Perspective Article

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Do Long-Term Care Insurance Services Help Elderly People who are Living Alone in Japan ?

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Abstract

More than half of the elderly people in Japan want to stay at home to recuperate when they cannot expect to recover from a disease, but the reality is that only 15.7% of them died at home in 2020. Japan is the world's most rapidly aging country. As a consequence of this, the government has reformed elderly policies and encourages mutual aid as well as long-term care insurance services. Nursing small-scale multifunctional in-home care was introduced in 2012 as one of the long-term care insurance services to support people with medical needs, including end-of-life care, while they continue to live at home. However, there remains a shortage of service personnel. With the increase in the number of people living alone and changing roles based on blood ties or neighborhood relationships, the Japanese government should take responsibility to support mutual aid, and the local governments need to develop both formal and informal services in line with regional characteristics.

Keywords: End-of-life care, home death, nursing small-scale multifunctional in-home care (NSMH), community-based integrated care system

Dissociation between reality and end-of-life hopes among Japanese people

Although 51.0% of Japanese people wanted to remain at home until the end of life when they did not expect to recover from illnesses such as cancer, heart disease, and senility in 2013[1], the actual mortality rate at home was around 15.7% in 2020[2]. The issue of where to die is an extension of the issues of where to obtain medical care and long-term care.

Japan has the world's most rapidly aging population. In 2019, 28.4% of the population (35.8 million of the total 126.2 million population) was aged 65 and over, with 14.7% (18.5 million) aged 75 and over[3]. Aging is progressing in households as well. In 2018, 48.9% of households included people aged 65 and over; 27.4% of them consisted of single households, and 32.3% consisted only of elderly couples[4]. As of 2015, the annual death toll in Japan was approximately 1.3 million[5]. By 2040, about 1.7 million people who were born between 1947 and 1949 will reach their end-of-life period[5] (Figure 1). However, 58.7% of the main care givers were family members living together[6]. Elderly care in Japan is generally carried out by the elderly spouse and their children who are also older. For example, children in their 50s are caring for parents in their 80s, and thus it is difficult for families to take care of the elderly at home.

Policies and long-term care insurance system for the elderly in Japan

The Japanese government has reformed elderly policies to respond to the needs of this aging population. The purpose of Regional Medical Care Visions is to build a medical care provision system that can respond to changes in medical needs due to the aging population[7]. Prefectures are estimating the medical demand and number of beds required for 2025 for each concept area in the discussion of future directions[7]. Also, a community-based care system has been advocated since 2013 by the Ministry of Health, Labour and Welfare[8]. The system has four proposed elements: self-help (Ji-jo), mutual aid (Go-jo), social solidarity care (Kyo-jo), and government care (Ko-jo) in housing, healthcare, long-term care, prevention, and life support in the daily living area[8]. Any discussion regarding the place of death is influenced by the content of the Regional Medical Care Visions and the community-based integrated care system in Japan[7,8].

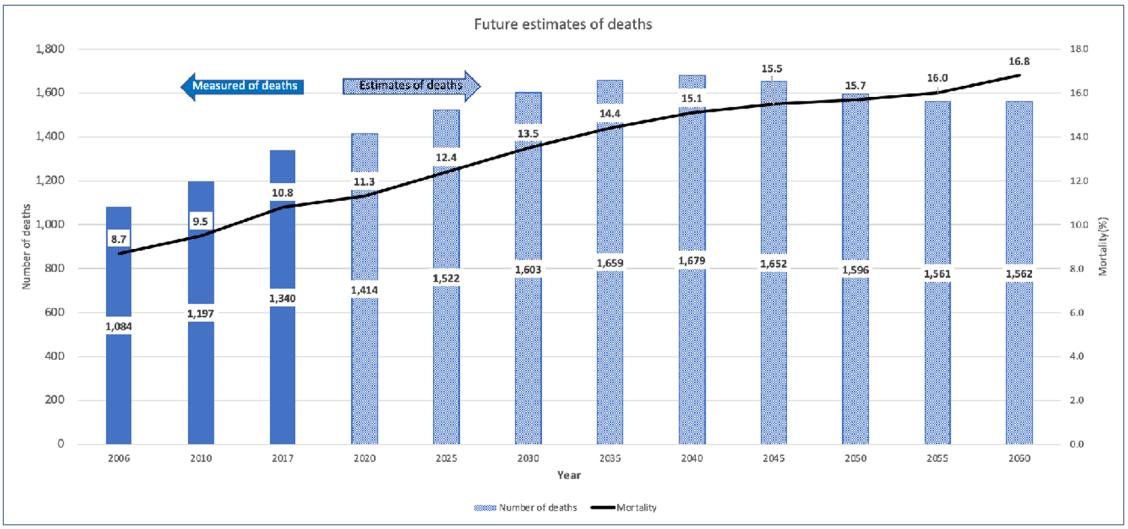

Figure 1 Future estimates of the number of deaths in Japan. The peak in the annual death toll is estimated to occur in 2040 and is expected to be about 1.7 million. Source: Data was modified from Figure 1-1-3, Cabinet Office of Japan, Annual Report on the Aging Society [Summary] FY2020. p.5

To address long - term care, the government introduced the long-term care insurance system in 2000, and it is expected that long-term care including end-of-life care will be shared by society instead of by the family. The services are provided both in the recipient's home and in facilities by welfare or medical professionals such as care workers, nurses, and rehabilitation professionals. Half of the financial resources to support this system come from taxes, and the other half come from insurance premiums paid by people over 40 years old. The individuals using the service pay 10% to 30%, with the rest paid from taxes and insurance fees[9,10]. People over 65 years old or 40 years old with designated diseases can use the service by application and certification following examination[9,10]. In 2020, 18.4% of people were aged over 65 years[11].

