



End of Life in Global Aging Introduction

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1



The Center for Global Aging Tsukuba (C-GAT)

The Center for Global Aging Tsukuba (C-GAT) was selected as a University Tsukuba pre-strategic initiative in 2003. The purpose of the center is to establish an international and interdisciplinary research and education addressing all aspects of aging that have become a global issue.

The policy on aging needs to respect not only medical and nursing care but also the way of living, culture, the family presence, religion and various backgrounds.

That is why C-GAT is looking forward to explore the innovative research outcomes and educational network cooperating with the multidisciplinary prospective in Japan and countries around the world **with mutual learning respecting each other.**



人生の最期をどう迎えるのか
All's well that ends well

— 終わりよければすべてよし —



Starting as a general physician 1980s, without LTCL, care managers, nor social workers...



As a Home-Care physician in 1990s



Almost all the patients to visit were PEG
because of the training for intern-physician to make PEG
without enough IC

As a physician in Intermediate long term care facility in
2010s



Interviewing all the old persons and families about PEG etc (End of Life
decision) at the admission

No advanced statement by old person, difficult for family to decide.
"Patient may recover by PEG, but if not, burden should be big...
not sure... but we love them..."

胃瘻を作る側の認識 Survey for the physicians

日本老年学会関東地方会へ参加した医師
110枚配布 43人より回答 in 1997
Delivered 110 Answered 43

- ・自ら胃瘻を造設した経験あり 23人(53%)
With experience who made PEG
- ・家族に施設入所が難しいことを話した 13人(57%)
Explained family the difficulty to enter nursing home
- ・自分の地域の受入状況を知っている 8人(35%)
Having knowledge the situation of acceptance of PEG in nursing home

経管栄養高齢者の割合との関連要因

Table 2. Likelihood of Having Tube Feeding: Clinical, Epidemiological, and Geographic Variables

Variable	Odds Ratio	P-value
Feeding restriction in advance directive	0.41	<.001
White race	0.45	<.001
Alzheimer's disease	0.47	<.001
Dementia (type not specified)	0.67	<.001
Living will	0.58	<.001
Medical power of attorney	0.75	<.001
DNR order	0.86	.017
Male sex	0.87	<.001
Other legal oversight	0.91	.079
Older age	0.98	<.001
Existence of legal guardian	0.99	.766
Parkinson's disease	1.07	.059
CNR order	1.11	<.001
Stroke	2.45	<.001
MI/ane	1.00	---
Nebraska	1.50	.001
South Dakota	1.52	.0048
Wisconsin	1.66	<.001
Missouri	2.82	<.001
Washington	3.08	<.001
Mississippi	5.49	<.001
New York	5.63	<.001
Ohio	5.83	<.001

Note: DNR = do not resuscitate; CNR = do not resuscitate

事前の方針決定が、
最も強い抑制要因

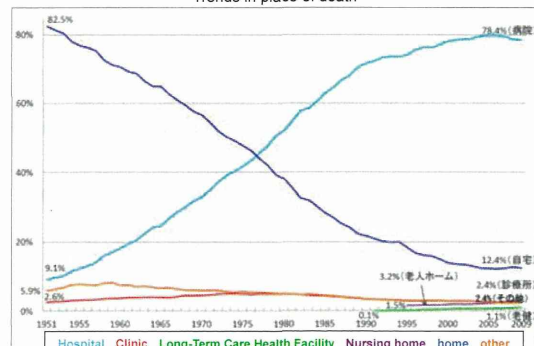
我が国では、事前
意志の確認には

まだ抵抗あり

欧米ではこうした研究が
一流雑誌に多数

Place of Death

Trends in place of death



A drastic change in the medical care for the elderly
Home to Hospital and
again...
Hospital to Home
End of life



