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End-of-Life care in Korea: Issues and trends

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Abstract

The first hospice in Korea was Galbari hospice initiated by the Australian Sisters of 'Little Company of Mary' in 1965. Since then, hospice programs in Korea have been largely based on volunteer activity, and religious or social service. In 2002, the government proclaimed a new policy to foster medically based hospice inpatient service and operated a primary demonstration hospice program from 2003 to 2005 to develop a per diem payment system. The Korean government designated 44 palliative care centers with 725 beds and a budget of 2.3 billion won in 2012. However, despite all the efforts of the private and public sectors, only 9% of terminal cancer patients used hospice service and 29% of the hospice bed demands (2,500 beds required) were satisfied. This article outlines the developing history, government involvement, facts and figures of hospice services in Korea, and discusses the challenges of the future.

Key words

hospice, palliative care, Korea

1. Introduction

A small proportion of patients with terminal diseases spend the majority of health care expenditures but there is evidence of poor health care quality despite the high expenditures (Emanuel 1996, Kim et al 2007, Lo 2002). Hospice palliative care has been suggested as an alternative to reduce medical cost and to improve quality of life in end-of-life care. Hospice palliative care focuses on achieving the best possible quality-of-life for patients and their family caregivers based on patient and family needs and goals (Meier 2011). Hospice palliative care is also associated with significant reductions in per diem costs, and total costs of palliative care are shown to decrease total medical expenses within 6 months of death by 27% in Korea (Jung et al 2012).

Although hospice in Korea was started in the 1960s, the same period in which modern hospice was developed by Dame Cicely Saunders in western countries, hospice has developed very

slowly because of national poverty after the Korean War. However, innovation of hospice in Korea began in the 2000s (Chung et al 2005). This review outlines the history, current status, policy, and challenges of hospice in Korea.

2. History of hospice in Korea

Hospice was first introduced by the sisters of Little Charity of Mary from Australia in 1963 and home hospice through Galbari Hospice in 1965 (Hong 2008). Because Korean society put all its efforts into rebuilding the nation after the Korean War in the 1960s and 1970s, hospice in Korea lay dormant until the 1980s. During the 1980s, hospices were established autogenously by devoted Korean nurses and physicians, sisters of the Catholic Church, and Ministers of the Protestant Church (Chung et al 2005). The first inpatient hospice service with 14 beds was opened in St. Mary's Hospital in 1988; on the other hand,

home hospice services and hospice education were initiated by US educated nursing professors at Severance Hospital and Yonsei University in the mid-1980s (Hong 2008). The 1990s were the era of constructing hospice bodies that called for legislation for hospice service and awareness of social issues in terminal care. The Korean Hospice Association led by Protestants, the Korean Catholic Hospice Association, the Korean Society for Hospice and Palliative Care, and the Korean Hospice and Palliative Nurses Association were established in 1990, 1991, 1998, and 2003, respectively. As the demand for hospice care in Korean society has been rapidly increasing, the government proclaimed a new policy to promote medically based hospice inpatient service and operated a primary demonstration hospice program from 2003 to 2005 (Choi et al 2012). Since hospice palliative care was introduced as a service to promote an increase in the quality of life of terminal cancer patients in the second-term 10-year National Cancer Control Plan in 2005, the Korean government has proposed a per diem payment system for inpatient palliative care, disseminated the standard hospice and palliative care education program, and subsidized delegated hospice programs (Kang et al 2010, Ministry of Health & Welfare 2005). The evolution of hospice in Korea is ongoing.

3. Current hospice services in Korea

3.1 Administration of hospice services

Cancer patients are the primary recipients of hospice services in Korea because palliative care is currently addressed only by the Cancer Control Act. In 2011, more than 72,000 people died from cancer in Korea, accounting for 28.2% of all deaths and making cancer one of the leading causes of death (National Statistical Office 2011). The total medical expenses of cancer were estimated to be \$9.4 billion, which was 1.72% of the gross domestic product in Korea in 2002 (Kim et al 2008). Cancer patients and their

families suffer from complex physical symptoms, emotional distress, and lower quality of life. Thus, care for terminal cancer patients has become one of the major public health issues in Korea.

There are approximately 110 hospice programs in Korea (Korean Society for Hospice and Palliative Care 2012), and the government designated 44 of them as palliative care centers with a total of 725 beds. The designated palliative center should fulfill the standards of infrastructure and composition of the hospice team to provide inpatient hospice services. The Korean Nurses Association defined hospice as 'helping hands to accept death and to relieve suffering' and emphasized the importance of quality of life and loving care from an interdisciplinary team (Korean Nurses Association 2002). The interdisciplinary team is composed of physicians, nurses, social workers, spiritual care providers, and volunteers. Funding for independent hospice programs mainly depends on donations and sponsorship (Yun et al 2002), except for hospital-based hospices. Hospital-based hospices can bill the national health insurance for medical costs, but not for counseling, various life-enhancing programs, or bereavement care. A demonstration project for developing a per diem payment system has been conducted for several years and is in the final stages. Although home hospice is neither officially recognized nor reimbursed by the government, some hospices provide home hospice because they believe death at home is ideal. Home hospice also helps to reduce the length of stay and institutionalized death (Choi et al 2012).

