

# Health Systems and Preferences for Places of Death: Poor Death vs Happy Death

Takeshi Mori

## Abstract

Public interest for quality of death is increasing worldwide. This paper overviews previous studies analyzing some factors influenced on death using Discrete Choice Experiments (DCEs). Only a little research, however, has been conducted globally to quantify which types of death people consider as a good death. Last half of the paper, I overviewed the real situations for places of death in Japan.

**Keyword:** DCE, quality of death, end-of-life care

## Table of contents

### Introduction

- I Specialists' and public view of life and death
- II Previous studies for the place of death using the DCEs
- III Three types of health systems
- IV Places of death in the Japanese version

### Conclusion

## Introduction

Growing number of people are certainly living longer, especially in developed countries. Japan and Europe's population has been among the fastest to be aged

and the USA is catching up them. With longevity, demand for the end-of-life care is likely to rise sharply and more costly care is needed. The number of people aged 65 and older is expected to reach one billion in the world, which means one in eight of the global population.

The Quality of Death Index is devised in 2015 by the Economist Intelligence Unit's research group, which collected data and interviewed a variety of doctors, specialists and experts across 40 countries. In building the index, they focused on basic end-of-life care environments, such as availability of end-of-life care, cost of end-of-life care and quality of end-of-life-care. The UK, Australia, and New Zealand are ranked in the overall ranking as the 1<sup>st</sup>, 2<sup>nd</sup> and 3<sup>rd</sup>, respectively. Japan is ranked as 14<sup>th</sup>, which has ranked up from 23<sup>rd</sup> in 2014 but is still lagged behind other developed countries.

Public interest for death is also increasing worldwide. In the current paper, previous studies analyzing some factors influenced on death using Discrete Choice Experiments (DCEs) are raised and how medical system situations influence on the preferences for end-of-life (EOL) care is examined. DCE is increasingly used recently in medical and health literature and a powerful method to elicit stated preferences for EOL care. Only a little research has been conducted globally to quantify which types of death people consider as a good death. Some researchers have recently challenged on this issue (Finkelstein et al., 2015; Malhotra et al., 2015; Shah et al., 2015). Those studies suggest the relative importance of each factors influencing EOL choice. From now on, similar studies are expected to challenge in other developed aging countries.

In the last half of the paper, medical systems in developed countries are categorized into three types and show merits and demerits for each system. Looking at a real situation of death places in Japan, I also consider how systems influence

Health Systems and Preferences for Places of Death: Poor Death vs Happy Death quality of death.

## **I Specialists' and public view of life and death**

Before considering factors influencing the quality of death, we focus specialists' view of life and death. Specialists such as physicians are expected to owe an absolute duty fidelity to each patient and to have their own view of life and death in caring the dying. Ethical debate in the USA is now shifting from rationing to waste avoidance and distributive justice is important for physicians. Howard Brody has proposed that physicians should pick up five wasteful, nonbeneficial treatments because physicians collectively owe loyal to patients (Brody, 2010). This means aggressive medical interventions regardless of intentions of patients are not always needed and clinical treatments and views of life and death are also needed based on the view of patients. Not only clinical effectiveness views but also cost effectiveness views are needed (Brody, 2012). These concepts expected for specialists expand from the micro level; interpersonal relationships between doctors and patients, through the mezzo level; academic societies, guidelines, community societies and each hospital, to the macro level; each nation and society.

On the other hand, some previous studies have examined public view of life and death. Japanese public preferences for death and their view of life and death have been also examined (Hirai et al., 2006; Matsumura et al., 2002) and a comparative study compared with other developed countries exists (Schumaker et al., 1991). One of most comprehensive studies examined the preference for death and dying is a survey paper analyzing the UK population (Cox, et. al, 2013). Any of them, however, do not analyze influencing factors on death simultaneously.