高齢者ケアの意思決定プロセスに関するガイドライン

人工的水分・栄養補給の導入を中心として

本ガイドラインの概要

1. 医療・介護における意思決定プロセス
医療・介護・福祉従事者は、患者本人およびその家族や代理人とのコミュニケーションを通して、皆が共に納得できる合意形成とそれに基づく選択・決定を目指す。
2. いのちについてどう考えるか
まきでいることは良いことであり、多くの場合本人の望みになる——このように評価するのは、本人の人生をより豊かにし得る限り、生命はより長く続いたほうが良いからである。医療・介護・福祉従事者は、このような価値観に基づいて、個別事例ごとに、本人の人生をより豊かにすること、少なくともより悪くしないことを目指して、本人のQOLの保持・向上および生命維持のために、どのような介入をする、あるいはしないのがよいかを判断する。
3. AI-HN導入に関する意思決定プロセスにおける留意点
AI-HN導入および導入後の減量・中止についても、以上の意思決定プロセスおよびいのちの考えかたについての指針を基本として考える。ことに次の諸点に配慮する。
① 経口摂取の可能性を適切に評価し、AI-HN導入の必要性を確認する。
② AI-HN導入に関する諸選択肢（導入しないことも含む）を、本人の人生にとっての益と害という観点で評価し、目的を明確にしつつ、最善のものを見出す。
③ 本人の人生にとっての最善を達成するという観点で、家族の事情や生活環境についても配慮する。

日本老年学会
平成24年6月27日

家族の意見が強い
日本のプロセスを考慮

世界（とくにアジア）に伝える意義大！

研究班で翻訳

A Position Statement from The Japan Geriatrics Society 2012: End-of-Life Care for the Elderly

The Japanese Geriatric Society Ethics Committee Geriatric Gerontol International 2014

The statement can be useful in many other countries, where aging of population is not yet an urgent concern but will be so in the future. We believe that this "Position Statement" can offer a guidance from ethical respect for those who are or will be engaged in the end-of-life care for older people. We also hope that the release of the current statement provide an avenue for broader discussion in the society with increasing aged population.

Position 2 — Care respecting individual preferences and culture

- The end-of-life care for the elderly should be provided with **full consideration of the family** and ethical values peculiar to the Japanese, and fully respecting each patient's views of life and death, their values, philosophy, faith and religion.

Acknowledgements
We would like to thank Drs. Nanako Tamiya and colleague (Tsukuba University) for contributing to English translation from original Japanese version of the position statement.

Position 4 — Care for the involved families

End-of-life care for the elderly includes care for their "families, etc." as well as the patients.

- **The patients' families play an important role in end-of-life care.** When a patient's family members and the patient agree, medical experts need to explain the medical condition to everyone.
- Medical experts need to **actively support families** by alleviating their sorrow. Support for families and persons attached to patients leads to better support for patients. **Support for families to accept** that patients are in the process of dying should be provided, as well as **grief care for families** after the patients' death.



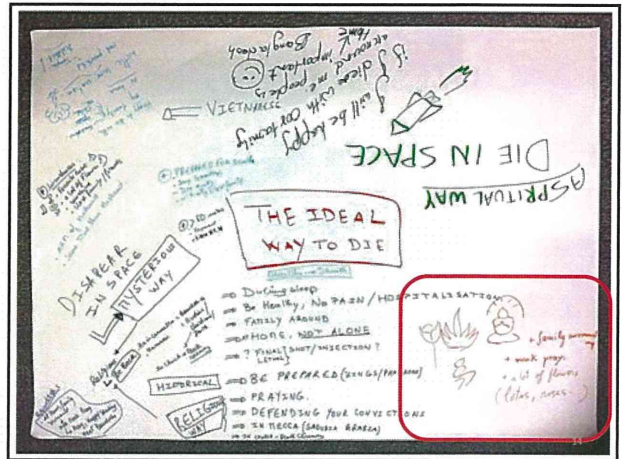
Education by CGAT : G30 special lecture

Borderless Challenge toward a Global Aging
Role of Young Power

13か国の学生が参加し議論



13



Let's discuss together



Mt Tskuba : Twin peaks (couple)

Palliative Care and Hospice in Thailand and the U.S.