The proportion of long-term care insurance costs among social security costs has been increasing (14.4% in 2000 vs. 21.8% in 2018), while that of pensions has decreased (51.7% in 2000 vs. 45.5% in 2018) and medical expenses have not changed (33.9% in 2000 vs. 32.7% in 2018)[12]. The proportion of social security costs in the overall GDP of Japan has been estimated to rise to about 24% in 2040. This is not much higher than those of Germany, France, and Sweden, which are estimated to be about 25%, and the rates of aging in the aforementioned countries are lower than in Japan[12].

The long-term care insurance system is operated under national law, and the local government provides short - term planning concerning the efficient implementation of the system considering the characteristic of the region[13]. More than 95% of services, however, are provided by private business[14], so service provision is based on market principles. Business owners are not obligated to follow government plans.

With the changes occurring in social support in the last two decades, the mortality rate in hospitals peaked at 82.4% in 2005 and gradually declined to 69.9% in 2020[2]. During the same period, mortality at long-term care facilities increased from 2.1% to 9.2%[2], suggesting that these facilities are becoming a substitute location for death. In 2012, nursing small-scale multifunctional in-home care (NSMH) was introduced as one of the long - term care insurance services to support the elderly who require medical care or end-of-life care at home[15]. However, even with NSMH, challenges remain in supporting the elderly at home. In this article, we discuss the remaining issues of the long-term care insurance system regarding end-of-life care to fulfill the wishes of those who want to stay at home until the end of their lives and review the case of an elderly woman who spent the end of her life at home.

Advantages and remaining problems of NSMH for end-of-life care at home

For the elderly with chronic diseases or disability to continue to live in their familiar community to the end of life, home-visiting services that provide professional nursing support are essential, as is professional medical support by medical doctors. Home-visiting nurses are expected to manage daily medications, disease prevention, rehabilitation, and coordination of medical and long-term care professionals[16], and they support the people who provide care for the patients in addition to the patients themselves. NSMH supports people with needs such as transitional care from hospital to home, continuous living at home during the end-of-life period or an unstable medical condition, and respite care or burden reduction for family members who support a patient[16,17]. NSMH provides in-facility services such as daytime or overnight care and visiting care services by both welfare workers and medical staff such as care workers and nurses[16,17]. The services are easily changed based on the conditions of the recipient or family because the user fee is fixed. A care manager, who belongs to the NSMH facility and manages service content, can arrange service contents flexibly. For the elderly to realize their end of life at home, NSMH is the most fulfilling service among the current long-term care services, but some problems remain.

A woman who used the NSMH and reached her end of life at home

One NSMH facility supported a 98-year-old woman who had a strong wish to live at home until the end of her life. Although she lived by herself, she was being supported by her granddaughter and son-in-law living nearby. She had been suffering from breathing difficulties for two months following a pacemaker reinsertion until she died. Her SpO_2 was around 90% at rest and around 70% after activity over the last week before her death. As her condition gradually worsened, she removed the oxygen mask by herself and in a state of low awareness, she repeated "help me". Because she wished for someone to stay close by, she stayed at the NSMH when her granddaughter needed to rest. However, about 36 hours before she was expected to

die, the care manager decided this was the time to give terminal care and proposed that her granddaughter and son-in-law take care of her at home using sedatives until the end came. After that, nurses and care givers from NSMH and doctors and nurses from a home clinic visited her home to monitor her and provided care several times from morning to evening for 30 minutes to 1 hour per visit, and finally, her granddaughter cared for her until she died.

Lessons learned and challenges for future social support

The NSMH provided maximum support to realize the woman's death at home under the long-term care insurance system, but two main issues were revealed. First, there remains a shortage of personnel to monitor terminal patients at home 24 hours a day even when using NSMH because NSMH is designed to provide care and not to monitor patients. Second, whether a patient can even use long-term care insurance services depends on where the patient lives. The woman mentioned above was just lucky to be able to use the services of NSMH, which was located in her residential area and had a vacancy. The Japanese government intended local governments to develop a variety of services including long-term insurance services depending on their regional characteristics as defined by the Community-Based Integrated Care System[8], so its services are different from area to area. Regarding NSMH, there were only 644 locations in 2020[18], and they are not present in all 1718 municipalities[19]. One of the reasons for the poor increase in NSMH facilities is that it costs more for basic facilities than for home-visiting nursing offices or day service centers[20]. Another possibility is that the patients may not use the services when needed because the number of users of the day-time NSMH service ranges from 15 to 18, and that of the overnight service is fixed at up to 9 users, with the maximum number of users registered limited to 2915.

The roles based on blood or territorial relations that used to be present in Japan are changing, and fewer elderly people are able to receive informal support. The woman mentioned above is a typical case of the future Japan in that she lived by herself and received support from a small number of relatives. The long-term care insurance service has helped such elderly people, but these formal services are not enough. The Japanese government is trying to curb the proportion of long-term care insurance costs in overall social security costs, and it encourages volunteers to promote community gathering places called "Kayoinoba", which were reported to suppress the risk of functional decline, in their own areas[21,22]. However, only 26.0% of Japanese are dedicated volunteers[23] . For people to continue to live at home until their end, both formal services and informal services are necessary. The Japanese government should take responsibility to support mutual aid (Go-jo)[24], and the local governments need to develop both formal and informal services in line with their regional characteristics.

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JS and MT mainly worked for drafting the work and revising it critically for important intellectual content. KT mainly worked for final approval of the version to be published. All authors read and approved the manuscript prior to submission for publication.

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Conflicts of Interest

KT reports personal fees from Novartis Pharma, Japan, as a lecture reward, outside of the submitted work. JS and MT have no conflicts of interest to disclose.

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