

Review Article

Advances in Hospice and Palliative Care in Japan: A Review Paper

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Over the past decade, hospice and palliative care in Japan have progressed rapidly under the national policies supported by the Cancer Control Act. The numbers of palliative care units/inpatient hospices, hospital palliative care teams, and clinics with a home hospice function have been steadily increasing. The increasing numbers of physicians, nurses, and pharmacists have been certified as specialists in palliative care by national associations. Collaborative efforts have been made to standardize and disseminate educational programs and training opportunities in undergraduate, postgraduate, and continuing medical education. Research activities in Japan have markedly contributed to the growing body of evidence, especially in the fields of terminal delirium, terminal dehydration, palliative sedation, care for dying patients, prognostication, communication, psycho-oncology, and regional palliative care programs. This review focuses on major palliative care settings, specialty, national associations, education, and research in palliative care in Japan.

Key Words: Hospices, Palliative care, Japan

INTRODUCTION

Since the establishment of St. Christopher Hospice in 1967, the past half century has seen unprecedented progress in hospice and palliative care worldwide. Palliative care is a highly-specialized discipline and an interdisciplinary approach focused on relieving suffering and the improving quality of life of patients with life-threatening illnesses and their families throughout the disease trajectory. Supported by national policies, palliative care in Japan has developed essentially in the oncology field. This review summarizes updates from two previous reviews (1,2), and focuses on major palliative care settings, specialty, national associations, education, and research on palliative care in Japan.

HISTORY OF PALLIATIVE CARE IN JAPAN

The first systematic palliative care service was launched at Yodogawa Christian Hospital, Osaka, in 1973. The hospice movement followed in Japan, and led to the establishment of the first palliative care unit (PCU) at Seirei Mikatahara General Hospital, Shizuoka, in 1981. The number of PCUs increased gradually until they became covered by national insurance in 1990, which markedly facilitated the increase of PCUs (Figure 1). After that, national insurance started to cover various palliative care services including home care nursing services in 1992, hospital palliative care teams in 2002, and clinics with a home hospice function and day care hospices in 2006.

With respect to the national policy, the Japanese government has implemented several 10-year strategies over the past

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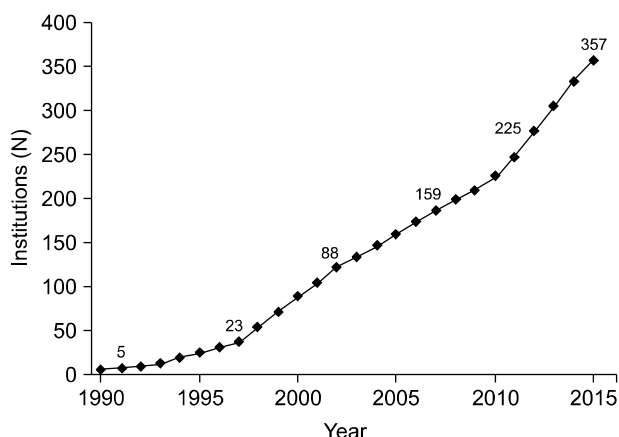


Figure 1. Trends in number of palliative care units.

three decades to tackle cancer, which has been the leading cause of death since 1981. In 2007, the Cancer Control Act was passed. Its basic concepts are: promotion of cancer research and utilization of research outcomes; equalization of cancer medical services; and development of cancer medical services to satisfy patients. Based on this law, the Japanese government developed the Basic Plan to Promote Cancer Control programs, among the focus areas of which was the promotion of palliative care from the time of cancer diagnosis (3). Many educational and research projects were started under the national policy. These included, but were not limited to, physician education (e.g., the Palliative care Emphasis program on symptom management and Assessment for Continuous medical Education: PEACE program); education for general public (e.g., the Orange Balloon Project to provide information to the general public about palliative care); and research (e.g., the Outreach Palliative care Trial of Integrated Regional Model: OPTIM, a mixed-method, complex-intervention study to measure the effects of a regional palliative care program on a variety of patient-, family-, clinician-, and healthcare-related outcomes).

In 2014, the World Health Organization (WHO) published the Global Atlas of Palliative Care at the End of Life, and categorized 20 countries including Japan into “Group 4b” where hospice-palliative care services are at a stage of advanced integration into mainstream service provision (4). In 2015, The Economist Intelligence Unit reported “The 2015 Quality of Death Index” which ranked palliative care across the world by assessing the “availability, affordability and quality of palliative care available” with 20 indicators in five

categories (i.e., “palliative and healthcare environment”, “human resources”, “affordability of care”, “quality of care”, and “community engagement”) (5). The Index ranked Japan the 14th, with 3 other Asian countries positioned in the top 20 countries (Taiwan, 6th; Singapore, 12th; and South Korea, 18th).

