- It offers healthcare professionals a decision framework.
- It imposes procedures in medical decision making.

# Leonetti's law : law on the end-of-life rights of patients

- **The Leonetti's law is based on the following values:**
  - The respect of the person's will (principle of autonomy)
  - The necessity of the patient and proxi information
  - The dignity of the person
  - The pain relief
  - The principle that the cessation of treatment, refusal of treatment must be accompanied by the establishment of a palliative care project
- **It imposes procedures in medical decision making:**
  - The collegiality in decision-making to stop or limit treatment.
  - Compulsory report of discussion: the decision must be recorded in the medical file. Time duration of the concertation with the team will be recorded as well as the opinions of the protagonists with the dates of meetings, names and qualifications of the persons concerned.

# Main articles of the Leonetti's law :

1. The refusal of unreasonable obstinacy
2. The patient refusal of treatment
3. Any adult can write « anticipated directives » in the case he would be unable in the future to express his will.
4. Collegial process to limit and discontinue a treatment in a patient unable to express his will
5. The principle of double “effect” The intention of the prescriber is to relieve suffering even if it hasten the end of life
6. Safeguard the dignity of the patient « Dignity is a word that describes the absolute and uncomparable value of human being regardless of his condition ».
7. Safeguard International ethical principles : Principle of autonomy, Principle of benevolence, Principle of non “malevolence”

« First do no harm. »

# French Society of Palliative care recommendations :

If there is 3 or more positive answers, the use of a specialized team in palliative care must be considered

	YOUR QUESTIONS?	COMPLEMENT	YES/NO
1	The patient is suffering from a disease that will not heal in the current state of knowledge	A positive answer to this question is a necessary condition for use Pallia 10 and go to the following questions	
2	There are pejorative prognostic factors	Validated in Oncology: hypoalbuminemia, inflammatory syndrome, lymphopenia, Performans Status > 3 or Karnofsky Index	
3	The disease is rapidly progressive		
4	The patient or his relatives are demanding for palliative care and support	Act No. 99-477 of 9 June 1999 to ensure the right of access to palliative care	
5	Persistence of symptoms not relieved despite the implementation of the first-line treatments	Spontaneous pain or caused during care, dyspnea, vomiting, occlusive syndrome, confusion, agitation...	

# French Society of Palliative care

If 3 or more positive answers, the use of a specialized team in palliative care must be considered

	YOUR QUESTIONS?	COMPLEMENT	YES/NO
6	You identify psychological factors of vulnerability in the patient and/or in his entourage	Sadness, anxiety, withdrawal or aggressive behavioural disorders, disorders of communication, family conflicts, preexisting psychopathology in the patient and/or in his entourage	
7	You identify social factors of vulnerability in the patient and/or in the entourage	Isolation, insecurity, physical dependence, precarity, financial difficulties, existence in the entourage of a dependent person, young children	
8	The patient or the entourage have difficulties to understand the information on the disease and/or the prognosis	Facing disease worsening, the patients and the entourage develop anxiety which in turn can implement psychological protection mechanisms that make communication difficult and complicate the implementation of a project of palliative care	

# French Society of Palliative care

If 3 or more positive answers, the use of a specialized team in palliative care must be considered

	YOUR QUESTIONS?	COMPLEMENT	YES/NO
9	You see questions or discrepancies regarding the consistency of the care project by the medical team	These questions may concern: • anticipated requirements • indications of: hydration, feeding, antibiotic, installation of probe, transfusion, monitoring of the patient (HGT, monitoring...) • indication and establishment of sedation • location of the most suitable support • reanimation status	
10	You have questions about the right attitude for example: • a refusal of treatment • a limitation or a decision of treatment • a request for euthanasia • the presence of a conflict of values	The Leonetti law relative to the patients rights and end of life deals with questions of refusal of treatment and /or the terms of decision making for limitation of treatment for all competent/conscious patients and for patients not in the situation to express their will	

# The French palliative care organisation relies on:

- The palliative care units (USP)
- Mobile teams of palliative care (EMSP)
- Identified beds in palliative care (LISP)
- Inpatient services at home (HAD)
- Palliative care networks

# Distribution of the provision of palliative care in France (31/12/2010)

	Number of palliative care units (USP)	Number of beds in palliative care unit	Number of identified palliative care beds (LISP) in 1164 establishments	Number of mobile team of palliative care
France	107	1176	4826	353

At mid-term of the national plan 2008-2012 on palliative care, nearly 6,000 palliative care beds were identified against 2000 before the plan. The progress report highlights two areas on which the plan needs to focus, "the completion of the territorial network of the supply of hospital palliative care, and dissemination of palliative approach in the nursing homes and home. "

# **End-of-life Care: Japan and the World**

International Comparison Study on  
Death and Dying in Place

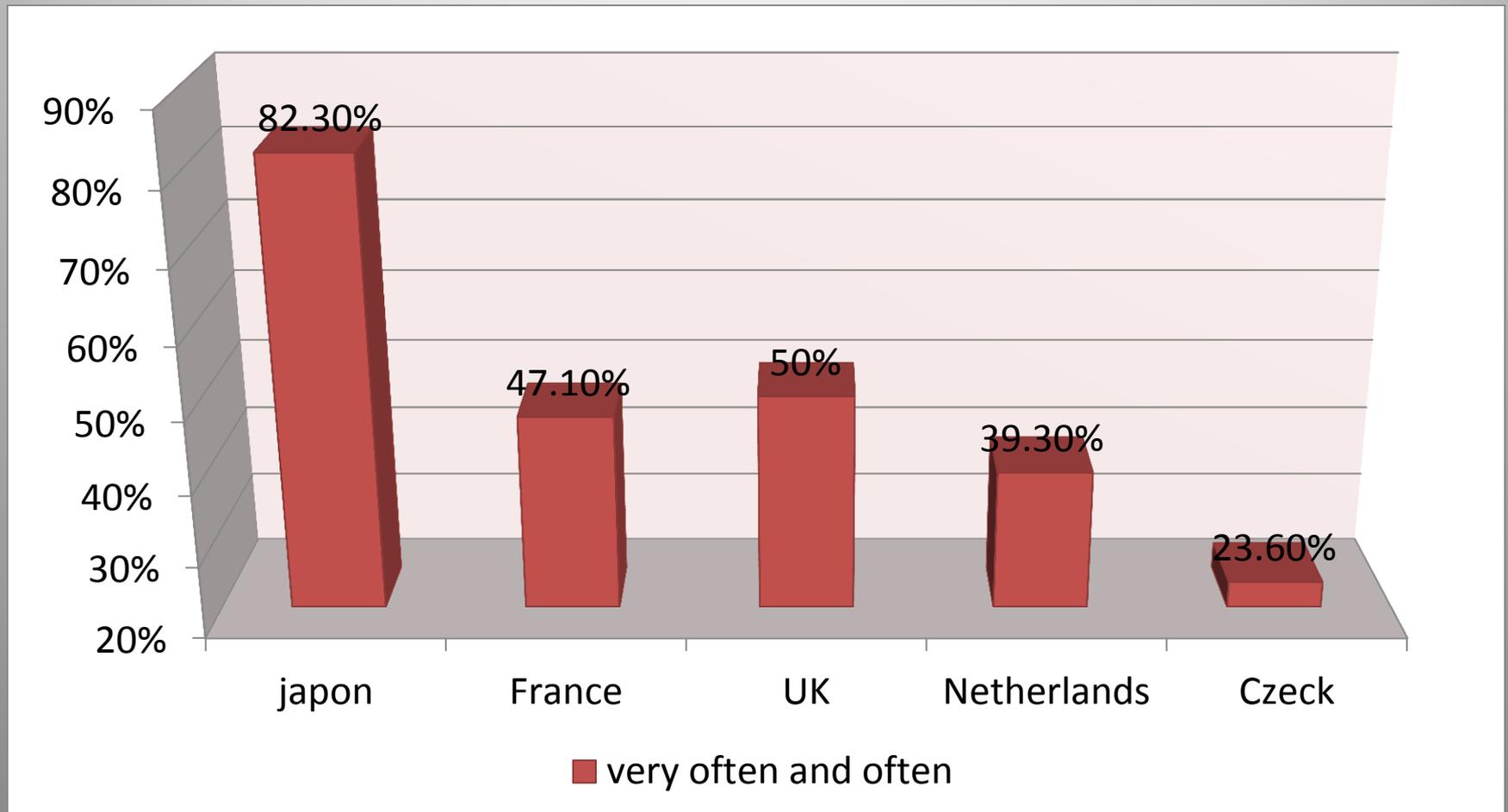
**Japan compared to European countries**