According to a study that analyzed the data from the Korean Terminal Cancer Patient Information System (eVelos system), the mean length of stay in inpatient hospices was 19.6 days (range 10.5 ~ 32.6 days) for each admission, and 73.2% (range 39.8% ~ 92.6%) of first admissions to hospice centers ended in death (Choi et al 2012). Due to considerable variations among hospice programs, the significance of standardization of hospice services was addressed. In another study,

the median duration of survival after enrollment in palliative care was 18 days (Baek et al 2011). This result implies that Korean terminal cancer patients are referred to hospice too late, and a system to promote earlier referrals needs to be established. According to a biannual evaluation of hospice programs conducted by the National Cancer Center, over 80% of patients and families admitted to a hospice center were satisfied with the services provided in 2010, and patients in hospice centers experienced a significant reduction in average pain scores 1 week after admission (Choi et al 2012).

3. 2 Cultural considerations

In Korea, hospice has been related to religious activities and volunteerism for a long time, and most hospices are associated with Christian and Catholic hospitals (Glass et al 2010). Various religions are currently practiced without predominance (Buddhist, 22.8%; Protestant, 18.3%; Roman Catholic, 10.9%; according to 2007 national census) (Kang et al 2012). Nevertheless, the principals and concepts of hospice were imported from Christian countries, especially by US educated nurses and physicians; however, hospice care must be conducted in ways that are sensitive to cultural values and tradition. Korean values include the tradition of respect for ancestors and parents, called 'Hyo (filial piety)', which is a heritage from Confucianism. One example of the cultural characteristics is found in the decision-making process. A significant portion of Korean patients (35.9%) do not desire to have the sole decision-making responsibility. Furthermore, awareness of their prognosis and active participation in the decision-making process were not significantly correlated with their satisfaction or quality of life (Mo et al 2011). Patient autonomy should not be considered absolute in Korea. Korean patients, especially elderly patients, tend to trust their families' or physicians' decisions about treatment, and do not consider family members' substitution as depriving them of their right to

autonomy but rather as a sign of caring. This is a fairly common phenomenon in the Confucian culture that reflects paternalism (Seo et al 2000).

It is considered a family obligation to take care of a dying family member in Korean culture. As we discussed above, Korean patients often leave decision-making to their families, and families tend to prefer more aggressive care because they feel it is their duty to extend the patient's life and to provide every treatment possible. This leads to late referral to the hospice service (Baek et al 2011).

The words 'palliative care' and 'hospice' has been used interchangeably in Korea, although the connotations of the two words differ. Because hospice reminds many of death and dying, many Koreans feel somewhat ambivalent and uncomfortable with the word 'hospice'. To reduce public repulsion toward hospice and to stress the pain and symptom management function of hospice service, the Korean government chose the terminology 'palliative care for the terminal cancer patients' in the Cancer Control Act.

3. 3 Education and qualification for hospice providers

The first formal training for hospice professionals began in 1985 as a continuing nursing education course by the Korean Nurses Association (Ro et al 1996). This was followed by short courses developed at the postgraduate level by several nursing colleges and institutions that varied in duration and content based on their practical needs. However, most of the educational programs were for nurses or volunteers and some were religiously oriented. To meet increasing needs for manpower of hospice professionals, the government developed a 60-hour standard hospice and palliative care education program for all disciplines involved in hospice care in 2005 (Korea National Cancer Center 2006). The standard hospice and palliative care education program in Korea has several characteristics. First, development of this program was initiated by the

government as part of a 10-year National Cancer Control Plan strategy (Kang et al 2010). The government requires completion of this program as the minimal educational requirement for hospice team members. Second, because this was developed as basic education for all disciplines to build up the infrastructure of palliative care in Korea, the need for an advanced education program for each discipline has emerged. Currently, the National Cancer Center in Korea is working on developing a discipline-specified advanced education program and certification system for advanced training. There is currently no formal certification system for palliative care education at this point, except in nursing. There are two levels of education programs for nurses. In 2011, the Korean Hospice and Palliative Nurses Association (KHPNA) began to certify 'General Hospice Palliative Nurse' who completed 130 hours of certified hospice palliative care education for nurses. There have been various levels of hospice nurse education courses offered sporadically for over 10 years. However, those programs have been standardized since KHPNA certification was initiated. 'Hospice Advanced Practice Nurse (APN)' accreditation is offered by the Korean Ministry of Health, Welfare, and Family Affairs (KMHWFA). To be a Hospice APN, a nurse should have at least 3 years of clinical experience and complete a master course in a graduate school. They must also pass the national board exam (Paper Based Test and Clinical Performance Test) run by the Korean Accreditation Board of Nursing (KABON). KABON, which was approved by the government, also defines the scope and practice of Hospice APN and evaluates APN programs. Eleven universities run Hospice APN programs, and approximately 330 Hospice APN have been produced since 2006 (Korean Accreditation Board of Nursing, 2012). Most hospice institutions independently offer 30 hours of hospice education for volunteers.