MAJOR PALLIATIVE CARE SETTINGS

Japan has three types of specialist-level palliative care settings: palliative care units, hospital palliative care teams, and specialized home-care clinics.

1. Palliative care unit (PCU)

Palliative care units (PCUs), or inpatient hospices, offer intensive symptom control, psychosocial support, and end-of-life (EOL) care for patients with incurable cancer or acquired immune-deficiency syndrome (AIDS) and their families.

PCUs are required to have a sufficient system to provide palliative care, at least one full-time physician who has completed palliative care training, several nurses during night shifts, and sufficient space for patients and their families. They are also obliged to ensure a system of cooperation with community-based medical institutions delivering home care to respond to emergent consultations about patient care from the community 24 hours a day; accept the emergent hospitalization of patients under home care; and coordinate transition to discharge.

As of 2015, 357 PCUs had a total of 7,184 beds (Figure 1). The ratio of PCUs per 1 million inhabitants is comparable to that in Western countries (6). The majority of PCUs belong to general hospitals and provide palliative care by an interdisciplinary team, and some stand as a separate building. PCUs are involved in approximately 10% of all cancer deaths. The average length of stay is 33 days, and the average deceased patient discharge rate (number of deceased patient discharges/number of patients hospitalized) is 84%.

The Japan Hospice and Palliative care Evaluation (J-HOPE) studies, a series of large cross-sectional surveys among bereaved family members, evaluated the quality of care (QOC) and quality of life (QOL) at PCUs by utilizing the Care Evaluation Scale (CES) and Good Death Inventory (GDI), respectively (7-12). The first, second, and third J-HOPE surveys

involved approximately 7,500~10,000 bereaved families from 100~133 PCUs in 2007, 2010, and 2014, respectively. These surveys consistently showed high-level overall satisfaction regarding the processes and outcomes of care received at PCUs. Responses to every survey have been fed back to each PCU for quality improvement.

2. Palliative care team (PCT)

Approximately 75% of all deaths and all cancer deaths occur in hospitals in Japan. However, the quality of care and quality of life of cancer patients who died in hospitals have reportedly been lower than those of patients who died at home or PCUs (13). In addition, the growing body of evidence on the effectiveness of early palliative care urges the early integration of palliative care on the diagnosis of advanced cancer (14-19). Thus, quality palliative care is essential for both hospitalized and ambulatory patients with cancer and other life-threatening illnesses throughout the disease trajectory. Palliative care teams (PCTs) are expected to provide specialist-level palliative care to all cancer patients.

The Cancer Control Act mandates all designated cancer hospitals (N=422) to have PCTs with the following: at least one full-time physician, at least one full-time nurse, and the availability of at least one psychiatrist. This has contributed to an increasing number of PCTs throughout Japan, but their activities vary markedly due to inconsistencies in resource availability.

The Japanese Society for Palliative Medicine (JSPM) registry includes data from a total of 513 palliative care teams (PCTs) (Table 1). The ratio of PCTs per 1 million inhabitants is comparable to that in Western countries (6). The main structures, processes, and outcomes of PCTs are shown in Table 1. PCTs see an average of 142 patients a year: 22%, 24%, 30%, 13%, and 10% of PCTs see 1~50, 51~100, 101~200, 201~300, and more than 300 patients a year, respectively. Of all the referred patients (N=72,879), 96.4% were adult patients with cancer, while 0.6% were children with cancer and 3.0% had diseases other than cancer. The timing of referral of all cancer patients (N=70,257) was from the diagnosis to before the initiation of the first anticancer treatment in 7.0%; during anticancer treatment in 40.9%; and after the discontinuation of anticancer treatment in 52.2%. The highest proportion of non-cancer patients referred

Table 1. Structures, Processes, and Outcomes of Palliative Care Teams in Japan (Registry of the Japanese Society for Palliative Medicine, 2014).

