

## Palliative Care for the Elderly: A Japanese Perspective

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### 1. Introduction

Japan currently has the fast growing aging society among industrialized countries. In 1970, the Japanese population aged 65 years or older accounted for 7% and by 1990, this rate had climbed to 12%. However, by 2006, 20.8% of the Japanese population was aged 65 or older - the highest rate in the world (**National Institute of Population and Social Security Research, 2011**). This trend is expected to continue for the next few decades and dealing with the country's aging population has become a serious concern for Japan.

Furthermore, in recent years, the number of elderly deaths has climbed very rapidly in Japan. The number of overall Japanese deaths is expected to continue rising from 1.1 million in 2007 to 1.7 million in 2040, a surge associated with the steady growth in elderly deaths (**Figure 1**)(**National Institute of Population and Social Security Research, 2011**).

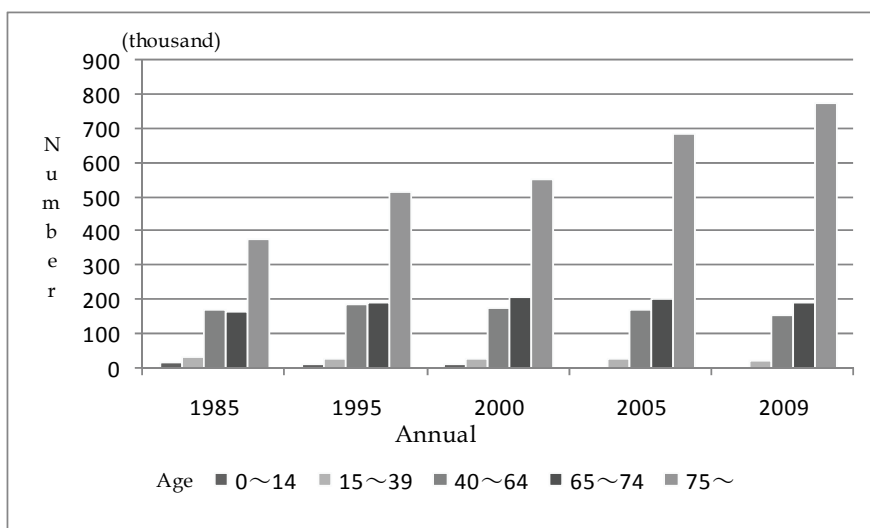


Fig. 1. Annual changes of mortality rates in the number of deaths by age class (**National Institute of Population and Social Security Research, Available from** <http://www.ipss.go.jp/syoushika/tohkei/Popular/Popular2011.asp?chap=0>)

This sudden escalation in the number of elderly and elderly deaths is contributing to an explosion of need for long-term and palliative care. In other industrialized countries, where a more gradual shift to an aging society has occurred, innovative elderly care services are being explored and reforms are ongoing. Even after 1990, nursing home and home care were not widely available in Japan (although the government implemented the “Gold Plan” to expand long-term care services including institutional care in 1989, and the “New Gold Plan” in 1994 to further enhance the service infrastructure) (Masuda, 2000). However, the elderly who required long-term care (LTC) often needed to stay in hospitals for months or even years, partly owing to the lack of long-term institutional or home care service. This situation has contributed to an increase in hospital deaths to the point where most Japanese elderly now die at the hospital. The proportion of elderly who die at long-term care facilities in Japan is still very low (1.7% in 1995, and 4.3% in 2009) (Figure 2), and the use of hospitals to care for elderly patients until their death and the lack of LTC resources constitute urgent social problems for the country.

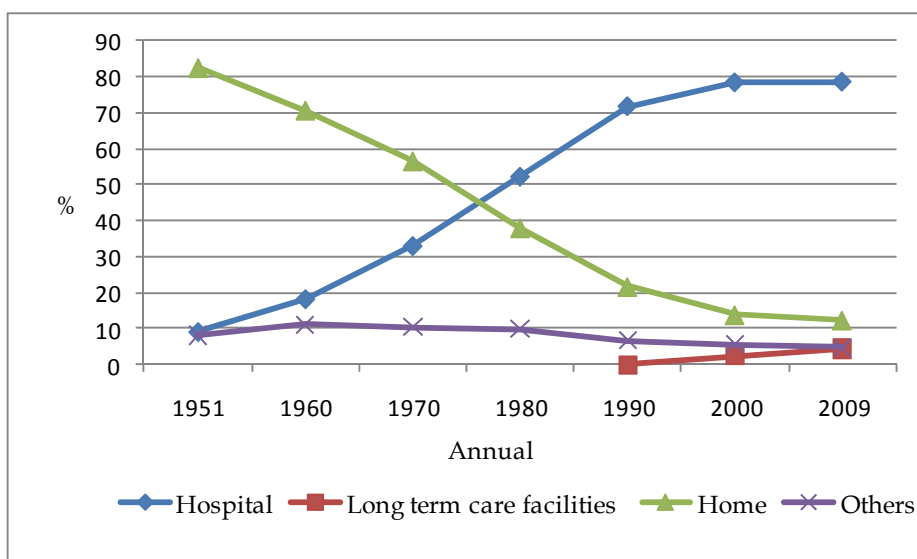


Fig. 2. Annual changes of the proportions seen in the number of deaths by place of death (Ministry of Health, Labour and Welfare, Available from <http://www.mhlw.go.jp/toukei/saikin/hw/jinkou/suii03/deth5.html>)