4. Policy and regulations

Hospice in Korea began as a grass-roots movement that primarily involved religious institutions. They were sporadic until the 1990s when hospice bodies started to be established. By the year 2002, there were 64 hospice services but most of them were not based on medical care (Yun et al 2002). The KMHWFA decided to promote medically based palliative care within the second-term cancer control plan in 2005 (Ministry of Health & Welfare, 2005). The strategies and goals to promote palliative care stated in the Cancer Control Plan 2015 are as follows: 1) supporting and raising palliative care facilities; 2) expansion of palliative care beds and building service delivery systems (goal 2,500 beds for 40,000 patients); 3) expansion of palliative care professionals; 4) widening public relations about hospice and palliative care; 5) developing a hospice reimbursement system through National Health Insurance (Ministry of Health & Welfare, 2005).

The Korean government subsidized approximately 2.3 billion won (2 million USD) to designated palliative care units, and planned to establish regulations and a payment system through an ongoing demonstration project. As a result of these efforts, palliative care units have increased from 15 in 2005 to 44 in 2011, and terminal cancer patients who used palliative care have increased to 9% (Shin et al 2010).

5. Challenges of the future

Although there have been great improvements in hospice in Korea over the last decade, hospice in Korea faces a number of challenges to improve the quality of life of terminal cancer patients.

5.1 Social consensus regarding futile treatment and advanced directives

In Korea, it is common for patients and their families to be reluctant to transfer to a hospice program when their physician recommends doing so. They may think that they will eventually go to

hospice but not yet. This may be because people misperceive hospice as a place for those facing imminent death. This misperception leads to late referral, short length of stay, low usage rate for hospice, and fear of receiving hospice service. Public relations via TV programs, campaigns, and social events should be used to promote a correct perception of hospice in Korea. Public education could help raise understanding and awareness of hospice and might lead to greater acceptance.

Besides educating the public about hospice, support of legal sanctions to withhold or withdraw futile treatment for terminal cancer patients needs to be established. In 2000, 'Natural Death Act' was legislated in Taiwan that allowed withdrawal of futile treatment and a legal basis for hospice (Hong 2005). The death with dignity bill is facing rough going in the National Assembly because there are concerns that this bill could have horrible consequences for patients with chronic diseases such as dementia, mental illness, and unconsciousness. We must therefore establish trusted safeguards against misapplication and should build a social consensus about liable informed decision-making and advanced medical directives, which are being implemented in Singapore and western countries (Heo 2006).

5. 2 Payment system of National Medical Insurance

There is no reimbursement system to cover hospice services in Korea. Therefore much of hospice service remains volunteer work, even though the providers are medical professionals (Kim and Kim 2008). The lack of a reimbursement system makes hospital administrators avoid providing hospice services, and the government is not able to invigilate and control the service quality, which significantly affects vulnerable terminal patients. Various services within hospice are not covered under the current National Medical Insurance system. Therefore, a per diem payment system has been suggested and a demonstration project is still ongoing. Establishing

a payment system will be an important basis for the development of hospice in Korea.

5. 3 Quality evaluation and outcome research

The Korean government has proposed a per diem payment system for inpatient palliative care, regardless of whether patients received high cost medical treatment or not. Therefore, monitoring quality and proving outcomes of the service has become more important. The government has defined the standards of inpatient palliative care services in terms of separate palliative care wards, human resources, equipment, and facilities. However, no evident quality markers have been suggested. One study suggested a survey of bereaved family members to evaluate the feasibility and efficiency of the service, but this study was limited by a low response rate (Shin et al 2011). Another study suggested length of stay and pain score after 1 week of admission as process and outcome indicators (Choi 2012), but it is hard to say that a longer stay implies better service quality and vice versa. Yet another study evaluated a symptom rating system, health-related quality of life (HRQOL), ease of access, and unexpected ER visits (Kim 2011). Considering the poor performance of terminal patients, it is very difficult to conduct a long questionnaire survey to evaluate quality of service. Therefore various measures of service outcome indicators should be developed.

5. 4 Strategies of promoting home hospice

Access to hospice care is a fundamental right for people and is a key component of hospice delivery models. There is an increasing demand for hospice due to increasing deaths from cancer, but there are not enough hospice beds available, especially in certain rural and regional areas in Korea (Korea National Cancer Center 2007). Home hospice could play a key role in improving accessibility to hospice service and promoting advisable utilization of medical resources. Other countries in which hospice service is settled have adopted home hospice as a preferred type

of hospice service in order to reduce the medical costs in hospice care through a home-based model (Kim and Kim 2008, Meier 2011). Aside from the financial benefit, Koreans value dying at home as one of the factors for death with dignity (Yun et al 2004). Therefore, strategies for promoting home hospice are needed.

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