From the report of International Longevity Center – Japan – March 2011

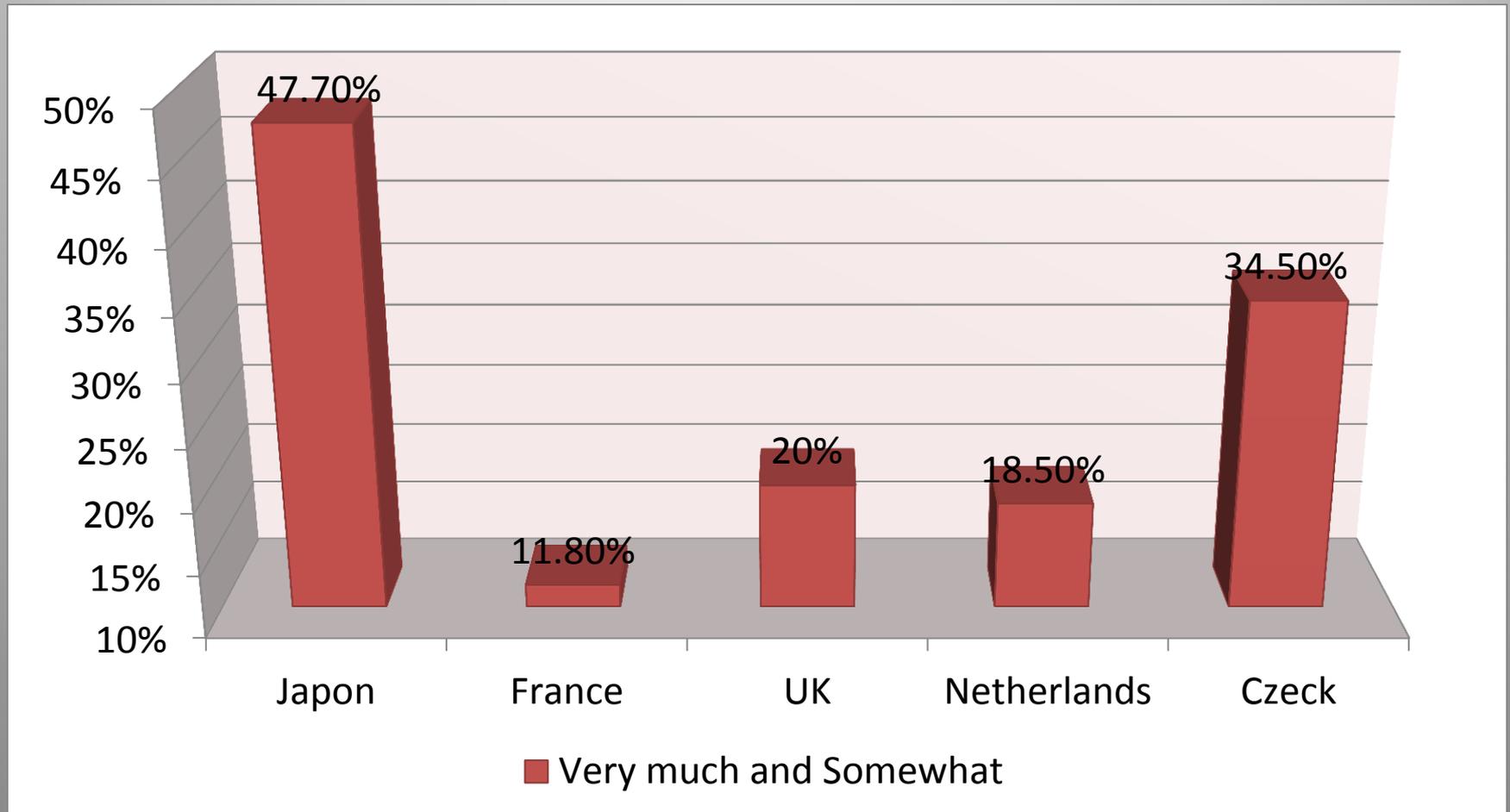
# Main conclusions (1)

- Major cultural discrepancies between Japan and EU on the following results :
  - Thinking about death
  - Feeling anxiety about death
  - Spending time together at the time of death
  - Receiving as much medical and care service as possible
  - Wanting to shorten the patient's final suffering period
  - Wanting treatment to follow the patient's religious or cultural rituals