Kate de Medeiros, PhD
Miami University
Oxford, Ohio USA

“Hospice” and “Palliative Care” Definitions

☞ Hospice – “end-of-life care provided by health professionals and volunteers. They give medical, psychological and spiritual support. The goal of the care is to help people who are dying have peace, comfort and dignity. The caregivers try to control pain and other symptoms so a person can remain as alert and comfortable as possible. Hospice programmes also provide services to support a patient’s family.”

☞ WHO,
http://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf

Palliative Care Definition

☞ Palliative care is defined as: “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

☞ WHO,
http://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf

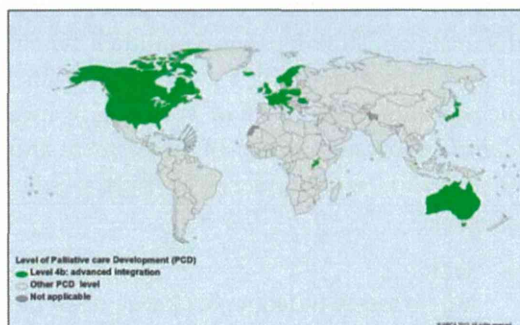
Advanced Health Care Provisions

- ☞ Palliative care activism is wide-spread and comprehensive; public policies in place.
- ☞ Provisions for palliative care providers and services widely available.
- ☞ Unrestricted availability of pain medications
- ☞ National palliative care associations and affiliations with major universities.
- ☞ Countries in this category include: Australia, Austria, Belgium, Canada, France, Germany, Hong Kong, Iceland, Ireland, Italy, Japan, Norway, Poland, Romania, Singapore, Sweden, Switzerland, Uganda, United Kingdom, United States of America

From: Global Atlas of Palliative Care, WHO, 2014.
http://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf

Advanced Health Care Provisions

Figure 36
Countries with advanced health system integration (Level 4b)



From: Global Atlas of Palliative Care, WHO, 2014.
http://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf

Location of Death in the U.S.

Table 1. Location of Hospice Patients at Death¹

Location of Death	2011	2010
Patient's Place of Residence	66.4%	66.7%
Private Residence	41.6%	41.1%
Nursing Home	18.3%	18.0%
Residential Facility	6.6%	7.3%
Hospice Inpatient Facility	26.1%	21.9%
Acute Care Hospital	7.4%	11.4%

National Hospice and Palliative Care Organization,
http://www.nhpco.org/sites/default/files/public/Statistics_Research/2012_Facts_Figures.pdf

Utilization Rates by Race in the U.S.

Table 5. Percentage of Hospice Patients by Race¹

Patient Race	2011	2010
White/Caucasian	82.8%	77.3%
Multiracial or Other Race	6.1%	11.0%
Black/African American	8.5%	8.9%
Asian, Hawaiian, Other Pacific Islander	2.4%	2.5%
American Indian or Alaskan Native	0.2%	0.3%

National Hospice and Palliative Care Organization,
http://www.nhpc.org/sites/default/files/public/Statistics_Research/2012_Facts_Figures.pdf

Percentages by Payer in the U.S.

Table 9. Percentage of Patients Served by Payer¹

Payer	2011	2010
Medicare Hospice Benefit	84.0%	83.8%
Managed Care or Private Insurance	7.7%	7.9%
Medicaid Hospice Benefit	5.2%	4.9%
Uncompensated or Charity Care	1.3%	1.5%
Self Pay	1.1%	1.1%
Other Payment Source	0.7%	0.8%

National Hospice and Palliative Care Organization,
http://www.nhpc.org/sites/default/files/public/Statistics_Research/2012_Facts_Figures.pdf