PCT structures	
Number of services	513
Total Number of patients	72,879
Number of patients (/PCT/year)	
Mean	142
Median	106
PCT professionals	
Full-time physicians	225 (43.9%)
Physicians for physical symptoms only	177 (34.5%)
Physicians for psychiatric symptoms only	32 (6.2%)
Both physicians for physical and psychiatric symptoms	16 (3.1%)
Full-time nurses	354 (69.0%)
Full-/part-time pharmacists	183 (35.7%)
Full-/part-time medical social workers	413 (80.5%)
Full-/part-time psychologists	291 (56.7%)
Full-/part-time rehabilitation therapists	353 (68.8%)
Full-/part-time nutritionists	357 (69.6%)
Dentists/dental hygienists	86 (16.8%)
PCT processes	
Patient care ≥ once a week, and availability of direct care on any weekdays	485 (94.5%)
PCT rounds or conferences ≥ once a week	500 (97.5%)
Availability of palliative care outpatient clinic	423 (82.5%)
Reasons for referral (for cancer patients only, N=70,257)	
Pain	41,789 (59.5%)
Other physical symptoms	30,843 (43.9%)
Psychological problems	23,665 (33.7%)
Family care	7,892 (11.2%)
Ethics	1,404 (2.0%)
Coordination	8,212 (11.7%)
Other	7,325 (10.4%)
ECOG Performance status on referral (for cancer patients only, N=70,257)	
0	4,135 (5.9%)
1	12,048 (17.1%)
2	15,945 (22.7%)
3	21,519 (30.6%)
4	16,610 (23.6%)
PCT outcomes (for cancer patients only, N=70,257)	
Discharge	25,604 (36.4%)
Discharge to palliative care units (PCUs)	8,356 (11.9%)
Discharge to other institutions	5,034 (7.2%)
Ending follow-up (alive)	5,849 (8.3%)
Continuing follow-up	4,397 (6.3%)
Death	21,017 (29.9%)

PCT: Palliative Care Team, ECOG: Eastern Cooperative Oncology Group, PCU: Palliative Care Unit.

to PCTs had cardiovascular disorders, followed by pulmonary, neurological, and renal disorders. Pain was the reason for referral in 42.1% of non-cancer patients. In total, 82.5% of PCTs offer outpatient clinics. Although the government strongly proposes “early palliative care” from shortly after the diagnosis of cancer, much remains to be done to implement early palliative care throughout Japan. Currently, only a third of PCTs can receive reimbursement for outpatient care, mainly due to the insufficient number of staff.

3. Home care services and regional palliative care resources

Although 50% of the general public want to die at home and 30% at PCUs, actual rates of death at home and PCUs were 12.8 and 3.1%, respectively, in 2014 (20). Similarly, the rates of death at home and PCUs among cancer patients were 9.9 and 10.6%, respectively. These numbers vary markedly from prefecture to prefecture. The number of clinics with a home hospice function and 24-h visiting nurse stations has increased rapidly over the past decade (Figure 2). Despite this rapid increase, the percentage of home deaths has increased only gradually.

In 2007, a national task force identified the following barriers to quality palliative care: 1) lack of standardized clinical tools; 2) lack of knowledge about palliative care of the general public; 3) lack of whole-region organization to coordinate community palliative care; and 4) availability of specialized palliative care services insufficient in the community (21). To develop a successful model of regional palliative care

suitable for Japan, a government-funded, mixed-methods study was conducted from 2006 to 2011 (OPTIM project) (22,23). The primary aim of this study was to evaluate the effectiveness of a systematic, multi-intervention regional palliative care program in four regions. The interventions were intended to overcome the aforementioned barriers, and included education, specialist support, and networking. A multitude of significant changes were noted after the intervention. These included increased proportions of home deaths, an increased number of patients who received palliative care services as a ration of all patients who died of cancer, and improved patient-reported and family-reported QOC. Qualitative interviews suggested that the improvement of communication between health-care professionals was the key to the improvement of services. Based on these findings, the government is planning to develop a system where designated cancer hospitals, PCUs, clinics, pharmacies, visiting nurse stations, and other regional services collaborate to optimize regional palliative care delivery.

SPECIALTY

There is a serious national shortage of palliative care clinicians. The demand will inevitably grow, as the number of annual deaths has been estimated to increase from 1.2 million in 2014 to 1.6 million in 2025, the number of patients with chronic conditions (e.g., cancer, heart failure, chronic obstructive pulmonary disorder, renal disease, cerebrovascular accident, and dementia) soars, and more hospitals and providers in community settings aim to offer palliative care.

Several national associations offer certification systems for palliative care. The Japanese Society for Palliative Medicine (JSPM) started Board certification of palliative medicine in 2010. For certification, physicians should have at least 2-year training in palliative care-specialized services. They should also have at least one article published in a peer-reviewed journal as the first author, and have completed 20 comprehensive reports of patient cases. Areas of specialties physicians should have been certified for prior to board certification of palliative care have yet to be determined. Physicians have to be re-certified every 5 years. As of 2016, a total of 136 physicians have been certified. This number is much smaller than that of certified hospice and palliative medicine phy-