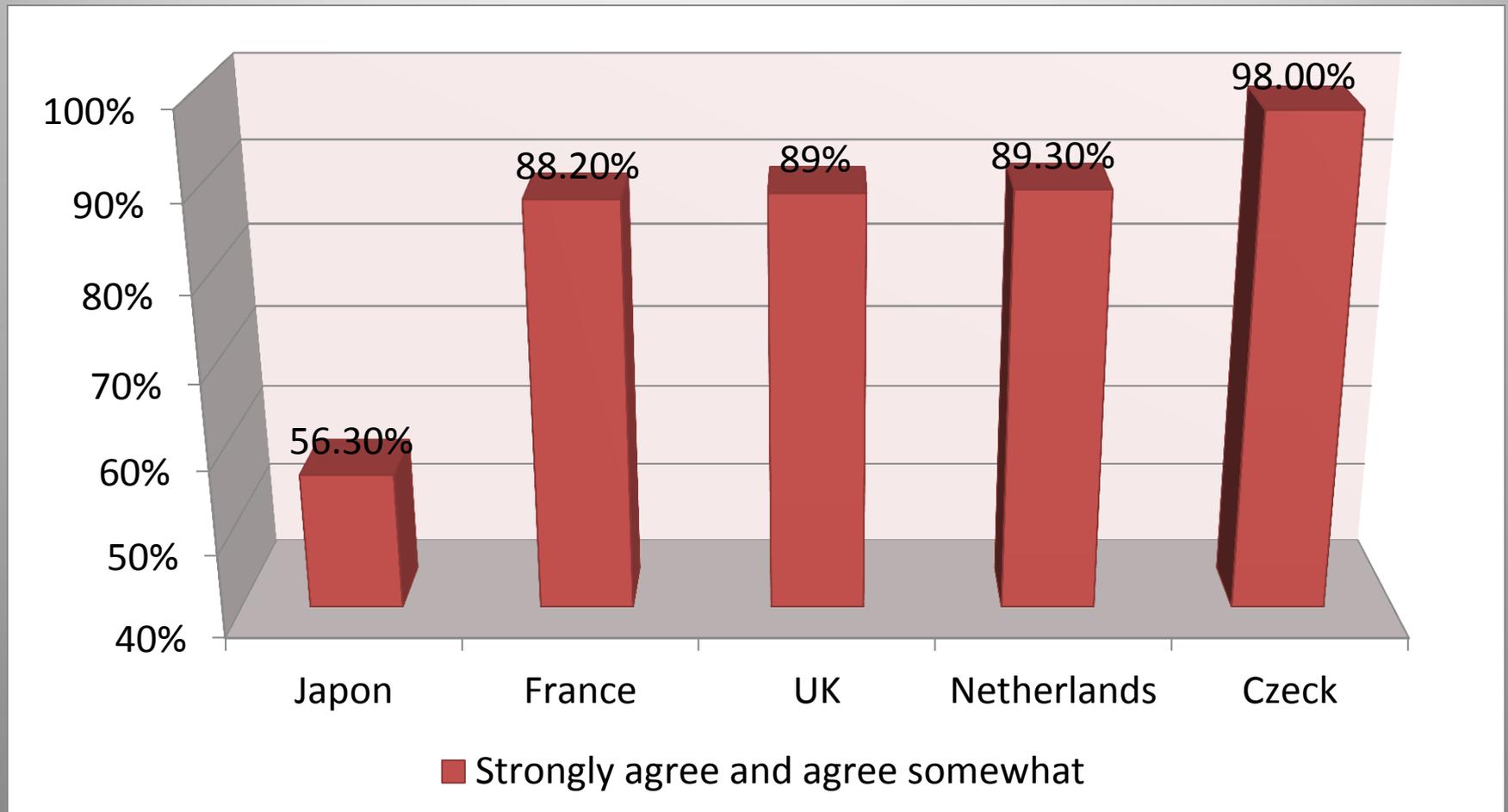
# How often do you think about death?



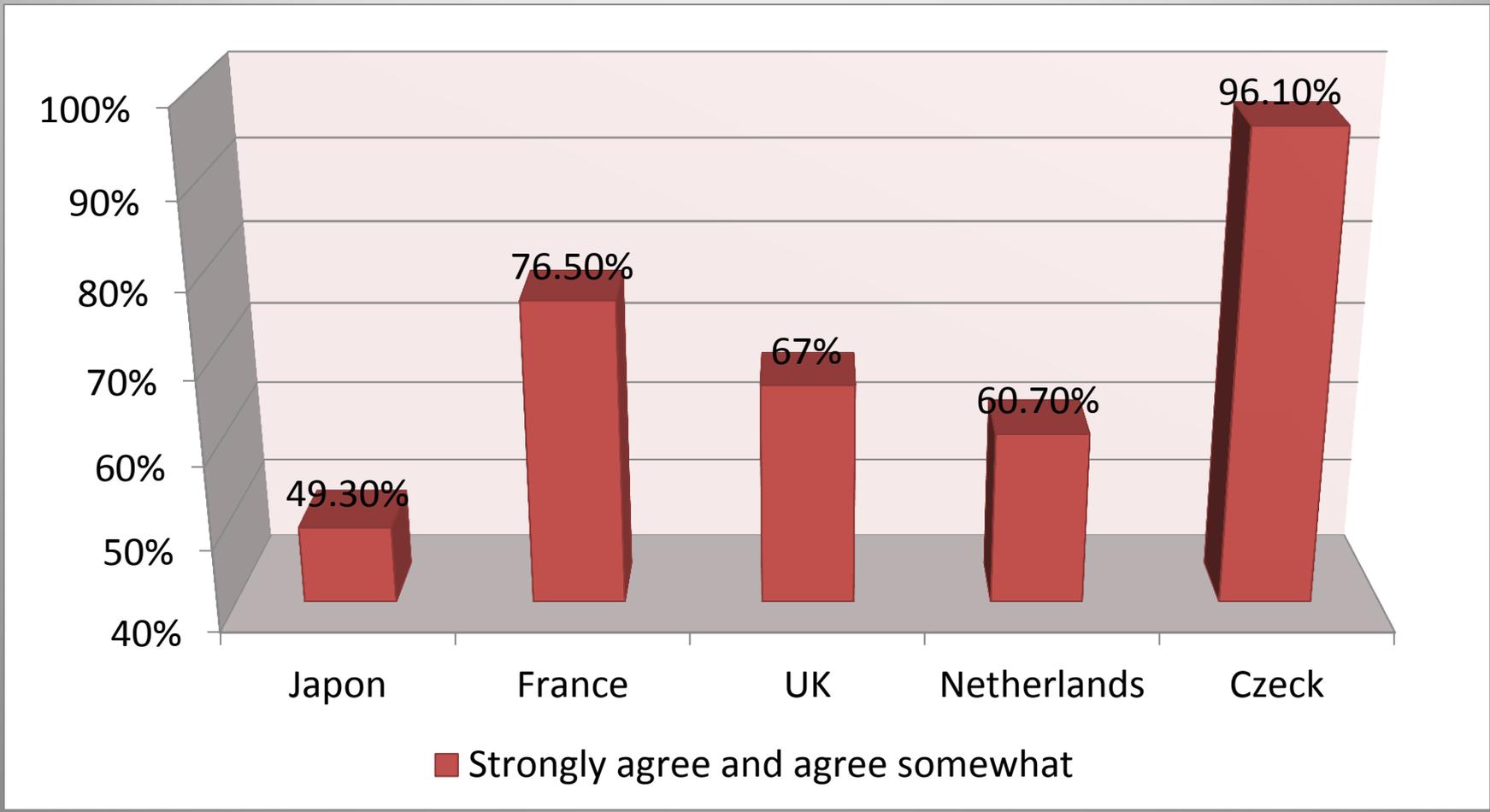
# Do you usually feel anxiety about and/or fear of death?