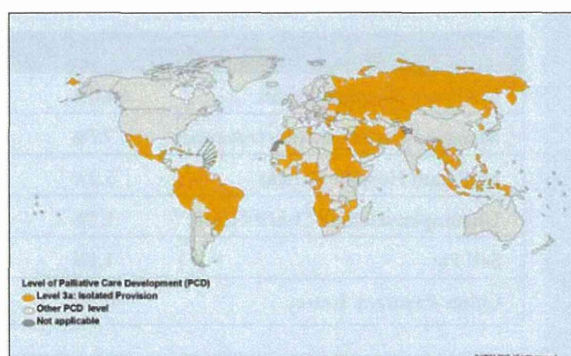
Isolated Provision of Palliative Care

- ☞ Palliative care activism is limited and not well supported.
- ☞ Funding primarily from private donor organizations
- ☞ Medications to alleviate pain (e.g., morphine) are limited
- ☞ Few programs available.
- ☞ Countries in this category include: Thailand, Philippines, South Korea, UAE, Saudi Arabia, Mexico, Venezuela

From: Global Atlas of Palliative Care, WHO, 2014.
http://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf

Isolated Provision of Palliative Care

Figure 33
Countries with isolated provision of palliative care (Level 3a)



From: Global Atlas of Palliative Care, WHO, 2014.
http://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf

Palliative Care in Thailand

- ☞ Almost exclusively delivered in the hospital setting at this time.
 - ☞ Monks, rather than physicians, are often involved with helping people come to terms with their ending lives.
- ☞ The largest hospice is Dhammarak Niwete Hospice located on the grounds of Phrabat Nampu Temple in Lopbur
- ☞ HIV/AIDS patients comprise a large population for whom palliative care is focused.

Palliative Care in Thailand

- ☞ Chulalongkorn Hospital has begun on outreach program for hospice care at home; Mahidol University is opening a large hospice center.
- ☞ Terminally ill cancer patients (adult and pediatric) are also a focus of hospice care.
- ☞ Data are not available regarding hospice/palliative care for older adults.
 - ☞ Anecdotally, some cite link between Buddhist values and beliefs as being a potential barrier to the wider acceptance of hospice.
 - ☞ E.g., Tube feeding for dementia patients.

ADVANCE CARE PLANNING: PROGRESS AND CHALLENGES

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University of California, San Francisco



Kameda Medical Center

San Francisco, California: View from Dr. Lawrence Tierney's office



Objectives

- List at least three reasons end-of-life decision making is both important and challenging
- Define advance care planning, goals for care, advance directives, durable power of attorney for healthcare, living will, and self-determination
- Recognize important medical-legal cases in the U.S. and Japan related to end-of-life decisions
- Describe two examples of advance care planning

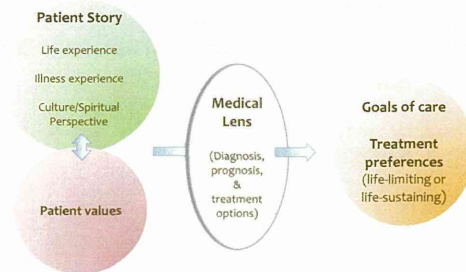
“Physicians now seem to pay more attention to prolonging life than to pain relief and other important aspects of quality of life as it relates to medical care.”

Hayashi & Kitamura, 2002

Discussing treatment decisions for the end of life

- Is one of the most important responsibilities a physician has in caring for patients
- It requires skillful communication and reliance on both the science and art of medicine
 - **Science:** Knowledge of disease, prognosis, treatment and the medical evidence
 - **Art:** Ability to communicate, utilize good clinical judgment and honor the doctor-patient relationship