Given these circumstances, Japan has introduced a number of care systems modeled after schemes employed in Western countries. For example, following Germany and Holland’s introduction of public long-term care insurance (LTCI) systems, Japan followed suit and launched its LTCI system to improve the quality of long-term and palliative care (Tsutsui & Muramatsu, 2007). This system was part of a social security policy reform designed to address a prolonged economic slump and soaring medical and LTC expenditures for older people. Also, a key aspect of Japan’s LTCI system, the Care Management System, was based on the experience of the United Kingdom (Jacobs & Challis, 2007).

However, there are notable cultural differences between Japan and these countries (**Japan Geriatric Society, 2001; Shimizu, 2009**). For example, in Japan, family members or physicians play a more critical role in making decisions when the patient lacks decision-making capacity. Also, the Japanese have developed a unique concept of life and death, represented by the patients' submissive attitudes to medical professionals or the acceptance of their own circumstances as fate. In addition, the Japanese hesitate to complain of pain because patience is a virtue in Japanese culture and Japanese elderly patients do not want to bother their physician. These values may differ from those in Western cultures, where patient autonomy is highly appreciated.

The purpose of this review is to offer a comprehensive view of the current palliative care situation for the elderly in Japan, including care system, education, symptom management, and ethical issues. The review also briefly examines the Position Statement of the Japan Geriatric Society Ethics Committee on the Terminal Care of the Elderly (**Japan Geriatric Society, 2001**).

## **2. Medical and long-term care systems affecting palliative care for the elderly**

In Japan, enrollment in the National Health Insurance Plan is compulsory for all residents, including the elderly. Japan's Health Insurance System allows people to choose their doctor or hospital freely, as long as they pay the fixed medical charges.

Moreover, for residents  $\geq 40$  years of age, enrollment in the Long-term Care Insurance Plan is mandatory; individuals aged  $\geq 65$  years who require long-term care can reap the benefits of this plan, as can individuals aged 40-65 years who require long-term care for diseases related to aging. The dramatic rise in the aging population in Japan has created serious economic problems as the social cost of medical care for the elderly has soared. More Japanese adults are surviving into old age, and older adults are facing physical or mental health problems that require LTC. To handle the anticipated explosion of need for long-term care for the elderly, Japan introduced the Public Long-term Care Insurance (LTCI) system in 2000 (**Matsuda & Yamamoto, 2001; Tsutsui & Muramatsu, 2007**). This system provides professionals with official recognition as Care Managers whose primary responsibility is to oversee the co-ordination of care services and draw up care plans for elderly people. Licensed professionals such as nurses, physicians, social workers, and physical therapists, can be certified as 'Care managers' after undergoing a special training. Under this system, anyone aged 65 or older can benefit from institutional or community-based care services on the basis of need for long-term care and under the care service coordination of care managers.

## **3. Position statement from the Japan Geriatrics Society**

In 2001, the Japan Geriatric Society released its Position Statement regarding palliative care for the elderly (**Japan Geriatric Society, 2001**) (**Table 1**). The position statement was drafted in September of 2000 and reviewed and edited by the Ethics Committee, which was established in 1998 (**Uemura, 2000**). The need for this position statement was founded on a questionnaire survey to the Japan Geriatric Society Council (**Iguchi, 2001; Iijima, 2009**). A total of 95.5% of the respondents answered that a position statement was needed, and several members of the Japan Geriatric Society agreed with this stance.

**Position statement from the Japan Geriatrics Society, 13 June 2001**

**Position 1** : Elderly patients should not be deprived of opportunities to receive relevant care because of their limited independence or other age-related disabilities.

**Position 2** : Care of dying patients should be carried out with full respect for each value, thought and faith.

**Position 3** : Care of dying patients should be directed toward the maintenance or improvement of quality of life

**Position 4** : The care of a dying patient includes support for the patient's family.

**Position 5** : Terminal care of dying patients is multidisciplinary care that encompasses a broad realm of disciplines that involve medicine, nursing and socio-psychology.

**Position 6** : Medical practice implemented in terminal care should warrant its profit to the patient.

**Position 7** : In consideration of the patient's dignity and to show respect for the patient's autonomy, individual cultural background should be taken into account.

**Position 8** : Medical professionals should receive special education in order to secure patients' right to receive optimal treatment and care.

**Position 9** : Broad understanding about how the terminal care of dying patients can improve the quality of life of the patients should be promoted nationwide.

Terminal care and death education should be made available to the general public in Japan.

**Position 10** : Health care reform is necessary to improve the terminal care of dying patients.

**Position 11** : Research on the optimal care of dying patients should be promoted by providing sufficient sources of funding.