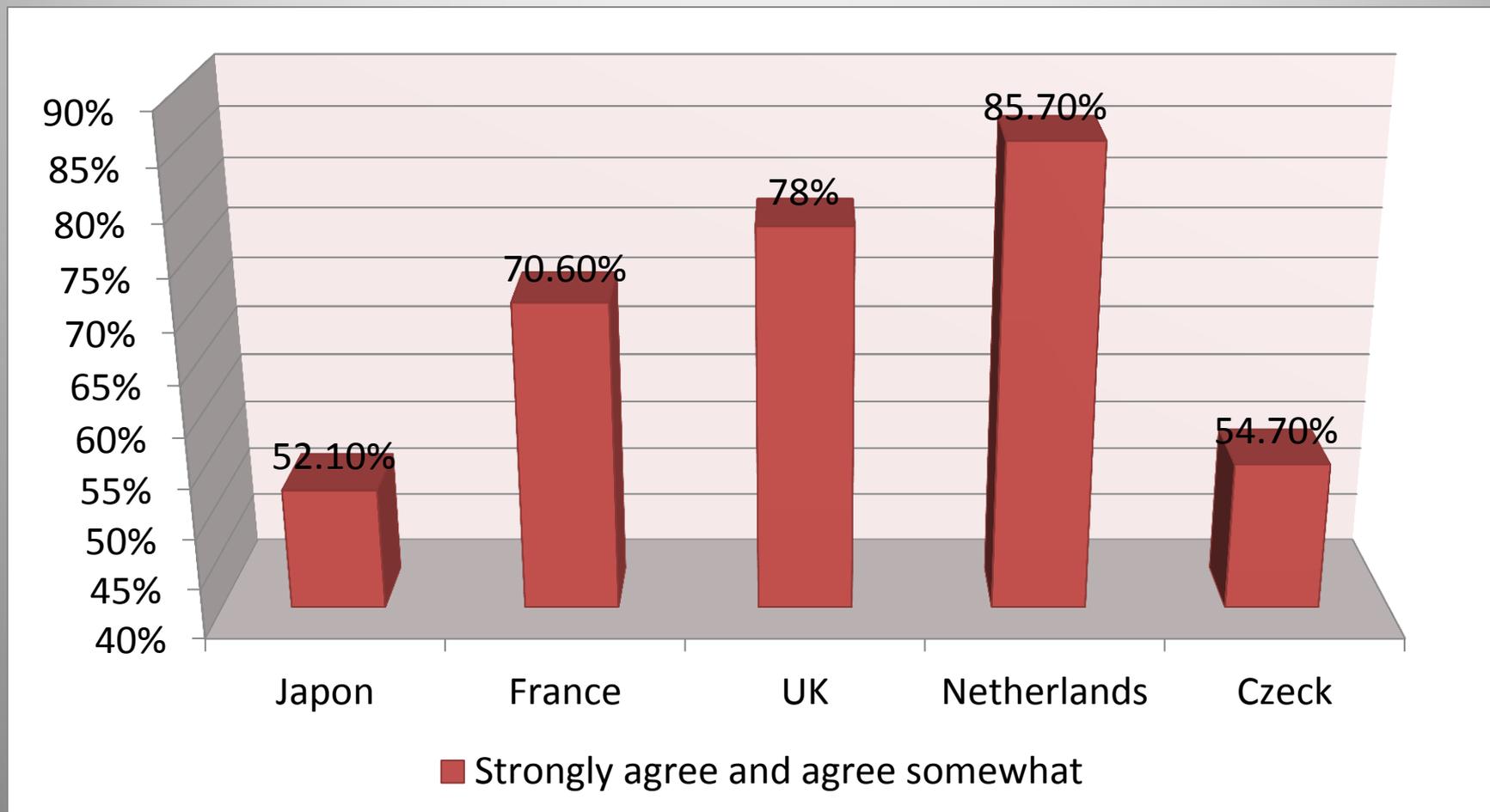
Want to spend as much time as possible together, even if unable to have conversation



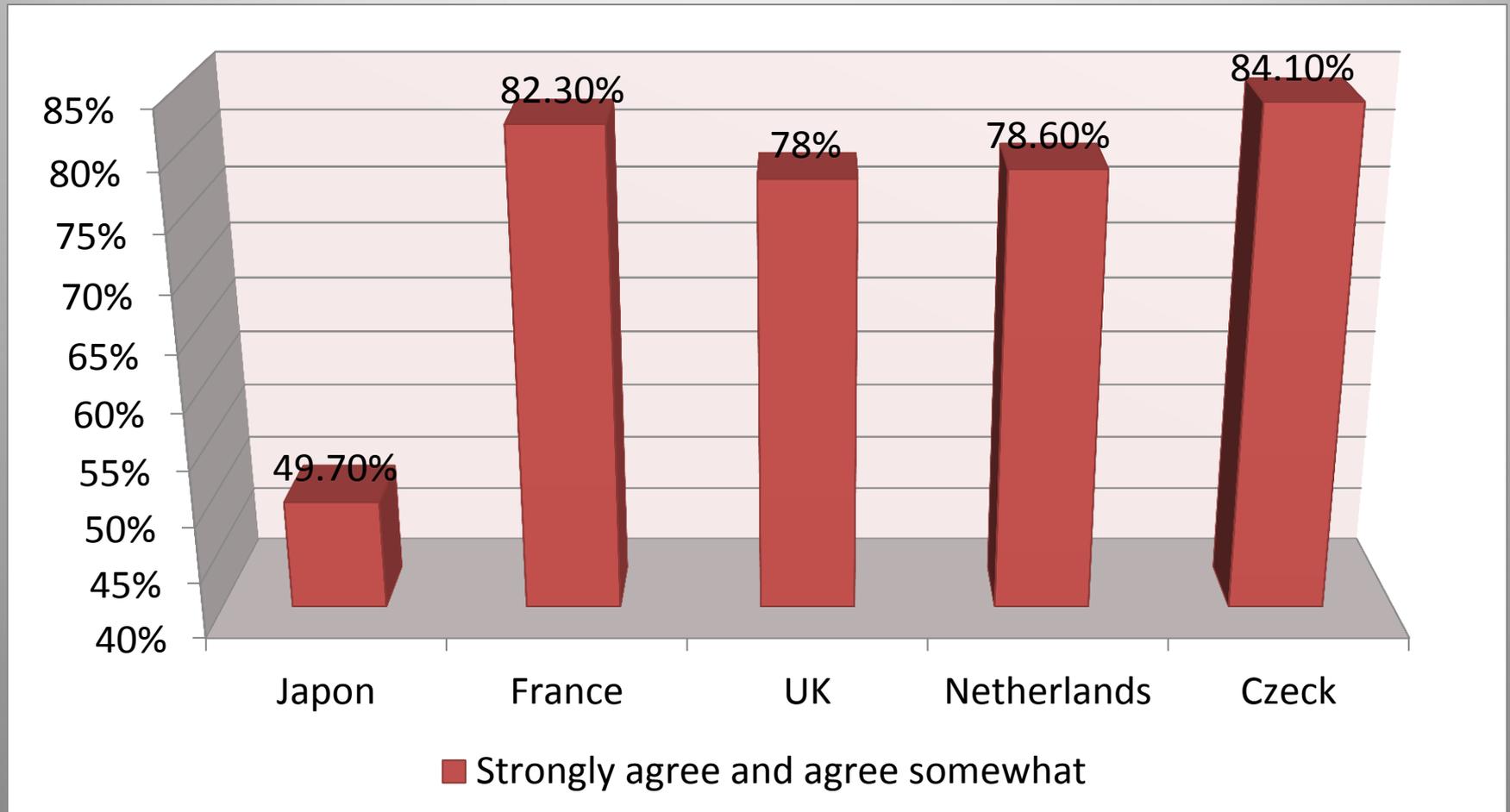
# Want environment prepared so as to receive as much medical and care service as possible



