

November 18, 2011, Tokyo

International Longevity Center Japan & Hasting Center

Life and Death

An International Comparison of End-of-Life Care "Mitori"

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Problems in End-of-Life Care

“Mitori” in Japan

- A Home Hospice Case -

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Japan is No.1 Aging country

The World is watching Japanese management

<Japan /US> population ;127/307mill.
over65y;22.2%/12.8% , life expectancy at birth;82.1/78.1y

	Total Death ; 1084450			
	1960	1996	2006	2007
Hospital	18.2%	74.1%	79.7%	79.4%
At Home	70.7%	18.3%	12.2%	12.3%
Nursing Home		1.5%	3.1%	3.3%

Number of the people with dementia is increasing rapidly

- 5million people receive nursing care,
2.5million have dementia(50%)**
- 80% of the residents at nursing home have dementia**
- After 20 years ; more than 3.5million**
- After 30 years ; 4.3million**

What does “Mitori” mean?

☆ “Mitori” has a soft image

「Peaceful death」 「Natural death」

「journey to the next world」

☆ Masking the real meaning of “Mitori”

**Definition; Care for the dying person ,forgoing
life-sustaining treatment**

=End-of-Life (palliative)care for the elderly

☆ It includes ethical and legal issues

Advance Directive?

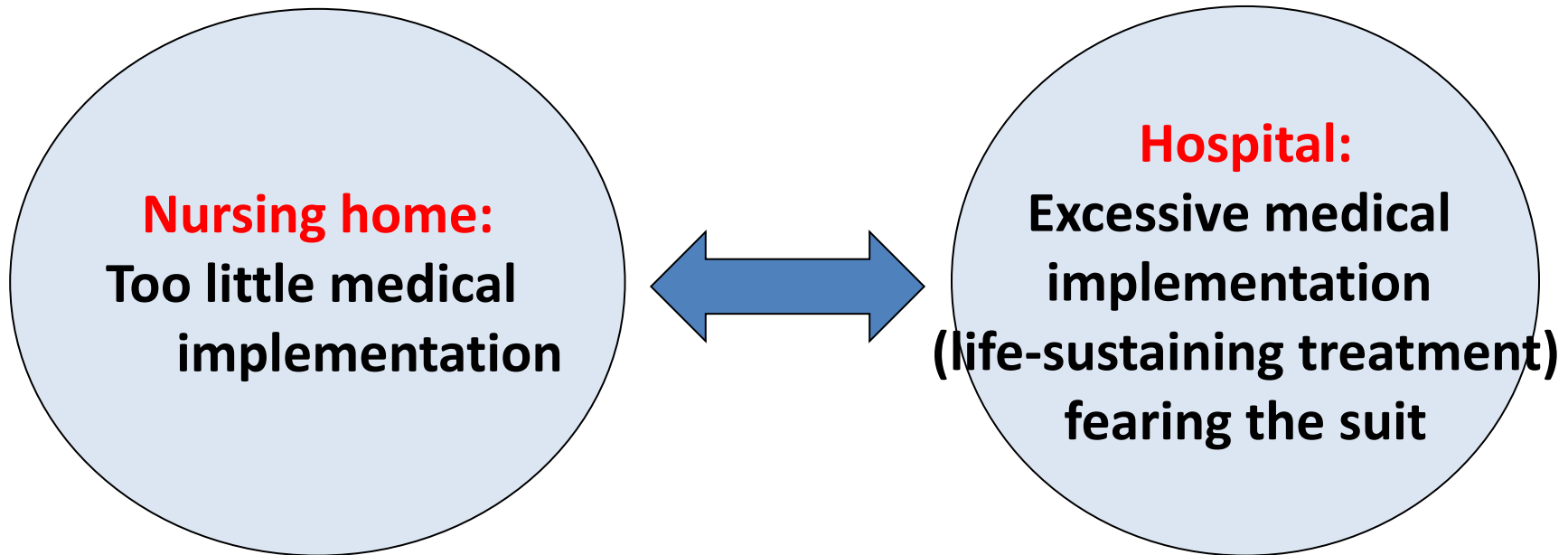
terminal stage?

futility of
the treatment?

limitation of
the treatment?