**Position 12** : It is strongly advised that each institution establish its ethical committee with a third party in attendance and discuss the propriety of its medical practices and care for dying patients. To achieve wide consensus, the general public should be allowed free access to the discussion through the disclosure of information.

**Position 13** : This position statement is transitional, and its appropriateness should be examined in light of further experience and investigations using scientific methods.

Table 1. Position statement from the Japan Geriatrics Society

The intent of the position statement was to provide the elderly and their families the support they needed to benefit from optimal care in the last stage of their lives, in full respect of their values, philosophy and faith. The questionnaire survey revealed a strong opposition to ageism: "Elderly patients should not be deprived of opportunities to receive proper care because of their limited independence or other age-related disabilities" (Position 1), and "Care of dying patients should be carried out in full respect for their values, philosophy and faith" (Position 2). The statement also emphasizes the pressing need for the creation of ethical committees and for professional education.

However, the results of the questionnaire survey also suggested a need for guidelines concerning a number of ethical issues including artificial nutrition and decision-making (Iijima, 2009). Some members of the society criticized the statement for being too abstract

regarding the provision of palliative care. To improve the position statement, additional investigation, practice and education are needed.

#### 4. Technical terms and definitions of palliative care for the elderly

In Japan, care for end-stage patients is generally called terminal care, hospice care, end-of-life care, or "palliative care". The terms "End-of-life care", "Hospice Care", and "Terminal Care" are considered synonyms for palliative care among Japanese professionals (Higuchi, 2010). According to empirically obtained information, Japanese medical professionals generally use the term "terminal care" to refer to care for patients who face imminent death, and "palliative care" to describe care for end-stage patients (Hirakawa, 2011). Incidentally, in the position statement from the Japan Geriatrics Society (Japan Geriatric Society, 2001), dated 13 June 2001, the society uses "terminal care" as a synonym for palliative care.

In this position statement, "Final Stage Patients" refer to people who are considered to be at the terminal stage of life when their illness is progressive and irreversible, when no available treatment can improve their condition or halt its deterioration, and death is considered to be unavoidable in the near future. In defining 'terminal stage', the length of time until death is not considered due to a lack of clinical evidence for accurately predicting when the patient will die. The reason of this may include difficulty of prognostic prediction on a terminal care stage. As Lunney JR et al. (2003) show, dying process of elderly people has 4 different trajectories or its combinations as follows; each of which suggests that prognostic prediction is so difficult that dying process is unpredictable. First pattern is sudden death, which refers to a case where those who seem to be in a good shape leading a normal life die suddenly. Heart disease is among the most common cause and cerebrovascular disease follows. As older people get and more care people need, a much higher risk they would face to. Second pattern is a terminal illness such as cancer. This pattern is related to a functional decline which results in death after progressive debilitation with a variety of pain. In this case, it might be possible to make predictions of a clinical course and a prognosis to some extent from observing appearance of time and frequency of physical symptoms such as general malaise, pain, anorexia and wheezing or from monitoring degree of decline in limited independence. Third pattern is a case of organ failure. The clinic course of this organ failure such as chronic heart failure, chronic liver failure, liver failure and respiratory insufficiency is characterized by repetitive and combinational progressive decline of physical function and acute exacerbation. When an individual suffers from organ failure, metabolic function works with functional decline in organs. And more limited metabolic function could lead to acute exacerbation. Even if acute treatment works effective, the function doesn't recover completely in most cases. After repeating these processes, function becomes uncompensated and death will follow in the end. Fourth pattern is frailty observed in apoplexy, dementia and being bedridden. Those who suffer from this trajectory have a prolong course with pneumonia and result in death. Therefore, the question of when to start terminal care for the elderly is a very controversial question in Japan.

The World Health Organization has suggested, in its definition, that "palliative care is an approach that improves the quality of life of patients and their families facing the problems 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" (Sepúlveda et al., 2002). Applying the definition to palliative care for the elderly, we can interpret that it is applicable early in the

course of their increasing long-term care need, in conjunction with other usual therapies that are intended to prolong life and manage distressing clinical complications. In Japan, where access to a hospice program is at present only available to patients with cancer or AIDS, but not to other dying elderly patients, the concept that long-term care and palliative care are inseparable in elderly care settings is spreading through the literature and educational programs.

## 5. Educational issues

### 5.1 Medical profession

In its Position Statement, the Japan Geriatric Society suggests that education is one of the most important aspects concerning palliative care for the elderly, and that “the majority of health care professionals receive insufficient specialized training in the care of terminally-ill patients. Concrete and practical instruction in the care of dying patients, including the management of symptoms and communication skills, should be given” (**Japan Geriatric Society, 2001**).

We performed a number of studies concerning palliative care education. In 2005, we conducted a national survey on the status of programs to teach end-of-life care to undergraduates of medical and nursing schools in Japan (**Hirakawa et al., 2005b**). Most of the medical and nursing schools offered palliative care education programs, but the mean number of teaching hours was too low (7.6 hours in medical schools vs. 35.5 hours in nursing schools) to allow for the acquisition of proper experience with palliative care in medical schools. Because palliative care education programs include palliative care for cancer patients in general, we can say that the lack of education on palliative care for the elderly is actually a more serious problem than we had anticipated from our results.