# Want to shorten the patient's final suffering period



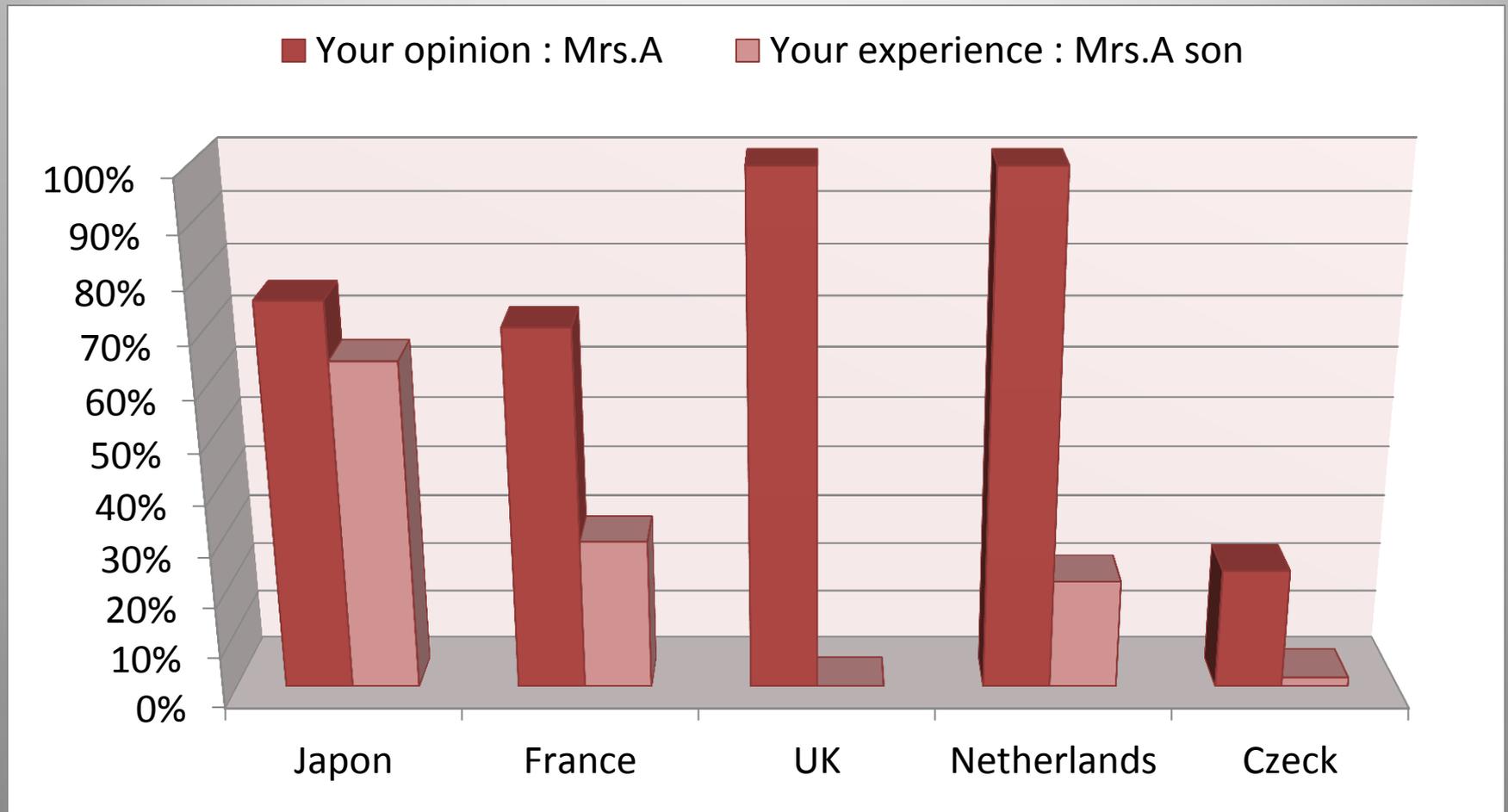
# Want treatment to follow the patient's religious or cultural rituals



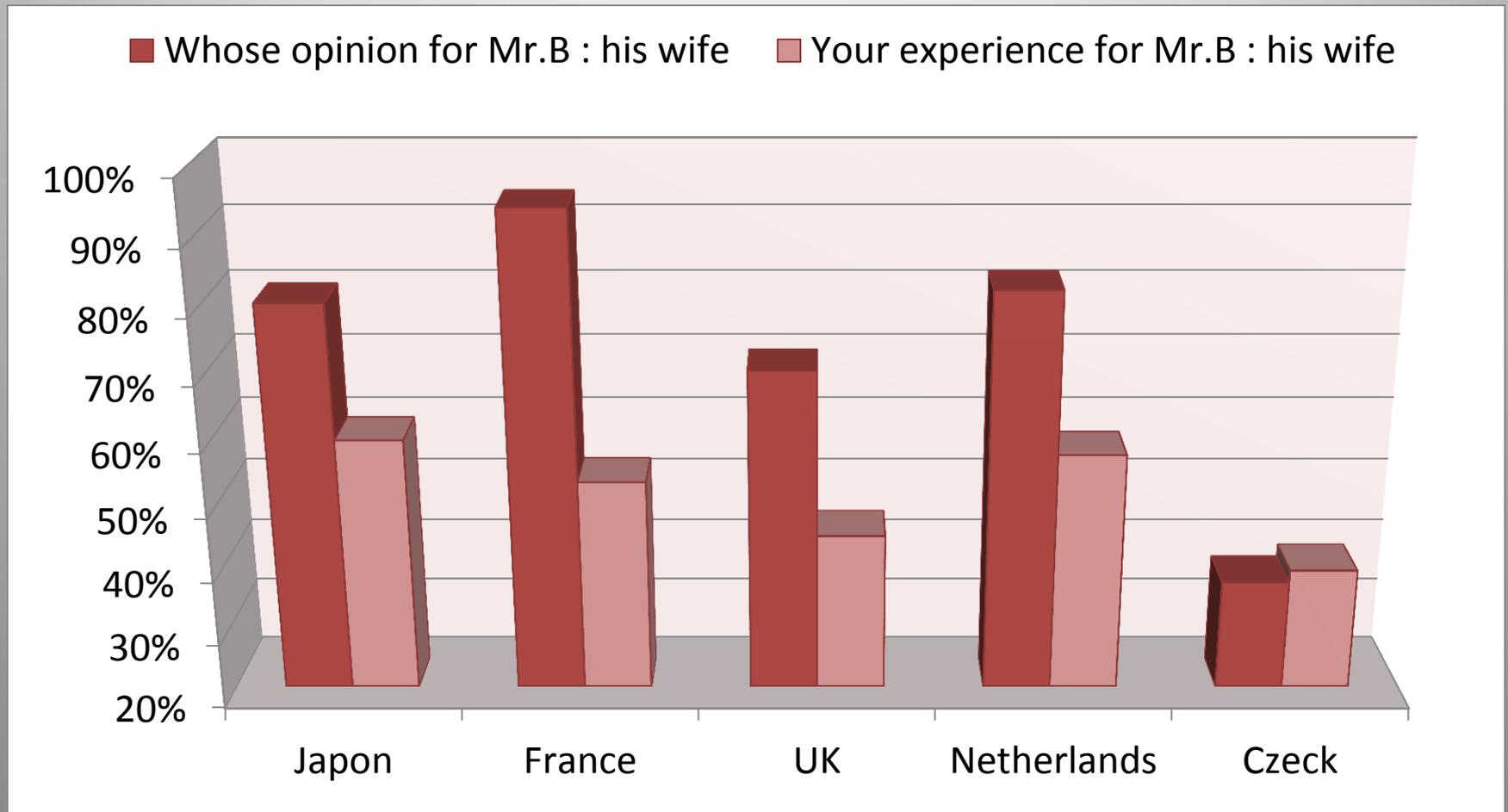
# Main conclusions (2)

- Countries discrepancies on end-of-life practices
  - Opinion on who is deciding medical treatment and terminal care policies?

Whose opinion do you think should be given “the highest priority” in discussions that decide medical treatment and terminal care policies for Mrs.A ?