Present situation of “Mitori”

1) Lack of enough ethical consideration



2) Many people wish to die at home.....

Recent case of ideal “Mitori” at home(1)

<79ys.female,Gastric cancer with LN.meta.>

She did all the house work and went to the trip to Kiyushu in May.

6/12; First visit to clinic, C.C:appetite loss,
U.S.:ascites(++)

6/15;University hospital, GF:Gastric cancer, CT:
LN. matastasis(+++)⇒No indication of treatment
Pt. &daughter hope for palliative care&“mitori”
at home.

Recent case of ideal “Mitori” at home(2)

- *Rent a bed using nursing care insurance**
- *Daughter(nurse) take time-off for to take care of mother. Dr. visit 3 times a week.**
- *6/30:Oral intake ↓, several sips/day**
- *ascites(+++)→abdominal fullness, nausea&vomiting**
- *Pain control: opioid(non-opium)→ (only for 3days)**
Opiato, Pentanyl
- *Family and relatives often visit her bed .**
- *Pt.「I can't pass this summer, but I am happy」**
She thanks to everyone 'Thank you'
- *7/14:She died**

Case of 79Ys. End stage of Gastric Cancer

- ☆ Her daughter is nurse, care everyday
- ☆ suitable environment
- ☆ Regular visit by Dr. - System for emergency

Understanding (recognition) the disease and prognosis by Pt. & family.

- ☆ Pain control
- ☆ Control of symptoms (ascites/abdominal fullness, nausea & vomiting/fever/candida)
- ☆ Comfort Care



I will die soon. But I am happy. Everyone takes care of me at home.

Will it be painful when I die?

Thank you, Thank you..

But, Reality is different.....

Problems with End-of Life Care at home

1) Truth telling

- Pt. does not know the truth

2) Concept of 'Death' :Inability to deal with death

3) Decision making by the Pt.

- Lack of Advance Directive

4) Decision making by the family

5) Lack of communication

6) Lack of manpower of the family

7) Unsuitable environment at home

8) Teamwork with Dr./ Nurse/Caregiver

9) Lack of enough palliative care

10) Artificial hydration and nutrition: medicine or food?

Problems on truth telling

I need truth telling



But I don't want to let my mother know the truth.



Pt. become depressive and weaker by truth telling



(1) Problems on truth telling

1) Tell the truth only to the family, not the Pt. (sometimes tell a lie)

- *Dr. is anxious about deterioration and depression

- *Pt. does not know his disease and prognosis

⇒ He can not make a plan for his end-of-life care

2) The way of truth telling

- *truth telling without compassion:

“There is nothing to do” ⇒ disappointment, distress

(2) Problems on “Concept of Death”

- Death should be best avoided
- Longer life is desirable
- Death is the worst result
- Death is defeat in medicine
- Not accept limitation of one's life
- Not accept incurable disease



- Death is inevitable in one's life

- Continue the useless treatment having a meaningless expectation
- Being upset at the sudden change → Call ambulance
- Hospital gives a sense of security

- 「for this Pt.」 「at this time of life」 「under this situation」
What is the best QOL?
- Facilitate conversation about 「What is the most desirable end-of-life? 」
 - Peaceful death

(2) Problems in “Concept of Death”

—Change the goal of treatment —

▪ Death should be best avoided
▪ Longer life is desirable
▪ Death is the worst result