Although information technology advances have enabled medical students and professionals to access a wider array of medical information, medical textbooks still play an important role in medical education. Quality textbooks contribute to higher standards in medical education. A number of studies on end-of-life content in foreign medical textbooks have revealed that coverage was indeed lacking in Japan (**Carron et al., 1999; Rabow et al., 2000**). A preliminary study on this issue reveals that most top-selling Japanese end-of-life care or geriatric textbooks lack proper coverage on end-of-life care, and efforts need to be made to improve this (**Hirakawa et al., 2008a**).

In 2009, we conducted an investigation concerning the syllabi of palliative care education or training course for undergraduates of medical and nursing schools in Japan to design a comprehensive undergraduate educational program model of palliative care for the elderly. We reviewed the syllabi in Japanese medical and nursing schools, and classified the content according to the items specified by the Japan Geriatric Society’s position statement. Our findings, which were published elsewhere (**Hirakawa et al., 2009a**), highlighted the need for education on quality of life of elderly who require palliative care and comprehensive geriatric assessment (CGA). Postgraduate clinical retraining on the palliative care of the elderly is important for long-term care facility physicians. Due to a lack of authorized and standardized palliative care or geriatric care education program for long-term care facility physicians in Japan, professionals in this field are not sufficiently educated on palliative care for the elderly. To get the information needed to develop a comprehensive palliative care education program for facility physicians, we conducted a questionnaire survey on

educational needs concerning end-of-life care for the elderly at long-term care facilities in Nagoya City in 2008 (**Hirakawa et al., 2008b**). Our results suggested that most directors wanted to receive additional training about their clients' decision-making process, communication skills, and legal issues related to palliative care.

In conclusion, medical care provider education on palliative care for the elderly is still lacking in Japan. There is a need to develop educational programs for medical professionals based on further research.

## 5.2 Care profession

Care staff education is one of the most important aspects of palliative care for the elderly. Also, as a result of new policies promoting home care as well as the recent changes in preferences of elderly patients and their families, greater numbers of frail elderly are now opting to spend their last years of life at home or at a long-term care facilities rather than a hospital. Therefore, staff involvement in delivering palliative care has increased (**Henderson et al., 2000**). Improving the quality and quantity of palliative care provision at home or at long-term care facilities has become an urgent priority in Japan (**Hirakawa et al., 2009b**).

The quality of palliative care at long-term care facilities, including group homes for demented elderly, greatly depends on the preparedness of care staff to deliver quality services. However, young care staff usually has little experience with death either on or off the job, and we therefore need to emphasize palliative care clinical training for care staff.

Palliative care educational programs or guides for care staff have been developed in several countries. In the United States, Henderson ML et al developed and published a palliative care training manual for long-term care staff (**Henderson et al., 2000**). In Canada, the National Advisory Committee developed the "Guide to end-of-life care for seniors", which is a useful and informative document for care staff working at long-term care facilities and community care settings (**National Advisory Committee., 2000**). Again in Canada, Kortess-Miller K et al developed a 15-hour interprofessional curriculum tailored to meet the needs of care staff (**Kortess-Miller K et al., 2007**).

In Japan, a project to develop an educational program for long-term care staff delivering palliative care for the elderly was launched in 2011 under the scheme of a research project funded by the Ministry of Education, Culture, Sports, Science and Technology. However, as shown in the position statement of the Japan Geriatric Society, there has been insufficient support for research or education contributing to the improvement of palliative care for elderly (**Japan Geriatric Society., 2001**).

In 2007, through a nationwide survey of chief nurses in geriatric health services facilities, we outlined the educational items which were frequently taught at long-term care facilities (**Hirakawa et al., 2007b**). With these results a a guide, we also conducted action research concerning care staff education. Finally, we developed a 9-hour workshop program to educate care staff who provide palliative care, and reported the effects elsewhere (**Hirakawa et al., 2011b**).

The attitudes of nurses and care workers toward death and caring for dying older adults are positively associated with the quality of palliative care at long-term care facilities. Matsui and Braun (**2010**) suggested, in their research, that better attitudes toward caring for the dying were positively associated with seminar attendance and negatively associated with

fear of death. We introduced a number of tools we believe can be helpful in modeling positive attitudes toward death, such as group discussions on death and dying among care staff, reading picture books on the topic of dying, and others.

### 5.3 Community

Family education is an essential component of long-term care for Japanese elderly patients. Effective communication based on reliable and comprehensive health information between health professionals and elderly patients and their family is an important part of home elderly care (Hirakawa et al., 2011a).