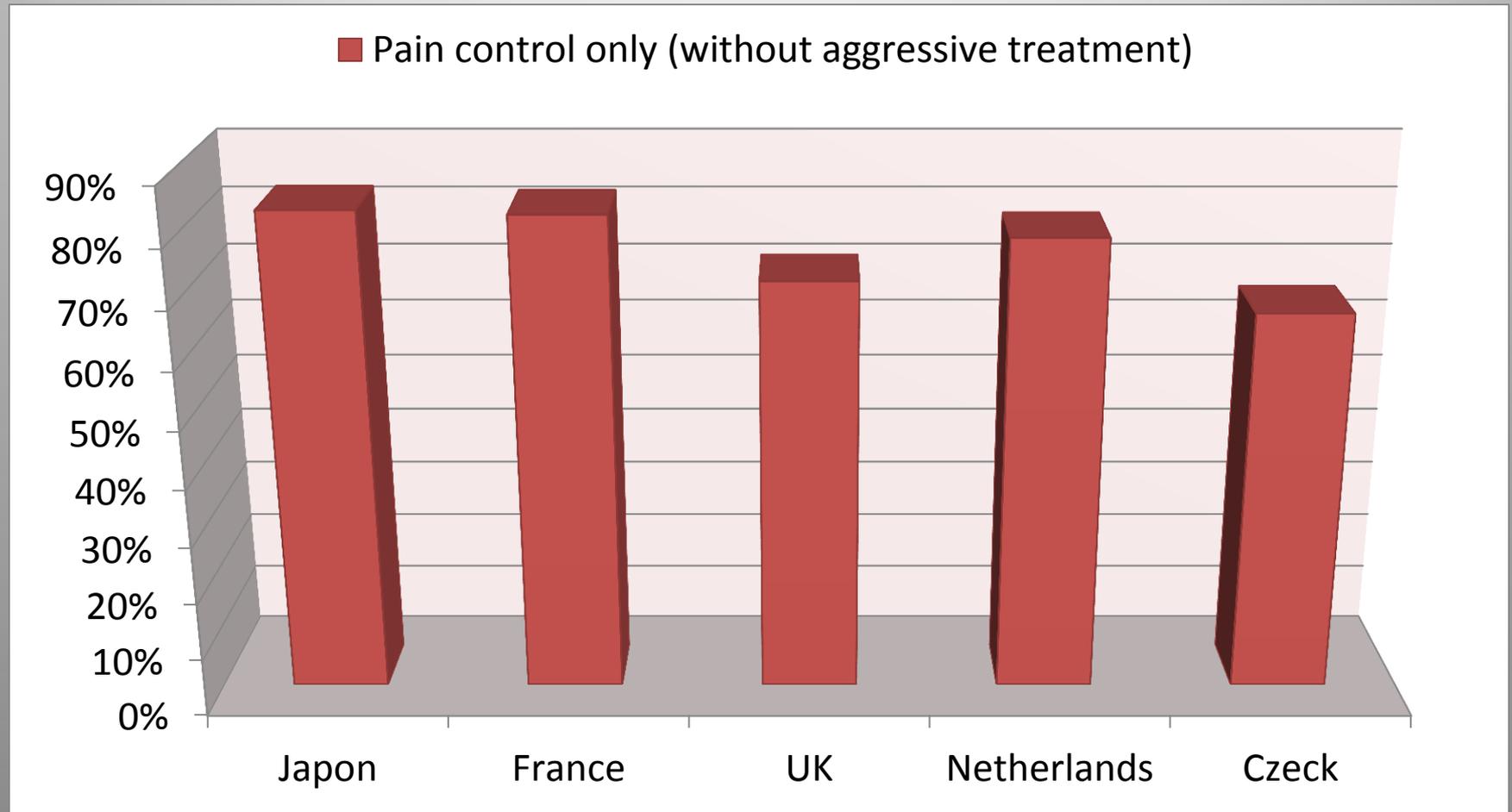
Whose opinion do you think should be given “the highest priority” in discussions that decide medical treatment and terminal care policies for Mr.B?



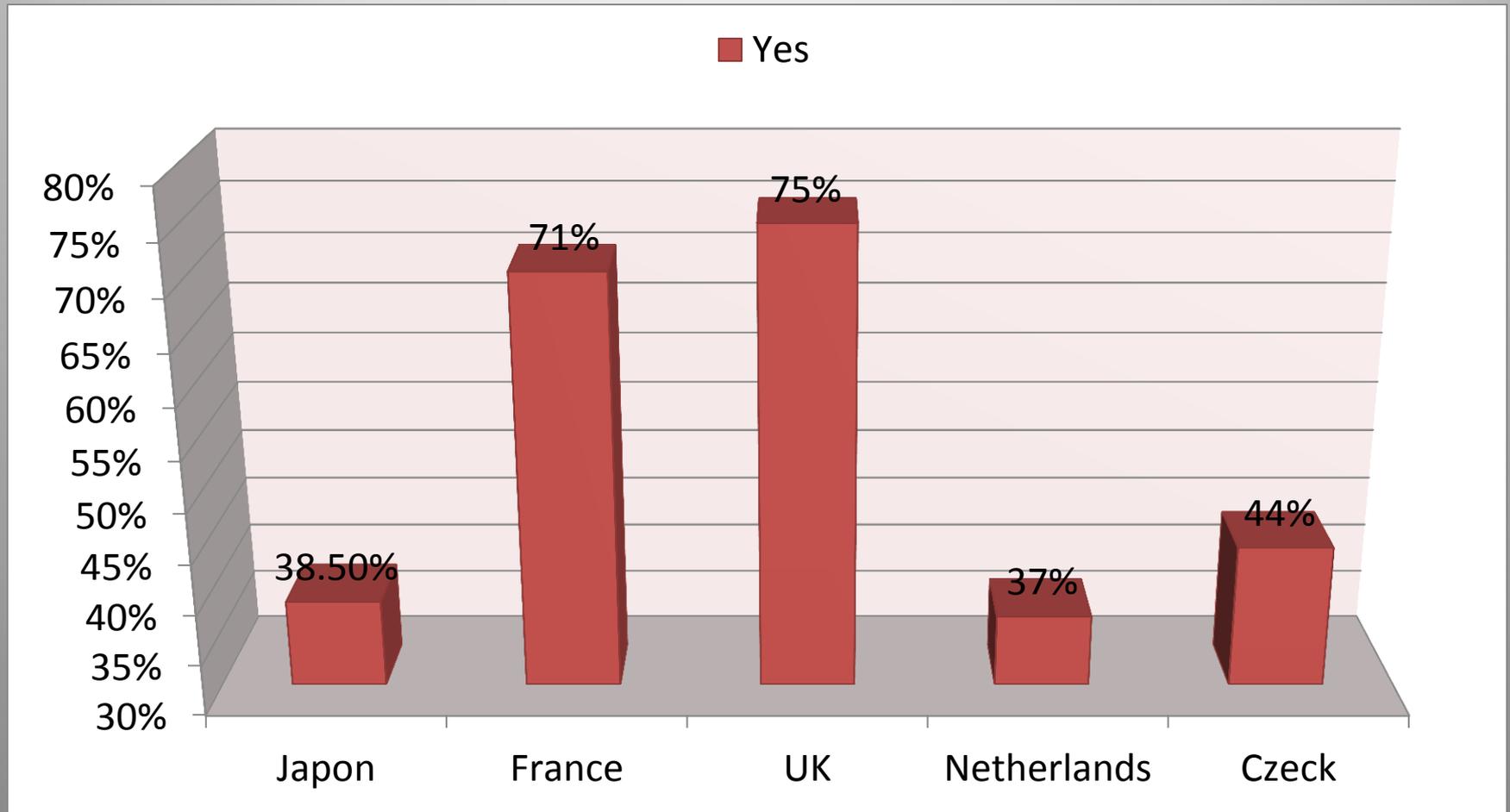
# Main conclusions (3)

- Countries similar attitude on end-of-life opinions and practices for Mrs. A, but different for Mr. B.
  - Pain control only without aggressive treatment should actually be taken as a basic principle for Mrs.A
  - End of life status of Mr. B? : Yes or no?
  - Artificial nutrition for Mr. B ? : Yes or no?