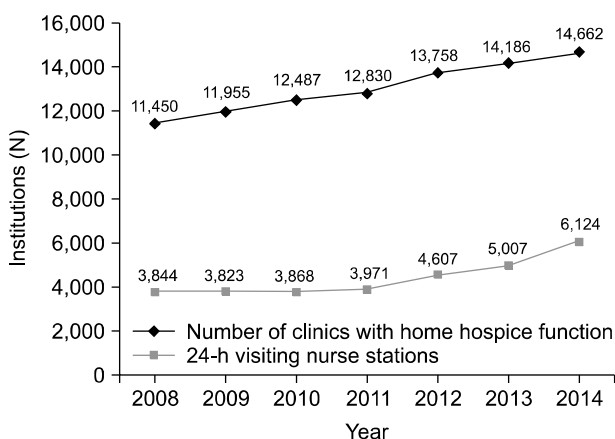


Figure 2. Trends in number of clinics with home hospice function and 24-h visiting nurse stations.

sicians (N=7,351 in 2016) in the USA (24). More palliative care specialists are urgently needed to provide quality palliative care throughout Japan.

The number of certified nurses and pharmacists is also rapidly increasing. As of 2016, the Japanese Nursing Association has certified 656 nurses for cancer nursing, 2,038 palliative care nurses, and 776 cancer pain nurses. The Japanese Society for Pharmaceutical Palliative Care and Sciences has certified 568 palliative care pharmacists.

NATIONAL ASSOCIATIONS

The Japanese Association for Clinical Research on Death and Dying is the oldest association to investigate terminal care for patients and families, being in operation since 1977. In 1991, Hospice and Palliative Care Japan was established as an association of PCUs, and almost all certified PCUs participated. Hospice and Palliative Care Japan has led projects on public awareness of hospice and palliative care; clinician education and training focusing on physicians, nurses, and medical social workers; improvement of quality of care; provision of information regarding availability of hospice and palliative care; national and international collaboration as part of Asia Pacific Hospice and Palliative Care Network; and proposals on future directions to the government.

The JSPM is the largest academic association of palliative care in Japan, with over 12,000 members including more than 5,700 physicians. The JSPM conducts a wide range of activities including the development of various Clinical Practice Guidelines on cancer pain, respiratory, gastrointestinal, and urological symptoms, hydration at EOL, palliative sedation, and complementary and alternative medicine; publication of research papers in its online journal; provision of various educational opportunities; board certification for physicians; and public awareness of palliative care. The JSPM Annual Congress facilitates national and international collaborations every year, and has invited speakers from many countries such as Korea, Taiwan, China, and the United States.

EDUCATION IN PALLIATIVE CARE

1. Undergraduate education

While only 16 of 80 medical schools in Japan have depart-

ments of palliative medicine, almost all medical schools provide palliative care lectures (25). A common syllabus of palliative care has been developed for undergraduate medical education (25). However, contents of actual lectures vary across schools. Nearly 40% of medical schools offer mandatory clinical clerkship on palliative care, whereas others offer elective or no clerkship opportunities.

2. Residency training

Since 2004, the government has required all newly-graduated physicians to undergo clinical training in 2-year residency programs. However, comprehensive bedside training in palliative care is only available upon residents' request in hospitals where palliative care divisions or teams are available. Physicians in postgraduate year (PGY) 2~5 are encouraged to participate in the PEACE program to learn basic concepts and knowledge of primary palliative care.

3. Specialty training

Specialty training in palliative care is provided mainly in 442 facilities certified for specialty training by the JSPM. Structures, processes, and outcomes of training programs remain to be standardized. Unlike in the United States where the Accreditation Council of Graduate Medical Education (ACGME) evaluates the quality of training programs based on standardized criteria, no quality monitoring of palliative care training exists mediated by a third party in Japan. A national survey revealed that physicians in palliative care specialty training had markedly unmet needs regarding training in comprehensive contents, education, and research support, and that they considered increasing the number of comprehensive quality training programs as a potential solution (26). Efforts to standardize the fellowship training curriculum have been undertaken by the JSPM.

4. Continuing medical education

Training for all clinicians taking care of seriously-ill patients is essential to meet the growing demand. Continuing medical education in palliative care is provided via various programs developed by national associations. The PEACE program is among the widely attended projects. It was originally developed by the JSPM in cooperation with the Japanese Psycho-Oncology Society under the national policy in 2008.

This 2-day, interactive education program adopts a trainer-trainee strategy, and provides physicians with basic palliative knowledge focusing on the concept of palliative care, cancer pain, physical and psychological symptoms, and communication skills. As of 2016, more than 3,100 physicians have become trainers, and more than 73,200 have learned from the program.