Goal of treatment
:Complete cure

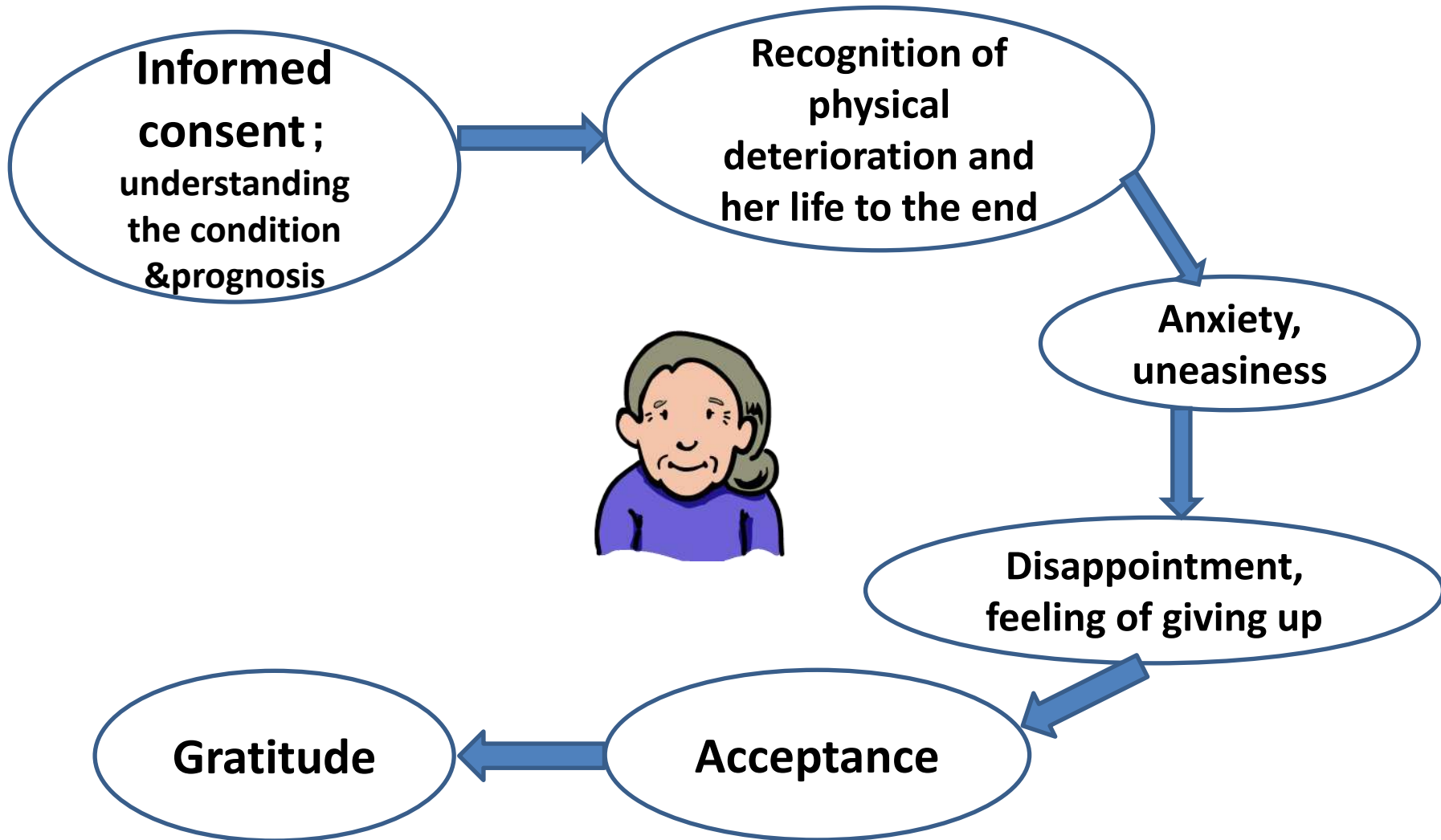
switchover

▪ Death is inevitable in one's life

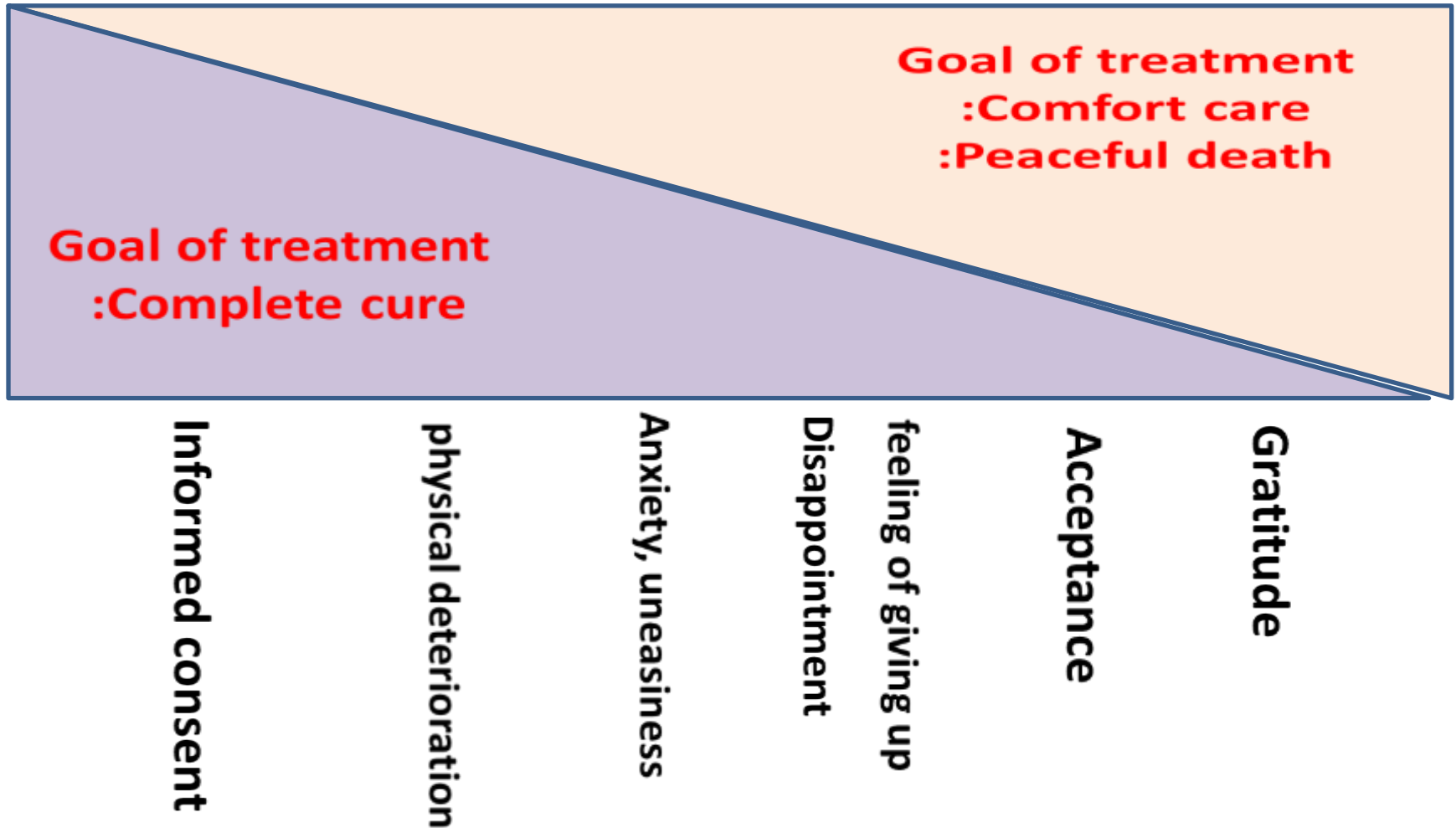
Goal of treatment
:Comfort care
:Peaceful death

* Not insist on acceptance of death, but wait the acceptance of death as a natural consequence with the change of the Pt's condition

(3) Change of Pt.'s value/wishes/feeling



(3) Pt.'s value/wishes/feeling —Change the goal of treatment—



(3) Problems in decision making by the Pt.