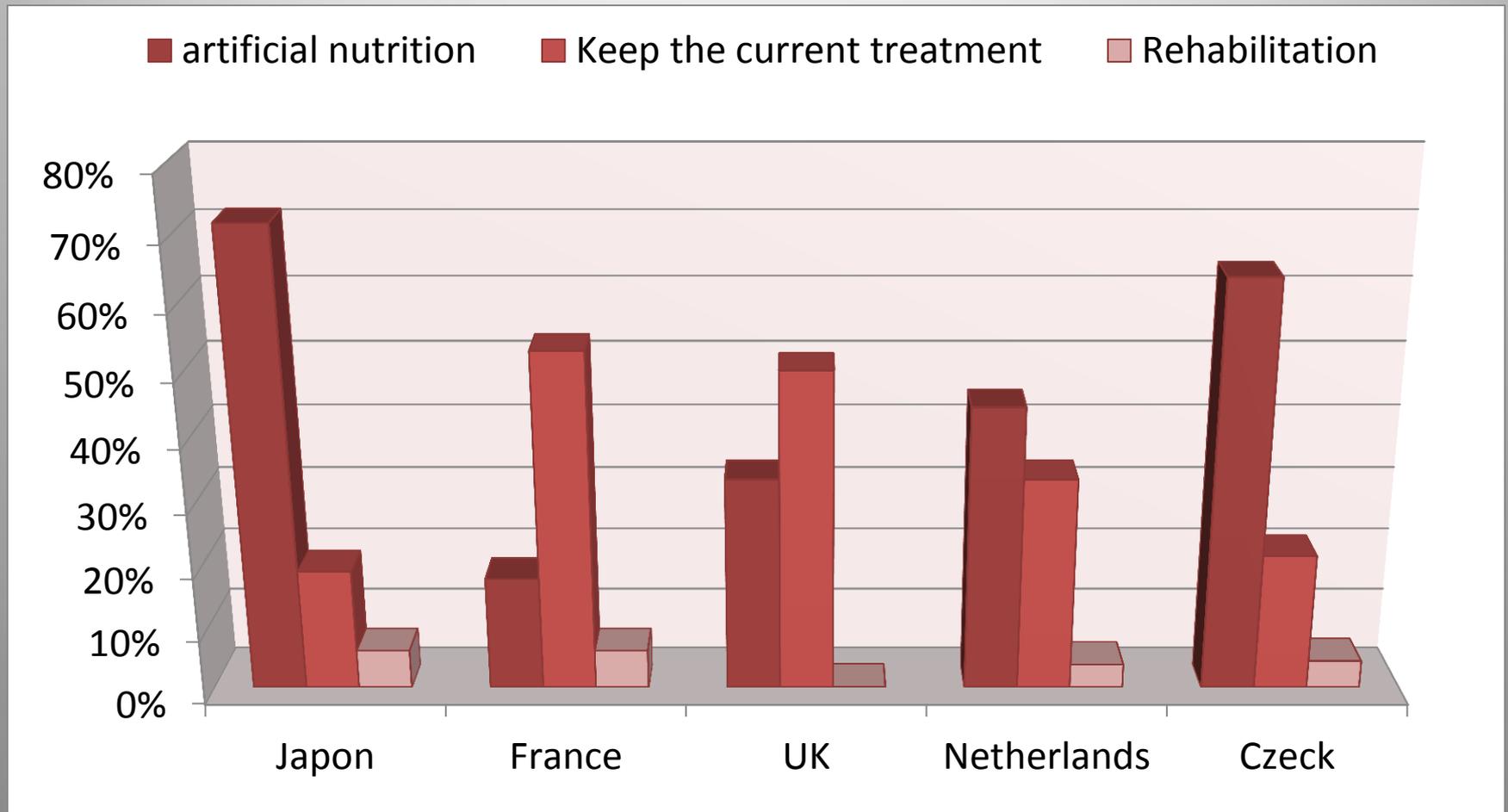
Based on your experience, which of the following do you think should actually be taken as a basic principle for working with Mrs. A?