## II Previous studies for the place of death using the DCEs

Some studies have recently analyzed the value of the quality of death using the DCEs (Finkelstein et al., 2015; Malhotra et al., 2015; Shah et al., 2015). The current paper focused on results from Finkelstein et al. (2015) and Malhotra et al. (2015) as typical ones and introduce the attributes and levels used in them. After introduction of the previous papers, the attributes I focused on in the case of Japan are raised. Both Finkelstein et al. (2015) and Malhotra et al. (2015) used the same attributes shown in Table—1. Respondents, half of whom were patients with advanced cancer, were administered questionnaires consisting of a

Table—1 Attributes and levels the DCEs for patients with advanced cancer

Attributes	0	1	2	3
severity of pain from diagnosis until death	none	mild	moderate	severe
amount of care required from family members and friends	10 h/week	16 h/week	24 h/week	40 h/week
expected length of survival	4 months	6 months	10 months	16 months
quality of health care experience	very good	good	fair	poor
expected cost of treatment from diagnosis until death	¥320,000	¥800,000	¥1,600,000	¥3,200,000
source of payment	own out-of-pocket	family member's out-of-pocket	own Medisave account	family member's Medisave account
place of death	home	institution such as hospitals	hospice or nursing homes	

Note: calculated by S\$1=¥80

Source: The table is made from Finkelstein et al. (2015).

Health Systems and Preferences for Places of Death: Poor Death vs Happy Death DCE. The DCE contain seven features of attributes influenced the quality of death, such as place of death, severity of pain, amount of care, expected length of survival, and etc. Participants are asked to choose their most preferred one from a series of two scenarios. The DCE consist of eight tasks with different levels of seven attributes.

Firstly, let me focus on the results from a study of Finkelstein et al. (2015), in which half of respondents are patients with advanced cancer and half of them are over-51-year-old adults. WTPs for each attribute are shown in Table—2. Table—2 shows pain care and the preference for home as the place of death are preferable extensively. For patients with stage IV cancer, pain reduction and dying at home value ¥3,500,000 and ¥1,500,000, respectively. It is interesting, however, to find public populations consider them less valuable. For older public, it is only one seventh value of patients' WTP. From the view of the opposite side, dying at home and reducing the burden for family members are priceless for patients, who consider them five times more valuable WTP than public adults'.

Table—2 The WTP for each attribute both by older adults and patients

Attribute	Level transition	WTP (¥): adults	WTP (¥): patients
Survival	4 months → 16 months	126,960	883,440
Quality of care	Poor → very good	391,280	1,041,280
Pain	Severe pain → no pain	748,640	3,464,640
Amount of care	40 h/week → 10 h/week	128,000	686,000
Place of death	Institution → home	296,960	1,543,600

Note: calculated by S\$1=¥80

Source: The table is made from Finkelstein et al. (2015).

Secondly, consider the results from a study of Malhotra et al. (2015), in which half of respondents are patients with stage IV cancer and half of them are their caregivers.

The willing to pay for each attribute by patients and their caregivers are summarized in Table—3. Table—3 shows every WTP of caregivers except ‘Amount of care required from family members’ attribute is much higher than patients’, especially WTP of caregivers for survival is three times higher than patients’. This means that extending the life of patients is more valuable for their caregivers than for patients themselves. In addition, caregivers have an emphasis and two times higher WTP both for ‘pain management’ and ‘quality of care’ than patients, which has an impact on how the end-of-life care treatment is decided and suggests that caregivers are more likely to prefer aggressive life-sustaining treatments for patients compared to the patients themselves. Considering a study of Finkelstein et al. (2015), while the WTP of patients to extend their life by 1 year was ¥1,500,000, the WTP of caregivers was around ¥5,000,000, which is consistent with their hypothesis that caregivers had a greater willing to pay than patients. In addition, the WTP of public population was just only ¥130,000. These results suggest the EOL care are too much for patients. More studies eliciting preferences of patients, public populations and caregivers in other developed countries are valuable and needed to consider in detail.

