

# The International Comparison Study on Death and Dying in Place

<Summary>

## **-1 Problems Concerning End of Life Care for People with Dementia**

**Kazuo Hasegawa, M.D., Ph.D.**

Professor Emeritus

St. Marianna University, School of Medicine

Honorable President

Tokyo Research and Training Center for Dementia Care

We have three problems in considering end of life care for people with dementia.

First, the definition of end of life is not clear; in case of underlying causes, for instance in the Alzheimer's disease, there remains a question whether it is universally known when and in what condition the end of life starts. Secondly, it is difficult to obtain patients' consent, because a key part of dementia is disorder of cognitive function including ability of understanding, judgment and verbal communication and it causes patients' drastic deterioration of their decision-making. Thirdly, it matters who and how appropriate judgment should be made from the aspects of medicine or welfare in order that people with dementia may spend respective end of life with dignity, maintaining each personality.

Dr. Hasegawa makes further reference to the outline of the Alzheimer's disease, definition of the end of life of dementia, and evaluation of the end of life of the Alzheimer's disease through summing up findings concerning end of life of dementia.

In case of dementia care, care based on 'personhood,' that is, mental identity to express or accept in the process of individual life — 'person-centered care' beyond 'psychological care' or 'corresponding care' serves as a backbone to affirm patients' dignity. It is also important in care-giving to respect relationship with the others who were born and brought up in life history, above all people around the patients. In such 'person-centered care,' we focus on understanding the patients' internal experiences with the intention of listening to their unique stories, while excluding care as a convenience to caregivers. It is highly expected to maintain this philosophy firmly even at the end of life.

## **-2 Conditions for the Final ‘Self-determination’ in Life**

**Rihito Kimura, Ph.D.**

President

Keisen University

In the US, from 1970s through 2000s, judicial cases as to ‘death with dignity’ were accumulated, and at the same time outstanding development was attained in social conditions or legal aspects to support ‘self-determination’ in medical care.

The characteristics of development were:

First, every state in the US has enacted Natural Death Act or Death with Dignity Act including living will or Durable Power of Attorney. Secondly, the federal government established Patients’ Self Determination Act, 1990, which regulates that hospitals and institutions related to the federal government should provide individual patients with written or verbal explanation that they can make a choice of ‘discontinued medical procedures aimed at prolonging life.’ Thirdly, Oregon State enacted Oregon Death with Dignity Act, 1994, which ‘allows terminally-ill Oregonians to end their lives through the voluntary self-administration.’

Meanwhile, hospice movement in the US aims for establishing a care system for patients to spend satisfactory and peaceful end of life in the place where they desires most (that is, home), which shows a concept of in-home care. Original support system of hospice care functions by means of ‘in-home end of life care’ centering on pain relief by nurses and support by volunteers who have received training for end of life care.

Furthermore, introducing ‘Five Wishes’ as a new advance directive, Dr. Kimura points out the necessity of heartfelt in-home hospice care system which unconditionally accepts people at the end of life not as a ‘patient’ but as the one and only ‘human being’ with dignity. It is a new hospice system formulated by the idea of ‘man-centered’ care by professionally educated and trained hospice staff. He concludes it is high time to examine this system toward future.

## **-1 Developmental Challenges and Opportunities for “Growth”**

### **—The Inner Life at the End of Life—**

**Robert N. Butler, M.D.**

President and CEO

International Longevity Center-USA

Dr. Butler raises the issue of the end of life from the patients' viewpoint, saying that even the end of life can be an opportunity to complete a chance of 'growth.' Therefore, he emphasizes the significance of internal study on the end of life.

Meanwhile, he disagrees to the tendency to emphasize autonomy or insist suicide, which is particularly seen in the US. He describes experience of death is not simply in the hands of physicians or dying patients.

From this perspective, it is pointed out that, in telling about the inner life at the end of life, what matters is not merely physical decline, pain and suffering, sorrow of death, separation from families or friends, and medical attack blunting consciousness. It is crucial that physicians, family members and other people close to patients with serious or terminal illness pay careful attention to their natural calls, so that they could accept their lives so far (find its meaning), keep in harmony with their surrounding people, resolve a conflict and make up past behavior or fault, regardless of their remaining period.

In fact, Dr. Butler's view is based on the standpoint that while we continue to grow to the last moment, our death is not only ours. He might indicate growth at the end of life exists in the relationship that people around the patients fully care for their effort to try to sum up their own life.

Standing on such an idea, he indicates: there is too much medical intervention placing useless and impatient burden; relationship among patients, family and physicians at the end of life has extremely important implications for death with dignity; physicians, nurses and other medical professionals untrained to provide a 'better death,' could hardly discuss about death.

## **-2 A Future Direction of Community-based End-of-Life which Centers around Care Facilities and Group Homes**

**Yukimi Uchide, Ph.D.**

General Director

Social Welfare Foundation Tenjin-kai

First, Ms. Uchide refers to the principle in group homes that ‘people spending the end of life together need to have a mental attitude to derive terminal fulfillment as a continuation of daily relationship so far, instead of merely making the end of life satisfactory. It is reported closer relationship makes it possible to understand the residents’ intention through a bit of conversation or expression.

She also finds out cultural differences in the collaborative research with Australia. For one thing, differences in the way of thinking about safety. While in Australia fencing is considered to ensure safe and comfortable life, it is regarded as business-centered care in Japan. It is possibly caused by different values in ‘freedom:’ that is, ‘freedom’ is an opportunity to do what they want to do in secure surroundings in Australia, however in Japan it means an opportunity to express ourselves by continued contribution to others.

