Japan has entered the ‘fifth stage’ of its demographic transition, in which the death rate exceeds the birth rate. We have more deaths than before and the average age at death is also increasing. Hospitals face the challenge of coping with the increasing numbers of people who die in their care. Many people wish to die at home, so palliative care in the community, which is often called ‘primary palliative care’, potentially has a significant role to play. Here, we describe the current status of primary palliative care in Japan and its potential to address this public health issue.

Primary palliative care in Japan

In Japan, no clear organisational boundaries exist between primary and secondary care. Healthcare has a greater focus on hospital care and tends to be categorised according to where the care takes place rather than its function, which makes the position of ‘family medicine’ and ‘primary care’ unclear. Because of this, and for other historical reasons, family medicine has not been recognised as an established specialty, unlike in many other countries. However, to tackle the current challenges in healthcare, the government has announced that family medicine will be a recognised medical specialty from 2017.

Meanwhile, the development of specialist palliative care has gained considerable momentum since the first palliative care unit (PCU) opened in 1973. The numbers of PCUs and palliative care consulting teams have increased dramatically. The government has supported this through the accreditation of PCUs and good medical remuneration rates for those providing palliative care.

However, the focus of palliative care in Japan has been cancer. Medical remuneration for cancer patients in PCUs is more than twice as high as for non-cancer patients. Owing to this tariff difference and to a lack of resources, most PCUs do not take non-cancer patients. For the same reasons, hospital palliative care consulting teams accept only a few non-cancer cases. Not only is most clinical care about cancer, but this is also the case of most palliative care research.

In addition, reflecting the fact that PCUs in Japan are usually hospital wards rather than community-based hospices, palliative care specialists tend to stay in hospitals and not provide services in the community. Organisational barriers and lack of resources prevent them from offering outreach services.

A majority of older people in Japan die from non-cancer conditions. Most of them cannot access specialist palliative care and hence cannot benefit from the support and planning that this would offer.

While specialist palliative care has been concentrated in hospitals, home care has recently been developed as a specialty. Doctors who specialise in home care have wider palliative care knowledge and skills than their counterparts in general medicine or family medicine.

Good deaths for all in Japan: the potential role of primary palliative care

So far, palliative care in Japan has focused on specialist care for cancer patients in hospitals. The country is now faced with the challenge of helping a growing number of older people and non-cancer patients achieve a ‘good death’, explain Ai Oishi and Jun Hamano, both trained family physicians in their country.
Some palliative care specialists have even moved their practice from PCUs to home care and to the community, in order to offer direct care to patients.

However, access to, and availability of, specialist palliative care in the community remain patchy. Most family doctors (either formally trained in family medicine or not) who are actively caring for the dying in the community are left without support from specialists, and without training on how to provide good palliative care.

Focusing on cancer patients in hospitals has led to many achievements, but there is an increasing need for community palliative care, with more focus on non-cancer patients and older people. The 67th World Health Assembly in May 2014 resolved that palliative care should be integrated into all healthcare settings, with an emphasis on primary care and community and home-based care.7

Signs of change

There are signs of an emerging awareness of the need for palliative care outside of hospitals and beyond cancer care. In 2010, a session on palliative care for older people and non-cancer patients was held for the first time at an academic conference of the Japanese Society for Palliative Medicine (JSPM). In recent years, the number of presentations and reports on palliative care for non-cancer patients has been increasing at conferences organised by the JSPM and the Japan Primary Care Association (JPCA).

This increasing interest in palliative care for non-cancer and older patients has led to organisational changes within the JSPM and the JPCA. The JSPM has set itself medium-term action goals for education in palliative care for non-cancer patients and older people. In August 2014, the JPCA created both a palliative care and a home care committee, with the aim of developing palliative care education for family physicians and primary care teams, and of improving the quality of palliative care in the community, respectively.

Since 2008, a nationwide educational programme in palliative care for community and hospital physicians has been deployed via a project called the Palliative Care Emphasis Program on Symptom Management and Assessment for Continuous Medical Education (PEACE).3,4 Although the PEACE project focuses on cancer care, the two-day interactive courses encourage participants to discuss ‘end-of-life care’ in general. By October 2014, the total number of participants had risen above 50,000. The PEACE programme has been highly valued by participating physicians and has contributed to the promotion of palliative care.

In 2010, a consensus syllabus in palliative medicine for medical undergraduates was developed.8 The syllabus innovatively involves the views of patients and families. Unfortunately, there have been no concrete plans so far to integrate it into any medical curricula, which would be a huge step forward for palliative care in medical education.
Increasing public awareness

Interest in end-of-life issues is also increasing among the general public. Preparing for death is becoming more common among middle-aged and older people. This is sometimes playfully referred to as ‘shukatsu’,9 which entails preparing for one’s funeral and sorting out what to do with one’s possessions. The term was coined by a magazine and the movement has been led mainly by publishing companies and funeral directors. It could potentially be the basis for a national discussion around death and dying; however, because it is mostly an industry-led phenomenon, end-of-life healthcare issues are not necessarily addressed adequately.

A recent national survey showed that 70% of Japanese people agreed with the idea of having a living will, but only 3.2% actually had one. The same survey also showed the need for open discussions on end-of-life care and the need to promote what good community palliative care can provide.

In response to these developments, some healthcare professionals, from both primary and palliative care, actively host events to discuss end-of-life issues with the public. Although these activities have not been well documented or investigated, such discussions with the general public can potentially inform a better model of primary palliative care.

The Yamato Clinic

There are some clinics providing palliative care for everyone in the community. One of them is the Yamato Clinic in the Ibaraki prefecture. It is located in a rural area with a population of around 50,000 people, of whom a quarter are aged 65 years and above.

The clinic’s staff comprises four family doctors and five practice nurses who provide home and ambulatory care. All doctors and nurses have had palliative care training (varying from three months to one year). In addition, the clinic has an adjacent home nursing station staffed with ten visiting nurses, which collaborates with other healthcare professionals in the area and provides training for them, as well as for medical students.

The Yamato Clinic is unique in that it is run by four doctors trained in family medicine, whereas the majority of clinics in Japan are run by a single doctor trained in hospital medicine. Clinics with family doctors and with connections to medical schools and other local healthcare organisations will have an important role to play in meeting palliative care needs in the community.

Summary

There are unmet palliative care needs in Japan, particularly in the community. To tackle the challenges, there are emerging movements from the government, academia, clinical organisations and the general public. These are moving forward in parallel towards the goal of achieving better deaths for all in Japan.

Declaration of interest

The authors declare that there is no conflict of interest.

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