Table—3 The WTP for each attribute both by patients and their caregivers

Attribute	Level transition	WTP(¥): caregivers	WTP(¥): patients
Survival	4 months → 16 months	4,909,440	1,485,600
Quality of care	Poor → very good	3,523,760	1,295,280
Pain	Severe pain → no pain	6,083,760	1,775,920
Amount of care	40 h/week → 10 h/week	-411,200	324,080
Place of death	Institution → home	5,417,840	2,500,480

Note: calculated by S\$1=¥80

Source: The table is made from Malhotra et al. (2015).

Pain management treatment in Japan is now lagged behind other developed

Health Systems and Preferences for Places of Death: Poor Death vs Happy Death countries such as England, Australia, and New Zealand. Provision of place of death differs across countries, which means that we should consider the difference of medical system situations between Singapore and Japan. Compared with other countries' EOL care, we need to consider the similar issues. The difference of medical systems in developed countries are summarized briefly in the following chapter.

### **III Three types of health systems**

Health systems in all developed countries are categorized into three types: the Beveridge, the Bismarck and the American model (Bhattacharya et al., 2013). Each health model has its own merits and shortcomings. In this section, three models are summarized in line with Bhattacharya et al. (2013).

#### **1 The Beveridge model**

During the World War II, William Beveridge laid out an ambitious plan which was an outline for a new health care system based on the notion of solidarity between countrymen (Abel - Smith, 1992). This system had three features: universal single-payer insurance, public provision, and free care. After a long debate, the National Health Services Bill was passed in 1946. Hospitals owned by private institutions, religious organizations, and local governments were nationalized by this law. The National Health Services (NHS) was established and a new hospital system began operation in 1948. The Beveridge model was later adopted by many Commonwealth nations (Canada, Australia, New Zealand) and Scandinavia countries (Sweden, Norway, Denmark) (Klein, 2010). The Beveridge model has its own merits that patients can receive health services irrespective of an individual's ability to pay. At the same time, it has shortcomings.

One of the most serious problems in the Beveridge model is queues. Free care provided in the Beveridge countries attracts high demand for health care. While physician and nurse salaries increase in the private markets so that supply matches demand, salaries set by the government in the Beveridge model cannot equilibrate. High demand and low supply results in queues. The median waiting time in 1990 for English patients was five months and it was over 2 months in 2012 for Canadian patients (Barua & Esmail, 2012). While many reforms since then focused on reducing long waiting times, queues still remain a political issue in every Beveridge country.

## **2 The Bismarck model**

This model is named after Otto von Bismarck, who was the first Chancellor of modern Germany. In 1881, he introduced a universal sickness insurance system (Henlock, 2007). Miners in Prussia could join mutual aid funds at that time. These funds worked by collecting some portion of workers' wages, and distributing to sick and injured workers to provide basic medical care expenses and cover some of their lost wages (Dawson, 1912). Since 1854, these funds became mandatory: all workers in the mine industry were required to enter the system (Companje et al., 2009). At first, health insurance was extended only to workers in some industries. Over time the government extended coverage to workers in other industries, family members of workers, and eventually the whole population (Amelung et al., 2003). As in Germany, other developed countries, such as Japan and many continental European countries; France, Switzerland, and Netherland adopted a universal insurance system. These countries that adopt the Bismarck model share some characteristics: Universal insurance, Community rating, and Regulated private health care provision (Hassenteufel &

Health Systems and Preferences for Places of Death: Poor Death vs Happy Death Palier, 2007).