Moreover, there are some differences also in the concept of residents’ adaptive range. In Australia where adaptive range is clearly defined, residents are required to move to a nursing home providing high care services, if their physical condition rises to a more serious stage. On the other hand in Japan, taking much account of sustainability of life or relationship, we tend to consider it is quite natural and would lead to preserving the dignity of residents to continue to live together with fellows under one roof until the end of life.

Thus advocated is ‘Building Communities where the whole town or region would become our own home, and everybody would team together.’

### **-3 Advance Directives in Japan, Singapore and Taiwan**

#### **—As What Supports the End of Life of Older People—**

**Mari Tsuruwaka, Ph.D.**

Associate Professor

St. Luke's College of Nursing

Advance directives are enshrined into law in several Asian countries including Taiwan and Singapore. In Taiwan and Singapore, however, it is hard to say advance directives spread among the general public. Exploring the causes or background of the low prevalence, Ms. Tsuruwaka shows findings of the survey on advance directives conducted in a senior college in Japan, and considers possibilities of advance directives in medical care.

In Singapore with a population of about 4.4 million, 3,840 persons have completed an advance directive as of May 2006, ten years after the legislation, which shows a low prevalence rate. In Taiwan, although the advance directives law was enacted in 2000, the enrollment is less than 15,000.

Ms. Tsuruwaka discusses causes of the extremely low prevalence rate in Singapore or Taiwan, additionally thinking of the results of the focused group interview survey covering senior college students in Japan.

First, with regard to drawing up an advance directive, what is required is provision of accurate information by professionals and establishment of counseling system.

It is also necessary to recognize the importance of the role of family members in the process of completing an advance directive. In Singapore, since family members are kept at a distance in this process, the patients cannot have a sense of completing it with the family. People completing an advance directive in the focus group interview survey think it particularly meaningful to leave a message to their family or avoid physical or mental burden rather than to recognize it the right as a patient or to aim for an autonomous life. Consequently she suggests the necessity of searching for circumstances to complete an advance directive, while maintaining relations with the family.

## - 4 My Mother's Death

**John C. Campbell, Ph.D.**

Professor Emeritus

University of Michigan

Dr. Campbell's report on end of life care for his mother provides considerable amount of information about end of life care in the US. What is worth noting most in the way of his mother's life might be the following issues:

### \* Strong sense of autonomy

- Continue to live alone
- Economic independence
- Move house in old age and create a comfortable place to live on her own
- Advance directives ('vest medical authority,' draw up a document called "Five Wishes," which is a variation on the "living will')
- Specify the contents of her memorial service

### \* Firm bonds with family members in the distance

- Communication by email or phone (*'Mother was as much in touch with her family as when she was living in New Jersey,'* though actual visits to her was not so frequent. )
- Family gathering (*Once in a while, all the family stayed at her apartment for a few days. It was the first occasion for her to see her grandson's Japanese wife, and two recently-born great-grandchildren. She had an extraordinary time.*)

Moreover, the following issues in Dr. Campbell's report draw attention.

### \* Problems in medical care and long-term care

- Provision System of medical care in the nursing center (Staff did not know his mother's attending doctor or the appointment schedule with him (her). *'...no one paid close attentions to her medications, which had been prescribed by various doctors and then not evaluated afterward. One medication was a powerful painkiller that left her very confused, and another one badly affected her eyesight.'*)
- MRSA infection (*'The quality of the procedures themselves is difficult to judge, but clearly her original surgical operation failed so she needed another serious operation. She also got an MRSA infection in the bed sore in her foot, either in the hospital or the LVL nursing center.'*)

-Long-term care (*'She was getting a lot of care services in her apartment, with different people coming every day, which she found confusing and irritating although more and more necessary.'*)

**\*Care management** (*'We had actually hired a professional "care management" firm in Albuquerque to serve as an advocate for her and a source of information for us. Unfortunately, this company turned out not to be very helpful, although we know of cases where this strategy has worked very well.'*)

**\*Hospice care** (In the US, about one million patients annually receive hospice care on their death bed, which is more than 35% of the total death toll. )

## **Toward the International Comparison Study on Ideal End of Life Care and Dying**

**Kanao Tsuji, M.D.**

President

Life Care System

**Daisuke Watanabe, Ph.D.**

Assistant Research Fellow

Center for Asian and Pacific Studies, Seikei University

**Taeko Nakashima, Ph.D.**

Senior Researcher

Institute for Health Economics and Policy

We are advancing the preparations of an international comparison study among the 7 countries, based on the problem consciousness that how older people could live a good life with their family, friends and acquaintances, and meet a good death at home or in a facility, on the extension of life they have ever followed. Accordingly we are planning to conduct an attitude survey concerning how they are conscious of 'ideal death' or 'ideal end of life care,' inquiring appropriate bodies selected through the global network of the ILC Alliance. In that case, we could grasp awareness of medical or welfare professionals, who play an important role to secure QOL of older people and their family at the end of life and also give a great influence on them, and additionally clarify differences of recognition among the family, physicians, nurses and welfare professionals as well as international differences.

The practical study will start next fiscal year in manner of an interview survey in use of a question method. We will prepare two virtual cases concerning ‘cancer’ and ‘dementia’ including issues of decision-making, and grasp awareness of people concerned about them.

## **Literature Review**

**Daisuke Watanabe, Ph.D.**

Assistant Research Fellow

Center for Asian and Pacific Studies, Seikei University

‘Literature Review’ is categorized by domestic and foreign researches. Intended literature includes 66 Japanese reports and 23 foreign reports. The literature enables us to survey the accumulated researches on ‘in-home care, medical care and end of life care’ both domestically and internationally.