While television and newspapers have traditionally been common sources of health information for the general public, many people are now turning to the internet to gather information (Hirakawa et al., 2011a). However, elderly patients vary widely in terms of health condition and daily living activities, and the issues surrounding their care are often complex. It is thus crucial that the elderly and their family caregivers not rely solely on general information through the mass media, but that they be provided with accurate, timely and tailored information about their condition and needs.

Family caregivers are often at a loss as to how to proceed to look after their loved ones. In 2009, we conducted a broad survey to find out about the kind of information family caregivers of home elderly patients seek and the way in which they generally obtain this information (Hirakawa et al., 2011a). A total of 475 family caregivers of home elderly patients residing in Nagoya city took part in the survey. Our results indicated that the 3 items they perceived as of most concern were dementia (especially dementia care), first aid, and public long-term care insurance services. Also, nearly half of the caregivers were interested in food and nutrition. The respondents either received health information from their physician or from a care manager, despite the fact that care manager is not a medical profession. Our results suggested that care managers are an important source of health information in Japan, and that they should be trained on how to deliver appropriate and tailored information to family caregivers.

Comprehensive palliative care for the elderly places emphasis on elderly patients' values and preferences; it is therefore essential that health care providers discuss the prognosis or clinical course of advanced illness in detail with the elderly and their family. Therefore, palliative care education in community settings should include a unit on decision-making with an emphasis on advance directives. Matsui recently evaluated the effectiveness of an educational intervention in the form of a discussion on end-of-life directed at older Japanese adults and their attitude toward and acceptance of this intervention (Matsui, 2010). The study revealed that, following the intervention, participants tended to view advance directives more favorably, while they began to view life-sustaining treatments by means of artificial nutrition more negatively.

It should be noted that there are some differences in attitudes toward palliative care education between Japan and other countries. The Institute for Health Economics and Policy of Japan conducted a study to assess the attitude of long-term care staff and residents' families toward a Canadian publication entitled: "Comfort Care at the End-of-Life for Persons with Alzheimer's Disease or Other Degenerative Disease of the Brain" (Institute for Health Economics and Policy of Japan, 2010). The study showed that decision-making on palliative care is likely to be performed by discussing options among health care providers



and families in Japan. The study also revealed a general dislike for guideline-based education by the Japanese people. It also stresses the fact that educating families concerning palliative care somehow tends to heighten their anxiety regarding the death of their loved ones or makes them uncomfortable as they view the approach as too aggressive.

## 6. Caregiver burden of family

Family caregivers play a critical role in caring for dying elderly relatives. At the request of family caregivers, health care providers should disclose available information on the elderly patient and provide support for the family in coping with the sorrow of losing an elderly patient. Because the quality of life of family caregivers has a direct influence on that of their elderly, providing the family the necessary support to cope will eventually help them better meet the needs of the patient. Within the framework of Japan's public long-term care insurance system, care managers play an important role in reducing the burden of family caregivers who care for elderly relatives at home.

Despite this support, Japanese family caregivers often suffer from stress caused by physical, psychological, social, and spiritual factors. Japanese elderly may also be reluctant to make decisions, and their family caregivers feel pressured into making decisions for their elderly relative (**Japan Geriatric Society, 2001**).

The burden of caring for an elderly relative is especially heavy for female caregivers. According to a comprehensive survey of living conditions conducted by the Ministry of Health, Labor and Welfare, women represent about 70% of all caregivers in Japan (**Ministry of Health, Labor and Welfare, 2010**). Many women caregivers find it extremely challenging to care for an elderly relative while also handling other responsibilities such as family, work and household duties, a feeling also shared by women rural areas of Canada (**Crosato & Leipert, 2006**).

Due to women's increased life expectancy, a greater number of women now care for an elderly relative. In Japan, women live approximately 6 years longer than men, and are thus in a position to care for their spouse by default (**WHO, 2011**).

In addition, Japanese women may feel that it is their duty to care for a spouse because Japanese cultural values place an expectation on women to provide care for an ill or ageing husband. Cultural values also influence the decision-making process regarding placement of an elder in a long-term care facility. Japanese female caregivers may also hold a negative view about placing their elderly relatives at long-term care facilities, even when such care is readily available. These beliefs and values place additional burdens on Japanese women, especially on those who cannot or do not wish to provide elder care. In rural Japan, there is a strong belief that women should assume the traditional caring role, and that being a caregiver is natural part of being a woman. Furthermore, the general belief is that caring for elderly parents is way for women to repay them for caring for them as children (**Okuyama, 2005**).

## 7. Nutrition care

As Endevelt et al suggested, providing disabled elderly people with nutritional care has become important in community settings (**Endevelt et al., 2006**). Elderly people who require care are likely to present with appetite loss, lower chewing ability, or protein energy malnutrition (PEM). PEM in elderly people is associated with loss of muscle tissue, impaired

cognitive function, high risk of infection and increased morbidity and mortality. Thus, health care providers should offer their elderly clients tailor-made care services based on their detailed assessment of their nutritional and life conditions.