① Lack of appropriate informed consent

⇒ Pt. does not know that he is in the terminal-stage and residual time is limited

② Unable to accept the limitation of aging and the human's mortality

⇒ Can not change the goal of treatment

⇒ desire futile life-sustaining treatment

③ Anxiety, Uneasiness

⇒ Can not spend peaceful end-of-life

④ Not want to give the family trouble and burden

Decision making in the relation among the family,

Value of Pt. < Value of family

⑤ Lack of Advance Directive

⇒ Can not decide one's end-of-life care by oneself,

⇒ can not respect Pt's value/wishes

Japanese Advance Directive

『私の四つのお願い』(My Four Wishes)

Person who makes end-of-life care decisions for you

Medical treatment that you wish and you don't wish

To make your end-of-life more comfortable and peaceful

Messages to your dearest persons

Copy Right; Masako Minooka

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(4) Change of family's value/wishes/feeling



**No operation,
No chemotherapy.
She can't stay at
university hospital.**

**What
should I
do?**

**Feeling of
anger and
distrust**

**Mama deserves
comfortable and
peaceful end-of-life!**

**Decision of
'Mitori' at home**

**Accept her
mother's
mortality**

**Facing her
mother's death**



(4) Problems in decision making by the family

① Issues on informed consent

- cannot understand medical information (treatment/prognosis) and medical futility

② Emotional issues

- cannot accept Pt.'s mortality
- anxiety, uneasiness, agony, distress, irritation
- ambivalent and changing feelings (anxiety ↔ giving up)
“I cannot just wait for her death.”

③ Issues on Surrogate (Proxy) judgment

- Who is most appropriate as a surrogate?
- How do we respect Pt.'s Advance Directive or wishes?

④ Issues on conflict of opinions among family

Japanese Guideline: End-of-life care for the people with advanced dementia

by study group on terminal care for the people with dementia

★ It is important for the Pt. spend peaceful end-of-life, family maintain peace of mind

***Get information about medical matters, and consider what is useful or futile treatment. To decide this, facilitate communication with medical team. It is important to think compassionately what is the most appropriate QOL ' for this Pt.' 'at this time of life' ' under this situation'**

★ It is important family have enough open-minded communication each other.

★ It is also important to recognize “Death is inevitable in one’s life”.

(5) Problems on communication

①Lack of common understanding about process and prognosis of disease toward death.

***present status, anticipated symptoms**

***choice of treatment, its advantage & disadvantage**

***futility of the treatment**

②Lack of conversation in the process of decision making

③Lack of Death Education

***"Death is inevitable in one's life"**

***Period of anxiety, sorrow, fear⇒Period of peaceful, gratitude**

***The moment of death: Symptoms toward death and on death**

***things to do when Pt. is going to die**

Japanese Guideline: End-of-life care for the people with advanced dementia

by study group on terminal care for the people with dementia

How is the last moment?

If Pt. is given comfort palliative care, death will be peaceful.

Respiration gradually becomes weaker and irregular.

And at his/her last moment, Pt. takes a deep breath.

It is preferable not to let Pt. alone, and family members touch Pt.

If Pt.'s death is peaceful, family members who have been with Pt. feel satisfaction of “mitori”

Japanese Guideline: End-of-life care for the people with advanced dementia

by study group on terminal care for the people with dementia

What should we do when the secretion in the throat is increasing?

When the secretion in the throat is increasing and becomes more viscous, you hear wheezing. For you, it might sound painful. But dying Pt. who is in a low level of consciousness or in a coma, does not feel one's own respiratory condition.