End-of-life decision making is a process



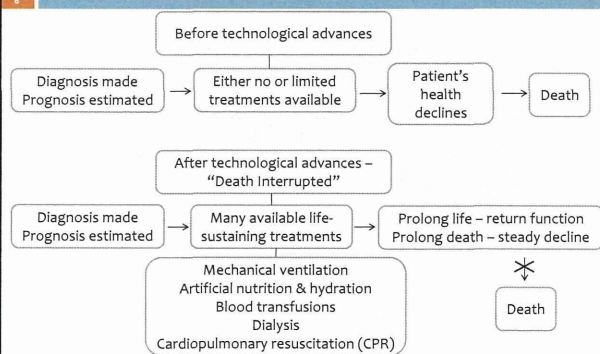
Kao H, Widera E, Moody S, 2009 (unpublished)

Technological medical advances

- Have led to the ability to prolong life (and to prolong the dying process)
- Implication
 - Physicians are forced to decide which ...
 - treatment(s) to offer and when to stop them
 - when they are no longer effective, or
 - when they become harmful, especially at the end of life

Derse AR, 2011

“Death interrupted”



9 Definitions

- Advance Care Planning
 - Goals for care
 - Advance Directives
- Self-determination

10 Advance care planning (ACP)

- Is a process of communication
 - Not a one time event
 - Should be reviewed and updated regularly, especially when health status changes
- To help individuals
 - Understand their choices for future healthcare
 - Reflect on values, beliefs (religious, spiritual, cultural) and personal goals
 - Talk to their doctors, healthcare agents (key person(s) who would decide treatment for individuals when they can no longer decide for themselves), and other loved ones

Hammes BJ, <http://www.gundersenhealth.org/respecting-choices>

11 ACP includes ...

*Applies to patients with both life-limiting cancer and non-cancer diagnoses (e.g., end-stage heart failure, kidney and liver disease, etc.)

12 ACP: Goals for care

- Health outcomes hoped for when a person is faced with a life-limiting disease

Potential goals for care

- Cure of disease
- Avoidance of premature death
- Maintenance or improvement of function
- Prolongation life
- Relieving of suffering
- Improved quality of life
- Maintenance of control
- A good death
- Support for families and loved ones

Stone MJ, BUMC Proceedings, 2001

ACP: Advance Directive

- A legal written document (instructions for future treatment)
 - Written with a lawyer by a person who is capable of making decisions now (at the time)
 - Description of medical treatments that a person would want in the future, if he or she could not make treatment decisions at that future time because of serious illness or injury
 - Used only when the person is too sick to make treatment decisions for himself or herself

Advance directives can be formal or informal

- Formal
 - Legal document (as in previous slide)
- Informal
 - Patient may also make an oral or spoken statement to family or their physicians, or
 - May express preferences for medical treatments in notes and letters

ACP: Goal of advance directive

- To guide treatment when a person is seriously ill and unable to communicate what they want

Two types of advance directives

- “Healthcare proxy” or “Durable Power of Attorney for Healthcare (DPOAHC)”
 - Person(s)—usually family or friends—identified by the patient to make treatment decisions for them by following the instructions in their advance directives
- Living will
 - Instructions for treatment—describes certain situations, such as persistent vegetative state, or certain treatments, such as feeding tubes, and what the person wants or do not want

One example of an advance directives form

17

Part 2: Make your own health care choices

Life support treatments are used to try to keep you alive. These can be CPR, a breathing machine, feeding tubes, dialysis, blood transfusions, or medicine.

Put an X next to the one choice you most agree with.
Please read this whole page before you make your choice.

If I am so sick that I may die soon:

- Try all life support treatments that my doctors think might help.
If the treatments do not work and there is little hope of getting better, I want to stay on life support machines.
- Try all life support treatments that my doctors think might help.
If the treatments do not work and there is little hope of getting better, I do not want to stay on life support machines.
- Try all life support treatments that my doctors think might help but not these treatments. Mark what you do not want.
 - CPR
 - dialysis
 - breathing machine
 - other treatments _____
 - feeding tube
 - blood transfusion
 - medicine
- I do not want any life support treatments.
- I want my health care agent to decide for me.
- I am not sure.