Dietitians working in the community are the main professionals responsible for counseling the elderly on nutritional issues. In Japan, under the medical and the long-term care insurance system, elderly patients and their family can benefit from home visits by dietitians (Hirakawa et al., 2003). Typical visits include cooking lessons, advice on energy intake, sharing new recipes, and anthropometric examinations. They also include education on ways to cope with an inability to swallow and on artificial nutrition therapy.

## 8. Multidisciplinary care

As stated in the position statement of the Japan Geriatric Society, a multidisciplinary approach to the care of dying patients is preferable. Physicians are expected to develop a broad knowledge and experience in comprehensive care in order to function as key members of the team. In Japan, the public long-term care insurance system has promoted the use of multidisciplinary care conferences (Hara, 2011). Unfortunately, few physicians ever attend these conferences because attendance is not compulsory.

The CGA is a multidimensional, interdisciplinary diagnostic process to determine the medical, psychological and functional capabilities of a frail elderly person that enables the development of a coordinated and integrated plan for treatment and long-term follow up (Ellis et al., 2011). In Japan, CGA is a useful tool for health care providers who offer long-term and palliative care for elderly. The assessment tool is widely used in geriatric care settings including hospitals, long-term care facilities, and the community. Under the scheme of a comprehensive research project for longevity sciences funded by the Ministry of Health, Labor and Welfare, a research team developed a CGA-based tool for discharge support (Hirakawa et al., 2010b).

## 9. Ethical issues

### 9.1 Tube feeding

Percutaneous endoscopic gastrostomy (PEG) tubes have become widely used among elderly patients. PEG tubes are now frequently used in elderly who have diseases or conditions that make it difficult to swallow or eat voluntarily. Though the procedure is fairly routine medically, there are many complex issues surrounding PEG use, particularly for elderly patients near the end of life. Clinical evidence supporting the use of PEG tube feedings in patients with advanced dementia is clearly lacking, yet PEG procedures continue to be performed in a large number of these cases. In Japan, artificial nutrition and hydration (ANH) for severely cognitively impaired elderly is considered standard care. Bito S and Asai A revealed, through an internet survey, that many physicians would initiate tube feeding for an 84-year-old bedridden man with dementia (Bito & Asai, 2007). Aita et al (2007) identified five factors related to the decision to provide ANH through PEG to older Japanese adults with severe cognitive impairment: (1) the national health insurance system that allows elderly patients to become long-term hospital in-patients; (2) legal barriers with regard to limiting treatment, including the risk of prosecution; (3) emotional barriers, especially abhorrence of death by 'starvation'; (4) cultural values that promote family-oriented end-of-life decision making; and (5) reimbursement-related factors involved in the

choice of PEG. There are also a few more factors including the caregiver burden of feeding orally, and the request for early discharge from hospital management.

In conclusion, the framework of Japan's medical-legal system unintentionally provides physicians with incentives to routinely offer ANH for this patient group through PEG tubes. End-of-life education should be imparted to medical providers in Japan to help change the automatic assumption that ANH must systematically be provided.

## 9.2 Decision making

Physicians and family members usually play a critical role in making decisions when the patient lacks decision-making capacity. Japan has developed a unique concept of life and death (**Japan Geriatric Society, 2001; Uemura, 2000**), represented by patients' submissive attitude toward medical professionals and the acceptance of their own circumstances as fate (which probably originates from Buddhist philosophy). Moreover, for fear of losing hope, some elderly patients with severe conditions prefer not to be informed of the deteriorating state of their health. As a result, Japanese physicians and family members therefore need to make decisions on their behalf and are required to develop the ability and insight to judge the will of an elderly who is unable to express his or her own will explicitly. If the wishes of an elderly patient are unclear, both the physician and family are in a very difficult position.

Discussing palliative care options with the elderly and their family in advance may reduce the mental stress of making decisions for the physician and family. A growing number of Japanese people now chose to outline advance directives, especially living wills, although there is no legislation recognizing such legal documents (**Masuda et al., 2003**). However, there are several problems associated with the use of advance directives in Japan. First, as stated in item 2 of the position statement, the will of the elderly patients may change, or the patients may be reluctant to make a decision. Hattori et al also stated in their paper that the will of elderly patients may easily change considering the feelings of others (**Hattori et al., 2005**). Second, Japanese people traditionally dislike discussing death and related issues, which is perceived as taboo (**Okuno et al, 1999**). The Japanese's hesitation to talk about death is exemplified in their avoidance of numbers 4 and 9 which are considered unlucky as they are pronounced the same as the words death and suffering. Also, the Japan Association of Geriatric Care Services Facilities (**2007**) as well as Tsuruwaka and Semba (**2010**) reported that discussing palliative care or life-sustaining treatment options on admission is psychologically difficult for care staff.

Third, the physician's explanations of advance directives have a strong influence on the decision-making of elderly patients and their families. We recently conducted a study to explore the factors affecting decision-making regarding cardiopulmonary resuscitate (CPR) and hospitalize orders at a long-term care hospital (**Hirakawa et al., 2007a**). We observed a wide variation in the likelihood of opting for CPR and hospitalize orders in families who had been given information on advance directives. There is a need for standardized methods for eliciting the end-of-life preferences of residents and families upon their admission to long-term care facilities.