(6) Problems on family relationship and manpower of the family

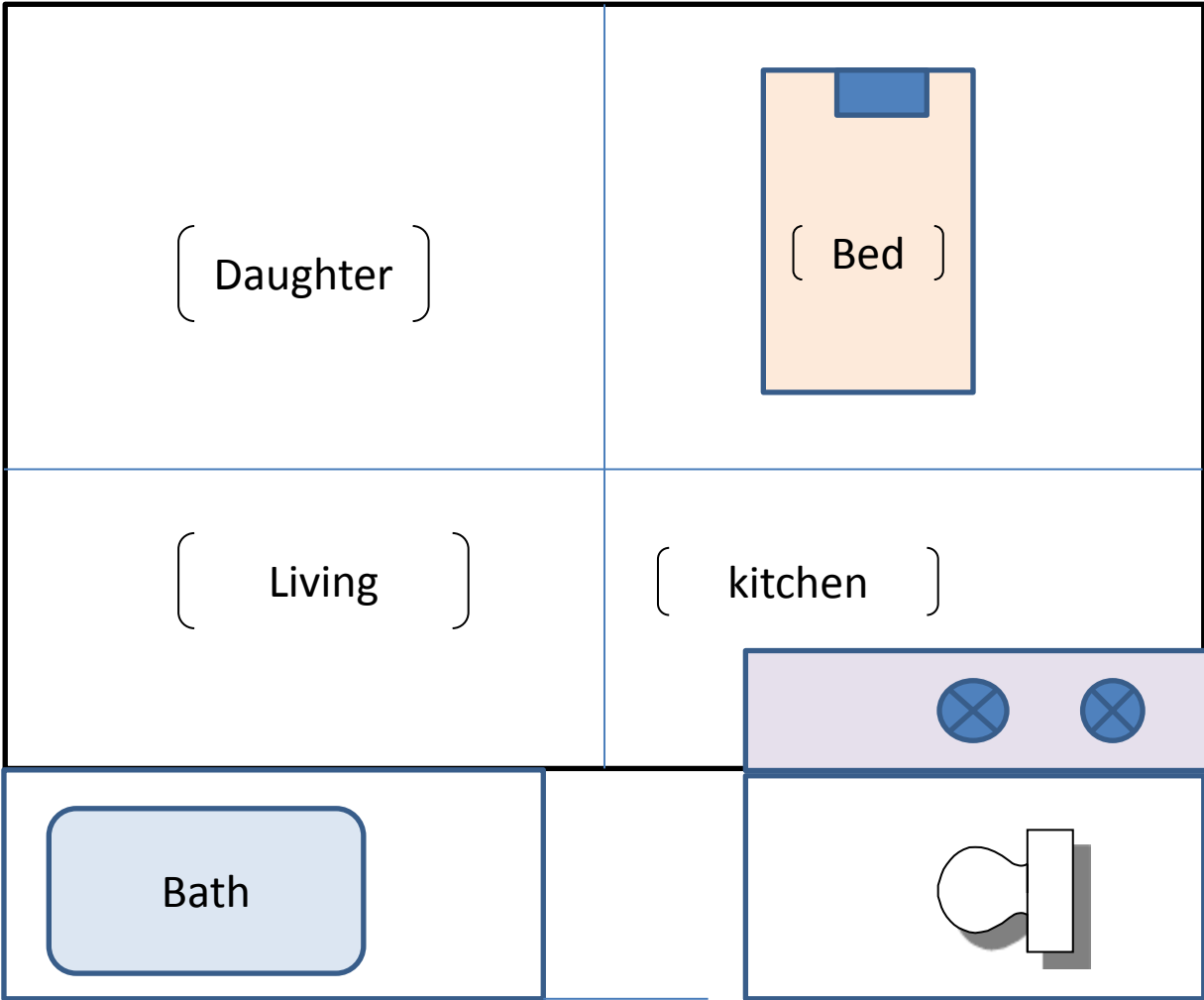
- ① *Trend toward nuclear family, *The aged care for the aged, *Loss of community, *Lack of social connectedness**
- ② Home care depends on manpower of family**
 - Help at mealtime, bathing-time, toilet-time, posture-change, taking-pills, suction sputum etc.
- ③ Lack of manpower of the family**
 - No key-caregiver who understand Pt.'s feelings and is relied by Pt.
- ④ Too many expectations on family caregivers**
 - Force professional value to family caregivers (each family has each ideal care)
- ⑤ Surrogate or Proxy is not key-caregiver**
- ⑥ Lack of communication on end-of-life care**
- ⑦ Balance with daily life**
- ⑧ Conflicts of interest among family**

(7) Problems on the care environment at home

Unsuitable environment at home

- Japanese houses are rather small.
- Private care room is not available.
- Disturb the pace and order of other family members' daily activities.
- Pt.is worried about causing trouble.
- Difficulty to keep oneself/room clean without family manpower
- Good environment is affected by incentive/cooperation/family budget

Actual care environment of the case



(8) Relationship between Pt./family and Dr./Nurse/care-worker

Care

Home helper
Care manager

**Patient
& Family**

Visiting
Nurse

Family
Doctor



(8) Relationship between Pt./family and Dr./Nurse/care-worker

① Fiduciary relationship between Pt./family and Dr. makes 'mitori' at home possible.