18

Self-determination

18

- Each person has the right to
 - Choose the kind of medical care they want
 - Refuse (deny) any medical treatment, even if denying treatment results in their death

Mehta, Anderson, Hunt, et al, 2011

20

Cultural Differences between Japan & the U.S. related to end-of-life discussions



Kenroku-en in Kanazawa

Cultural differences between Japan and U.S.

21

Characteristic	Japan	United States*
Clinicians primary duty	<ul style="list-style-type: none"> • Patient + family 	<ul style="list-style-type: none"> • Patient
Unit of care	<ul style="list-style-type: none"> • Family 	<ul style="list-style-type: none"> • Patient (pt) • Palliative care: pt + family
Regarding decisions about withholding life-sustaining treatments	<ul style="list-style-type: none"> • Patients prefer to rely on physicians and family members to decide 	<ul style="list-style-type: none"> • In general, patients prefer to make decisions themselves
Who makes most of the decisions?	<ul style="list-style-type: none"> • Doctors (little input from patient; little information given to patients; patients have few opportunities to question doctor) 	<ul style="list-style-type: none"> • Shared decision making: doctor + patient and/or family
Advance directives Living wills	<ul style="list-style-type: none"> • Rare 	<ul style="list-style-type: none"> • Common • Widely used

*In the U.S., there is a diversity of populations, and these statements are not true for all groups

Matsui, Braun, & Karel, 2008; Hayashi & Kitamura, 2002

Progress: Evolution of ACP

22

Progress: Evolution of ACP

- History
- Influence of important medical-legal cases

Brief history

23

- 1967 – advance directives (AD) first suggested by Euthanasia Society of America
- 1976 – California first state to adopt an AD law
- 1983 – California first to adopt “healthcare power of attorney”
- 1986 – 41 (out of 50) states adopted AD laws
- 1990 – “Patient Self-Determination Act” passed by Congress
 - Hospitals, nursing homes, home care, hospices had to ask patients if they had an AD
- 1991 – “out-of-hospital” DNR protocol started
- 1997 – all states adopted AD laws
- 2000’s – shift from “legal approach” (AD) to “communication approach” (ACP)

Sabatino CP, Milbank Q, 2010

Important Medical-legal Cases in the U.S. and Japan

24

Important Medical-legal Cases in the U.S. and Japan

The United States (U.S.)

25



Important “Right to Die” Medical-legal Cases in U.S. (1)

26

- *Karen Ann Quinlan* – 1975
 - 21-year-old young woman who became unconscious after arriving home from a party; she remained in a persistent vegetative state (PVS)
 - Legal argument – withdraw from ventilator
 - 1985 (9 years later) – the Court ruled that ventilator support may be withdrawn

Meier DE, 2010

Important “Right to Die” Medical-legal Cases in U.S. (2)

27

- *Nancy Cruzan* – 1983
 - 25-year-old woman who was thrown from her car in a car accident.
 - After resuscitation, she survived in a PVS Legal argument – to stop artificial nutrition (feeding tube)
 - 1990 (7 years later) – the Court ruled to remove the feeding tube, and she died 12 days later

Meier DE, 2010

Important “Right to Die” Medical-legal Cases in U.S. (3)

28

- *Terri Schiavo* – 1990
 - 26-year-old woman who suffered cardiac arrest at home; was resuscitated to a PVS
 - Legal argument – to terminate life support
 - 2005 (15 years later) – the Court ruled to remove the feeding tube; she died 13 days later

Meier DE, 2010

Resulting significant legal decisions from the “right-to-die” cases (1)

29

- Decisions to continue or withdraw life support is to be guided by patient’s preferences or wishes

- Establishment of hospital ethics committees and advance care planning

Meier DE, 2010; Derse AR, 2011

Significant legal decisions resulting from the “right-to-die” cases (2)