Fourth, although living wills and advance directives are gaining popularity, few people actually want to draw an official document. According to national data (**Ministry of Health, Labour and Welfare., 2004**), less than half of the Japanese population wants to enact a living will or draw advance directives. Other studies suggest that Japanese people do not

want to make a concrete plan of treatment but general instructions concerning end-of-life (Akabayashi et al., 1997; Hirakawa et al., 2006b).

### 9.3 Dementia care

As a byproduct of the aging of the population, Japan has witnessed a dramatic rise in patients with dementia, and it is now important to ascertain how cognitive impairment is associated with acute or palliative care received. Several studies have suggested that patients with dementia often receive poor end-of-life care, with inadequate pain or other symptom control in the other industrialized countries (Morrison et al., 2000; Sampson et al., 2005).

On the other hand, we have observed that Japanese physicians tend to ignore dementia in their patients. For example, we assessed the cases of 123 people aged 65 and older who died at two long-term care hospitals in order to clarify the use of aggressive and palliative treatments, artificial nutrition and sedation (Hirakawa et al., 2004). Also, we observed that dementia itself was not a significant independent predictor of uncontrolled pain or use of end-of-life care in a home setting (Hirakawa et al., 2006a). Our findings indicated that regardless of whether patients suffered from dementia, they received similar acute or palliative treatments in the end-stage.

A greater understanding of the course of dementia is needed to further discussions on the terminal care of people with dementia. A national consensus on how to treat end-stage demented patients is also needed.

### 9.4 Ethical committee and guidelines

In Japan, the need to set up ethical committees has been the focus of public attention at conferences discussing ethical issues (Uemura, 2000). Recently, the realization of the impact of such issues as patient's rights, population aging and development of advanced medical techniques has intensified the relationship between health care providers and elderly patients and their families. In the position statement, it is strongly advised that each institution establish its ethical committee with a third party in attendance and discuss the propriety of its medical practices and care for dying patients (Position 12). Health care providers are now more likely to face important ethical issues surrounding death and palliative care.

However, institutional ethical committees are still not widespread in Japan. Nakao et al (2003) suggested that many nurses would rather discuss ethical issues with the persons directly involved or with complete outsiders to the situation than to consult an ethical committee. A national survey also suggested that there are currently few ethical committees at Japanese hospitals (Hirakawa et al., 2007c).

In long-term care settings, death conferences are becoming an important tool. Reflecting on palliative care for the elderly after their death is important from an educational point of view. Death conferences also trigger a peer support effect among health care providers who have experienced the death of a patient. However, the death conference is not widely and frequently adopted at long-term care facilities. Hayasaka (2010) reported in a small study covering 10 long-term care facilities and 3 hospitals with a palliative care unit, that only 11% of the 200 care staff had participated in a death conference, while 100% of the 40 nurses had.

Palliative care discussions as part of ethical committee consultations or death conferences should be encouraged at hospitals and long-term care facilities.

There are a number of tools for the discussion of ethical issues, such as a contingency table reported in “A practical Approach to Ethical Decisions in Clinical Medicine” (Jonsen et al., 2002). In addition, Higuchi et al (2010) developed a death conference sheet package which was published elsewhere. The conference package includes sheets on the will of elderly patients and families, care support, medical care, and care management, which are considered key factors of high quality palliative care.

Standardization through authorized palliative care guidelines for the elderly can help reduce the stress of facing ethical complications. The Ministry of Health, Labor and Welfare’s “Guidelines for decision-making process for end-of-life care” outlines the following key components: 1) Team approach, 2) Discussion with and confirmation of the will of patients, 3) Discussion between family and health care team (if the will of the patient is unclear) (Shimizu, 2009). Referring to the Ministry guidelines, we developed a decision-making process model for application at long-term care facilities (Hirakawa & Uemura, 2009). With this model (Figure 3), if an elderly resident get suddenly worse and possibly requires hospitalization, facility staff will convene a meeting to confirm the desire to transfer to a hospital. If there is a do-not-hospitalize order, facility staff will reach a decision after discussing the ethical implications of the case. If the resident needs to be provided palliative care at the facility, a palliative care team will be set up and will draw a palliative care plan based on the will of the resident and family. Care staff may also need to reexamine the care plan and make change1s if necessary.

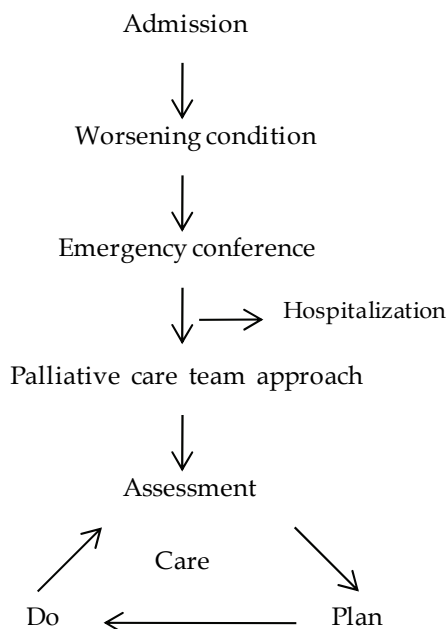


Fig. 3. Palliative care pathway at long term care facilities

## 10. Pain and distress symptom control

Pain and distress symptom management is one of the most important issues in palliative care. For elderly patients with advanced cancer or dementia, there are reliable and authorized guidelines for pharmacological approaches to the relief of pain.