*Cooperation/support by Dr. & Ns. is essential.

② Family's incentive/cooperation/understanding medical information is indispensable.

③ Close contact or teamwork among Pt./family, Dr., visiting-Ns., care-worker is important.

*System ;contact and visit easily at any time

⇒sense of security

*information about possible symptoms

⇒prevent panic or upset

*Prepare medicine at home

④ QWL(Quality of Working Life) of Dr. ; be on duty 24hrs, 365days.

(9) Problems on palliative care

① not recognize medical futility

- *forgoing life-sustaining treatment,
but doing comfort care& necessary treatment to control symptoms
- *Cure sometimes, comfort Always

② Late onset of palliative care

- *not recognize in end-stage→continue to struggle against disease
→no peaceful end-of-life

③ not enough palliative care

- *pain control/sedation/mitigating discomfort symptoms(dyspnea, nausea, etc)
- *remove psychological & emotional pain, *giving peace of mind

④ Home Palliative care is not so common

- *inform Pt./family home palliative care or pain control at home is realizable
- *inform family about side effect of opioid/opium
- *Analgesic is always available whenever Pt. needs it
- *Peace of mind can reduce dose of opioid/opium

(10) Problems on artificial hydration & nutrition

① Tube feeding(PEG): medicine? food?

② Number of Pt. with PEG in Japan: 400,000

③ Tube feeding for the people with advanced dementia

***to extend life for a few more sickly months**

***not cure disease, not improve QOL**

④ Insufficient data(evidence) as for the efficacy of tube feeding for the people with advanced dementia in Japan

***improve survival rate?**

***prevent pneumonia?**

**<Reference>; Japanese court case
Case of Tokai University:1995**

<obiter dictum>

**3 Prerequisite for withholding & withdrawing
life-sustaining treatment**

- ①Pt. suffers from incurable disease without possibility of recovery.Pt.is in the terminal stage and death is inevitable.**
- ②Pt. express his/her intention to withdraw treatment at the point when the treatment is withdrawn.**

**<Reference>; Japanese court case
Case of Tokai University:1995**

③

**medication/chemotherapy/dialysis/respirator/
blood transfusion/artificial hydration &
nutrition, etc can be withdrawn.**

- * Medical futility should be judged considering how withdrawing treatment influences the time of death to approach natural death.**
- * Expression of Pt.'s intention can be substituted with the sincere surmise by family who understand Pt.'s value.**

**<Reference> ; Japanese court case
Case of Kawasaki kyodo Hospital:2005**

Prerequisite for withholding & withdrawing life-sustaining treatment

- ①Pt. suffers from incurable disease without possibility of recovery.Pt.is in the terminal stage and death is very soon.(All the examination should be done listening to the second opinions.)**
- ②Appropriate informed consent(enough information, express Pt.'s real intention)**

In case Pt. can not express : Search for Pt.'s real intention by living will or surmise by the close people

In case Pt. real intention is not clear : If it is doubtful, all should be done for the benefit of human life. Dr. should not decide instead of the Pt.

<Reference>; The Tokyo High court pointed out: Case of Kawasaki kyodo Hospital, 2007

★ Substituted judgment or assumption by his family is to be made as to the patient who rapidly lost his consciousness, there is a danger, however, that the family expects to avoid the financial or economic and mental burden with terminal care, and fictitious aspects in confirming the real will of the patient (Kai Katsunori, 2009, Euthanasia and Death with Dignity in Japanese Law)

Pt. has the fundamental right of the individual to decide which medical interventions will be accepted and which will not.

Decision of a family member etc. for the Pt. is just a substitution. It does not vest the family

member with the Pt's right of decision making.