The JSPM also developed ELNEC-J, a Japanese version of the palliative care and EOL care basic education program, End-of-Life Nursing Education Consortium (ELNEC), which was originally developed in the US for educating nurses (27). Now in 2016, there are more than 1,500 trainers and nearly 5,000 participants in the ELNEC-J program. Similarly, the Japanese Society for Pharmaceutical Palliative Care and Sciences developed palliative care and an EOL care basic education program for pharmacists (Pharmacy Education for Oncology and Palliative care Leading to happy End-of-life: PEOPLE) (28). In 2012, the Ministry of Health, Labour and Welfare started palliative care education program for pediatricians (Care for Life-threatening Illnesses in Childhood: CLIC) (29). CLIC is currently sponsored by the Japanese Society of Pediatric Hematology/Oncology, in association with the JSPM. The JSPM further developed Care for Life-threatening Illnesses in Childhood for palliative care Team (CLIC-T), and provides clinicians in palliative care teams with the concepts of pediatric palliative care, pain management in children, terminal care and bereavement (30).

RESEARCH IN PALLIATIVE CARE

Over the past 15 years, Japanese researchers have successfully developed infrastructure for multicenter observational studies on palliative care and psychosocial issues, and large surveys of physicians and bereaved family members. Many findings were reflected in developing clinical practice guidelines (31,32). Main research areas have included: terminal dehydration (33-37), terminal delirium (38-39), palliative sedation (31,40-43), fatigue/anorexia (44,45), care for dying patients (33,46-50), prognostication (51,52), communication (53,54), psycho-oncology (55-58), and regional palliative care programs (22).

In addition, two research supporting organizations have recently been established: the Japanese Organisation for

Research and Treatment of Cancer (JORTC) (59) and Japan Supportive, Palliative and Psychosocial Oncology Group (J-SUPPORT) (60). These organizations offer intellectual and technical support throughout research projects such as concept building, protocol writing, and mentorship. They are essentially intended to support clinical trials, both exploratory and confirmatory, in palliative and supportive care. In addition, collaboration with the oncology field will be critical to advance clinical trials in palliative care. Various government and private competitive funding opportunities are available for palliative care research.

Notably, international collaborative research projects have recently started in East Asian countries. In 2013~2014, a collaborative cross-cultural study took place in Korea, Taiwan, and Japan, to better understand similarities and differences in physicians' attitudes toward patient autonomy and good death as well as physicians' beliefs in terminal care (61,62). Another example of such collaborative efforts is a successful external validation of a Korean prognostication tool, the Objective Prognostic Score, in a Japanese dataset (63). Future collaboration is promising in East Asian countries.

FUTURE CHALLENGES

Palliative care in Japan has rapidly progressed in clinical, academic, educational, and administrative areas, especially since the Cancer Control Act. However, Japan has many challenges to advancing palliative care further. Clinically, Japan needs to develop a structure for palliative care in the community, and strategies to integrate palliative care not only with oncology earlier in the disease trajectory, but also with non-cancer disciplines such as cardiology, pulmonology, neurology, nephrology, internal medicine, and critical care. With respect to education, the development of standardized, comprehensive specialty training programs for palliative care is urgently required. Academically, national research infrastructure should be refined to enable quality clinical trials in palliative care, supportive care, and psychosocial issues. Furthermore, collaborative efforts should be made to strengthen global research networks to advance culturally-appropriate palliative care. Administratively, evidence-based policy making should be implemented for government-led national projects.

Clearly, we have a long way to go before relieving the

suffering of all patients and their families. However, with the regional, national, and international collaborations, we stand ready to face these challenges.

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요 약

지난 10년 동안 암 관리법에 의한 국가 정책에 따라 일본에서는 호스피스 및 완화의료이 급속히 발전해왔다. 완화의료 시설 및 입원 환자의 호스피스, 병원의 완화 의료팀, 가정 호스피스 기능을 갖춘 진료소의 수는 꾸준히 증가하고 있으며 국가 협회로부터 완화의료 전문가로 공인된 의사, 간호사, 약사의 수도 증가하고 있다. 학부, 대학원 및 계속적인 의학 교육을 통해서 교육 프로그램 및 교육의 기회를 표준화하고 보급하기 위한 공동 노력이 이루어졌다. 일본의 연구 활동은 말기 섬망, 말기 탈수증, 완화적 진정, 임종 환자의 의료, 예후, 의사 소통, 정신 종양학, 지역적인 완화의료 프로그램의 분야에서 현저하게 기여하였다. 이 보고서에서는 일본에서의 주요 완화의료 환경, 특성, 국가 협회, 교육, 완화의료 연구에 초점을 맞추었다.

중심단어: 호스피스, 완화의료, 일본

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