Under-treatment and estimation are two critical issues of palliative care for the elderly. A few studies have suggested that many elderly residents at long-term care facilities feel uncontrolled pain (Krulwich et al, 2000; Morrison et al, 2000). Elderly people are likely to have difficulty communicating their symptoms due to poor hearing or dementia. In addition, Japanese elderly generally do not want to complain about pain or distress symptoms because they think that patience is a virtue.

To improve the situation, the author recently launched a project to develop a communication and symptom assessment tool called the "Nagoya Graphical Symptom Scale for the Elderly" (NGSSE) (Hirakawa & Uemura., 2010). This project was geared toward elderly patients requiring palliative care under the scheme of a research project funded by the Ministry of Health, Labour and Welfare in Japan. The rating scale, which featured symptoms frequently observed among the elderly who require care, was drawn using "manga (cartoons) rather than text or illustrations. Manga is a good communication tool that can be used to convey important information in a humorous and pleasurable fashion across the generations.

## 11. Complementary therapies

Complementary medicine is another approach to palliative care for the elderly. The aged are vulnerable to various chronic medical problems that are difficult to alleviate by relying solely on Western medicine; attention has thus recently increasingly focused on ways to enhance the quality of life of the elderly through complementary and alternative medicine. The Japan Geriatrics Society's position statement emphasizes that geriatric medicine, a discipline that deals with aging and death, should be regarded as holistic medicine that stands on the achievements of the life sciences with particular emphasis on bioethics (Japan Geriatric Society, 2001). Holistic medicine emphasizes the need to look at the whole person, from the combine perspective of physical, nutritional, environmental, emotional, social state as well as spiritual and lifestyle values. Thus, complementary therapies are considered non-pharmacological interventions used to enhance and support the patient's palliative plan of care, that should be integrated to palliative care for the elderly. For example, bathing in a hot spring ("onsen" in Japanese) or taking a bath is often recommended to elderly patients in Japan; as a matter of fact, the benefits balneotherapy have been widely examined in Japan. Also widely available in Japan are music therapy, aroma therapy, electroacupuncture, and thermotherapy.

Other very popular complementary therapies in Japan are acupuncture/moxibustion and massage which have been used since ancient times. These therapies are offered by trained professionals and are partially covered by public medical insurance as an alternative medical service. Home massage rehabilitation therapy by trained professionals is widely available to the bed-ridden elderly as an alternative home rehabilitation service in Japan (Hirakawa et al., 2005a). Although relatively few studies have been conducted on the effect of acupuncture/moxibustion and massage on the frail elderly, a number of papers have

highlighted their positive influence on their well-being, including pain and distress symptom relief (Ferrell-Torry & Click, 1993; Meek SS, 1993; Weinrich & Winrich, 1990).

In Japan, tea is also widely available and popular as a complementary therapy. Scientific research has shown that drinking green tea promotes a healthy metabolism. Because of the health benefits of green tea, it is widely used in elderly care settings. Fujii et al (2004) used green tea as a foot care tool for elderly who require care. Their investigation highlighted the positive effect of green-tea based foot care for patients with BPSD. Fukuoka et al (2009) used green tea as a component for a finger grip bag to reduce the smell of the contracted hand grip of bedridden patients. Hirakawa et al (2010a) used "Persimmon Leaf Tea," which is also widely popular in Japan, as air freshener at a long-term care facility.

Post obitum treatment "Angel Care" and the embalmer' art "Angel Make" are also popular as a complementary therapy. At the terminal stage of life or even after death, paying attention to the appearance of the elderly could contribute to improving the quality of their life and that of their family members. Japanese health care providers often refer to post obitum treatment as "Angel Care", and to the art of the embalming as "Angel Make", which are generally practiced by nurses. The nurses who perform Angel Care or Angel Make have a certain level of formal training and they also benefit from informal training from senior staff.

## 12. Conclusion

This paper aims to examine characteristics observed in palliative care service in Japan. One of them is an ambiguity that Japanese elderly people often show when they express their intensions or demands based on their self-decision. And we show that providing elderly people with tube feeding such as PEG is very much common in care service and also show that elderly people hesitate to complain of pain because they don't want bother others. Though Japan have developed medical care by introducing a number of systems modeled after schemes employed in Western countries, we can not discuss palliative care without considering cultural backgrounds that differ between different countries. Therefore, in this paper we propose that it is important for us to take into account Japanese cultural characteristics to build an original care system for Japanese while reviewing and examining western schemes we have employed.

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