Regulated private health care provision is the most striking feature in this model. Most hospitals and clinics are run privately. In practice, however, prices are set periodically through negotiations between professionals and payers. In Japan, the price lists are set each year by the Japanese Ministry of Health, Labor, and Welfare through negotiation with the Japanese Medical Association. In France, price-settings for the health care are conducted through negotiations between doctors' trade unions and sickness funds (Hassenteufel & Palier, 2007). To control the public burden of health care costs, Bismarck model nations have recently introduced other strategies, such as gatekeeping and health technology assessment (HTA). These strategies are common in the Beveridge model. While Beveridge systems emphasize equity and equal access to health care, Bismarck systems emphasize patient's choice and provider competition. Recent reforms in Bismarck models such as gatekeeping bring the result that restrict patients' choice in certain ways. Beveridge nations' reform have recently focused on increasing choice for patients and provider competition. In the result, Beveridge and Bismarck systems are moving closer.

### **3 The American model**

Most people in the US today are covered through the employer-sponsored insurance. Outside the employer insurance, it is difficult and expensive to obtain insurance. As for elderly and disabled people, they are covered through the Medicare, which is financed and run by the federal government. People in the poverty situation are covered through the Medicaid, which is financed and run by the local and federal governments. While the American model is, in fact, a patch-work health system, it is basically a market system model. This unique system

is characterized by the following three features: Private health insurance, Partial universal health insurance (Medicare and Medicaid), and Private health care provision. Among them, private health care provision is the striking feature which differs from both Beveridge and Bismarck models. There are a few restrictions on where hospitals and doctor's clinics can open. There is also no direct price control, which enables doctors charge any price they choose. While American patients with a nice insurance can visit whichever doctor they want, and can receive any health care treatment, there is also a large group, more than 50 million people, without any insurance. In the result, some people in the US can receive the most developed medical treatment, the other people have a few treatment or nothing at all.

#### **IV Places of death in the Japanese version**

After curing and the health conditions stabilizing, three main places for the elderly to spend their last of life outside their homes exist; geriatric health services facilities ('roken nursing homes'), special nursing homes for the elderly ('special nursing homes'), and private nursing homes.

These three institutions have their merits and demerits. In term of costs, special nursing homes are the most reasonable among them. It costs about ¥70,000 per month, but the elderly has to share a room with the other older people. Special nursing homes are public facilities, but their price are low for a large amount of public subsidy, which results in queues. The elderly applicants to special nursing homes have been reported about 524,000 people (Ministry of Health, Labour and Welfare March 2014). In fact, the number of care certified person over the age of 65 is estimated as more than 600 million people ("Long-term care insurance business situation report", Ministry of Health, Labour and

Health Systems and Preferences for Places of Death: Poor Death vs Happy Death Welfare 2014), so the actual waiting elderly number is considered to be up to 100 million people. This situation looks like a nursing version of the Beverage model, which have a merit of low prices and demerits of long queues.

Next, we look at private nursing homes. Private nursing homes are run privately, the elderly have to pay ¥200,000 monthly. The residents have their own private room, provided with comfortable facilities, with a variety of recreation. For this reason, it has become a place where the elderly who can afford to pay choose. These nursing systems look like the nursing version of the “American model”.

Lastly, we look at geriatric health services facilities (‘roken nursing homes’). It costs about ¥90,000 per month for residents, but the elderly people have to leave in three months. Roken nursing homes are originally established as a rehabilitation facility for the aim of the recovery of the elderly, not for the place of safe haven at the end of life of the patient. However, it is also possible for patients to remove another roken nursing homes after a diagnosis of a doctor. In fact, there are a lot of older people to wander many roken nursing homes, who have no family and no relatives to care themselves at the last moment at home, or who cannot afford to pay private homes.

This may reflect the Japanese situation of the end of life care, in which half of the end of life care is left to the private sector and the other half is supported by the public sector, because governments could not build enough nursing homes for the elderly.

In a sense, it can be said that the social security system of roken homes look like the Bismarck type, which took the balance between equity and freedom of individual choice. However, the number of elderly is certainly possible to increase in the near future, and so it is inevitable for public burden to increase.