# Do you think Mr. B is in “the terminal phase”?

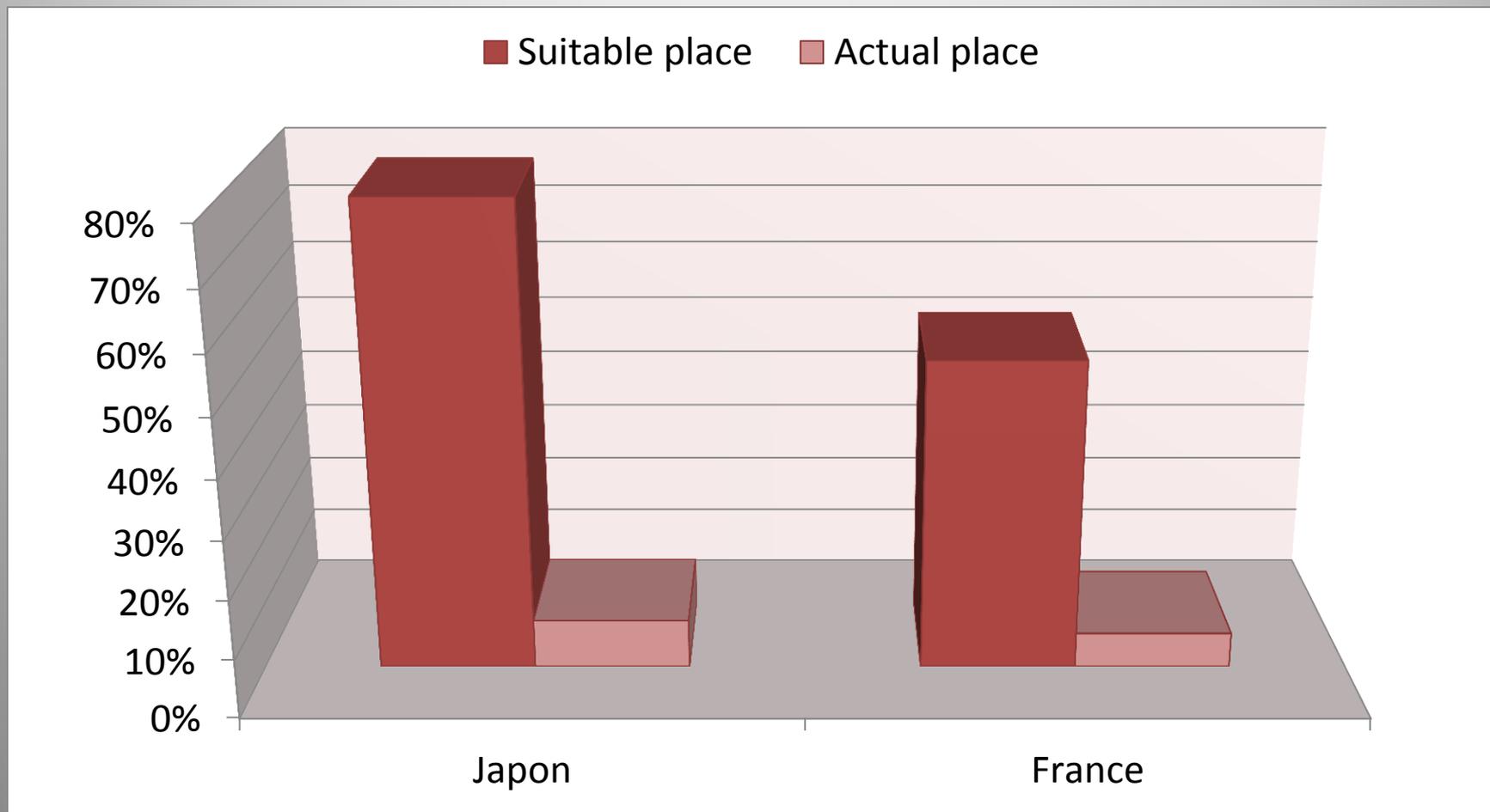


Based on your experience, which of the following do you think is should be actually taken as a basic principle for working with Mr.B ?



# Some Comments on the french study results

the “suitable” place for Mrs. A to spend her final days would be “at home” but this is not realized.



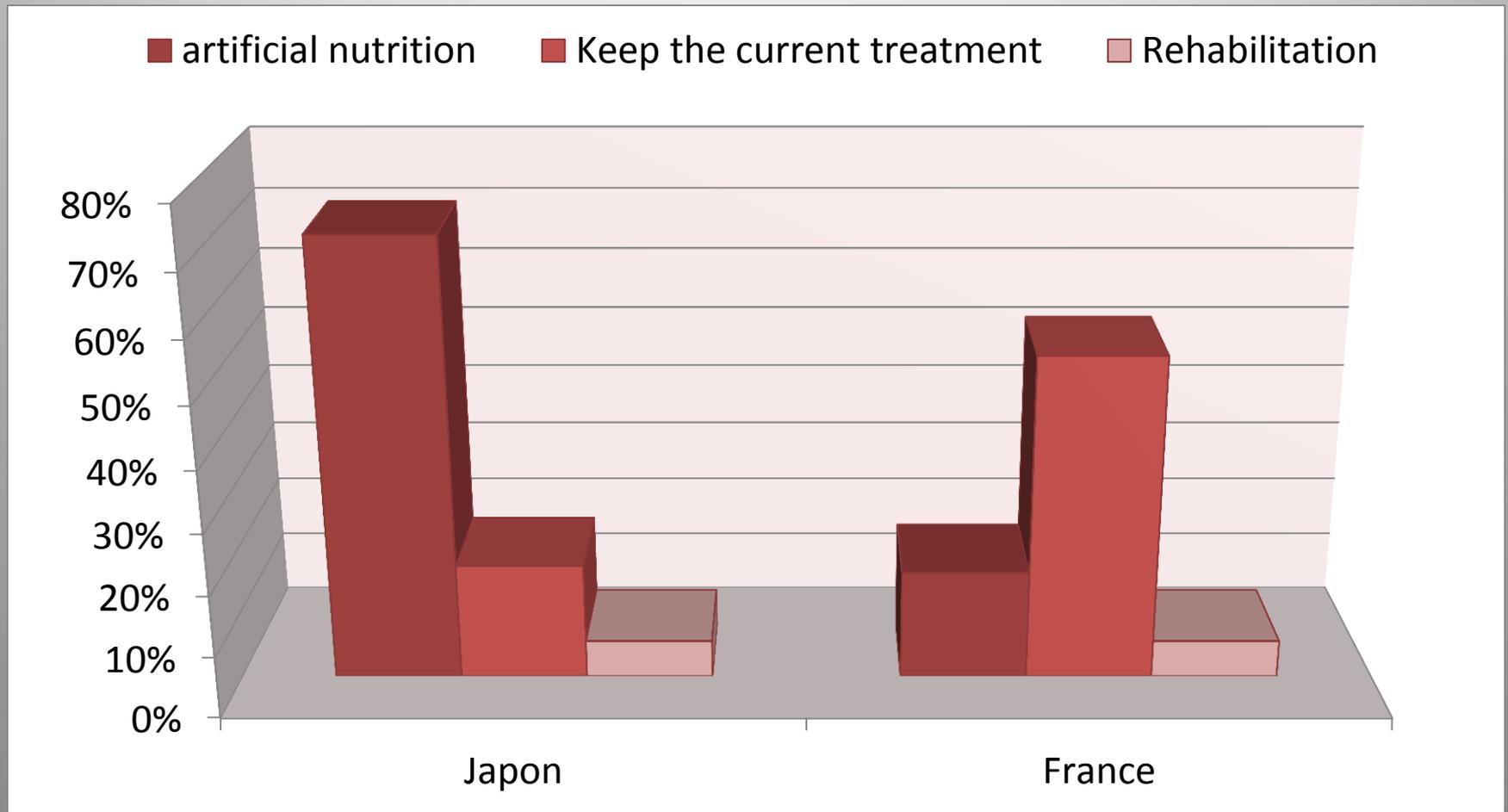
# End-of-life in France : there is cultural difficulties to accept the end of life at home by the relatives

Where are we dying in France?

IGAS (Inspection Générale des Affaires Sociales) report in 2010 shows that the proportion of people who died in a health institution (58%) is stable for 30 years in France, 27% died at home, 11% in a retirement home and 2% on the street.

Nevertheless, the way to move from life to death varies with geography: one dies more at home in the South of France (as in Italy) than in the North (as in UK).

# Why “the actual choice” as a basic principle for working with Mr.B is not artificial nutrition in France unlike Japan?



# End-of-life in France and enteral nutrition

- In France, we strongly think that Mr. B is in terminal phase and artificial nutrition would not be actually recommended for him. Hydration is provided in all cases by SC or IV perfusion when necessary.
- When a patient is in palliative care for a terminal illness, obstinacy in treatment and nutrition are discouraged by the Leonetti Law.
- Furthermore, we have to follow the guideline set by the FNCLCC (National Federation of Cancer Centers):
- No enteral nutrition if Performance status (PS)  $>2$  or if life expectancy  $< 3$  months. (PS: Performance Status, or WHO scale (0 = health/activity normal; 1 = symptoms but professional activity is still possible 2 = symptoms prevent the occupation; 3 = must lie more than half of the day; 4 = no longer rises).
- The Ratio benefit/risk of enteral nutrition must be considered but PEG is also possible at home in case of HAD (Hospitalisation at home)
- The collegial process would be applied in Mr.B Case

January 2011 :

## French public opinion is moving in favour of PC and become reticent about a law on euthanasia

- **This Opinion Survey analyses the choice between two ways of "*assisted dying*": palliative and/or euthanasia**
- 60% of the questioned people "*prefer the development of palliative care to the legalization of euthanasia*".
- 52% think that a law on euthanasia would lead to "*risks of abuses*":
- 57% are worried about the possibility that "*non consenting patients would be euthanized*",
- 56% think that vulnerable patients may be put under pressure to accept euthanasia.
- These figures are in sharp contrast with the results of previous surveys, such as the one carried out in November 2010 for IFOP which showed that 94% of French people were favourable to euthanasia. But in this survey, the theme of palliative care was not mentioned.

Thank you very much