30

- Passage of the Self-Determination Act of 1991
 - ▣ Healthcare facilities must offer patients information about *advance directives* and inform them of their *right to refuse medical treatments*

- Artificial nutrition and hydration are considered medical treatments and *may be legally and ethically withdrawn* under the right circumstances

Meier DE, 2010; Derse AR, 2011

Legal agreement regarding life-sustaining treatment

31

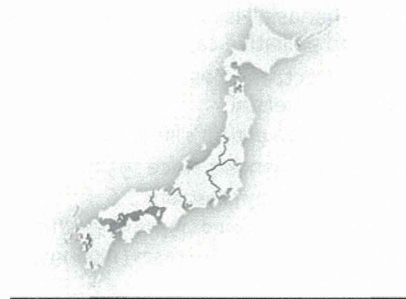
- When patients die after they request that life-sustaining therapies be withheld or withdrawn
 - ▣ Their death is not considered homicide or suicide
 - ▣ Their physicians are not held legally responsible

- Physicians are not obligated to offer treatment they believe would not be effective or is not consistent with professional treatment standards

Mehta, Anderson, Hunt, et al, 2011

Japan

32



Euthanasia in Japan

33

- Definition
 - “An act to ease pain of patients and let them die peacefully in the final stage of a terminal illness, in a situation of serious physical suffering with no prospects of recovery”
- 4 types of euthanasia
 - 1. Active euthanasia
 - Intentional acceleration, with no therapeutic purpose, of ending a patient’s life who is in final stage of a terminal illness with no hope of recovery

Hayashi & Kitamura, 2002

Euthanasia in Japan (2)

34

- 2. Indirect euthanasia
 - Giving of treatment to alleviate agonizing symptoms, but with side effect of shortening the life of the terminally ill patient – in West, “principle of double effect”
- 3. Passive euthanasia
 - Withdrawal of life sustaining treatment from terminally ill patients, ... an issue of some moral concern
- 4. Pure euthanasia
 - Treatment to alleviate symptoms of severe pain in a terminally ill patient, without substantial shortening life but facilitating a peaceful death – in West, “palliative care”

Hayashi & Kitamura, 2002

Euthanasia in Japan (3)

35

- “Pure euthanasia” is not controversial → considered palliative care
- Active, indirect, and passive euthanasia are legally controversial
 - Termination of a patient’s life is involved
- 10 cases of euthanasia since 1950
 - Of these, 2 were by physicians
 - 7 have been prosecuted (1950-1995) – “found guilty”
 - As of 2002, most recent 3 cases (1996-1997) were still pending decision

Hayashi & Kitamura, 2002

Withdrawal of life support: Two cases

36

- Both went to trial – each physician was punished
 - One case was tried in lower courts
 - Second case tried in both lower courts and in higher courts on appeal

Table 1. The acceptability of previously made living will and substituted judgments by the patient’s family members.

	Title	Publication	Previously made living will	Substituted judgments
Judiciary decisions	Case 1 (trial)	1995	○	○
	Case 2 (trial)	2005	○	X
	Case 2 (retrial)	2007	X	X

○ = Yes; X = No

Kamishiraki, Maeda & Ikeda, 2009

37 Successes & Challenges of Advance Care Planning

38 ACP Successes in the U.S. (1)

- Development and implementation of advance care planning methods
 - “Respecting Your Choices” (Hammes et al.)
 - Combines the legal and communication aspects of advance care planning
 - Physician Orders for Life-Sustaining Treatment (POLST)
 - Physician order sheet based on a person’s current medical condition and wishes
 - Complements the advance directive; does not replace it
 - This order sheet goes with the patient when taken from one place of care to another, e.g., from home to hospital

39 POLST

40 ACP Successes in the U.S. (2)

- Despite the successes, only about 26.3% of general U.S. population have an advance directive, but more than 70% of older adults do
 - One study found that AD completion was associated with older age, more education, and higher income

Rao JK, et al. Am J Prev Med, 2014