## Conclusion

The current paper shows recent studies analyzing public preferences for a place of death and overview the EOL care and the place of death in Japan considering different medical systems among developed countries. First half of the paper, results from a study analyzing the preference of patients with advanced cancer in Singapore for the EOL care are introduced and highlight the importance of ‘place of death’, ‘pain management’, and ‘amount of care required by family members’. In addition, three type of medical systems adopted by developed countries are introduced and their merits and shortcomings are summarized. Last half of the paper, I overviewed the real situations for places of death in Japan and confirmed that these situations are influenced by the mixture of healthcare systems. As the society aging, we will confront the difficult problem which one should be chosen as a goal for the nation’s healthcare policy; equity, wealth, and health. The disparity of choosing death places is widening between the older of the haves and the older of the have-not in Japan.

## References

- Abel - Smith, B. (1992). The Beveridge Report: its origins and outcomes. *International Social Security Review*, 45, 5-16.
- Amelung, V., Glied, S., & Topan, A. (2003). Health care and the labor market: learning from the german experience. *Journal of Health Politics, Policy and Law*, 28, 693-714.
- Barua, B., & Esmail, N. (2012). Waiting Your Turn: Wait Times for Health Care in Canada, 2012 Report. *Studies in Health Policy, Fraser Institute*.
- Bhattacharya, J., Hyde, T., & Tu, P. (2013). *Health economics*: Palgrave Macmillan.
- Brody, H. (2010). Medicine’s ethical responsibility for health care reform—the top five list. *New England Journal of Medicine*, 362, 283-285.
- Brody, H. (2012). From an ethics of rationing to an ethics of waste avoidance. *New England Journal of Medicine*, 366, 1949-1951.
- Companje, K.-P., Veraghtert, K. F., Hendriks, R. H., & Widdershoven, B. E. (2009). Two

## Health Systems and Preferences for Places of Death: Poor Death vs Happy Death

centuries of solidarity. *German, Belgian and.*

- Cox, Karen, et al. "Public attitudes to death and dying in the UK: a review of published literature." *BMJ supportive & palliative care* 3.1 (2013): 37-45.
- Dawson, W. (1912). *Social Insurance in Germany 1883-1911: Its History. Operation, Results (New York, 1913).*
- Finkelstein, E. A., Bilger, M., Flynn, T. N., & Malhotra, C. (2015). Preferences for end-of-life care among community-dwelling older adults and patients with advanced cancer: A discrete choice experiment. *Health Policy*, 119, 1482-1489.
- Hassenteufel, P., & Palier, B. (2007). Towards Neo - Bismarckian Health Care States? Comparing Health Insurance Reforms in Bismarckian Welfare Systems. *Social Policy & Administration*, 41, 574-596.
- Hennock, E. P. (2007). *The origin of the welfare state in England and Germany, 1850-1914: social policies compared*: Cambridge University Press.
- Hirai, K., Miyashita, M., Morita, T., Sanjo, M., & Uchitomi, Y. (2006). Good death in Japanese cancer care: a qualitative study. *Journal of pain and symptom management*, 31, 140-147.
- Klein, R. (2010). *The new politics of the NHS: from creation to reinvention*: Radcliffe Publishing.
- Malhotra, C., Farooqui, M. A., Kanesvaran, R., Bilger, M., & Finkelstein, E. (2015). Comparison of preferences for end-of-life care among patients with advanced cancer and their caregivers: A discrete choice experiment. *Palliative medicine*, 29, 842-850.
- Matsumura, S., Bito, S., Liu, H., Kahn, K., Fukuhara, S., Kagawa - Singer, M., et al. (2002). Acculturation of attitudes toward end-of-life care. *Journal of general internal medicine*, 17, 531-539.
- Schumaker, J. F., Warren, W. G., & Groth-Marnat, G. (1991). Death anxiety in Japan and Australia. *The Journal of social psychology*, 131, 511-518.
- Shah, K. K., Tsuchiya, A., & Wailoo, A. J. (2015). Valuing health at the end of life: A stated preference discrete choice experiment. *Social Science & Medicine*, 124, 48-56.