Original Article

Japanese People's Preference for Place of End-of-Life Care and Death: A Population-Based Nationwide Survey

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Abstract

Context. Japanese people's preferred place of end-of-life care may be affected by their experiences, perceptions, and knowledge related to the end of life.

Objectives. The aims of this study were to clarify the Japanese population's preferences for the place of end-of-life care and death and to identify the determinants of each choice of preferred place of end-of-life care within their experiences, perceptions, and knowledge.

Methods. A total of 2000 Japanese people aged 40–79 years participated in a cross-sectional nationwide survey.

Results. Fifty-five percent ($n = 1042$) responded. Regarding place of end-of-life care, approximately 44% of the general population preferred home, 15% preferred hospital, 19% preferred palliative care unit, 10% preferred public nursing home, 2% preferred private nursing home, and the remaining 11% was unsure. Multinomial logistic regression analysis revealed that the following factors affect people's preferences regarding place of care: 1) experiences, such as "visiting hospital regularly" and "experiencing home death of relatives," 2) perceptions, such as "giving due thought to their own death on a daily basis" and "perceiving lower home palliative care costs to be appropriate after comparing hospital admission fees," and 3) knowledge of "home care nursing" and "24-hour home palliative system by physicians and nurses using insurance." These factors correlated with preference for hospital, palliative care unit, or public nursing home, when compared with the preference of home.

Conclusion. The present findings may help to develop an effective end-of-life care system in Japan, in line with people's various preferred locations for such care. J Pain Symptom Manage 2011;42:882–892. *Crown Copyright © 2011 Published by Elsevier Inc. on behalf of U.S. Cancer Pain Relief Committee. All rights reserved.*

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Accepted for publication: February 22, 2011.

0885-3924/$ - see front matter
doi:10.1016/j.jpainsymman.2011.02.024

Key Words
End-of-life care, preference, place of death, place of care, Japan

Introduction

Global mortality rates are expected to rise rapidly, with a dramatic shift to older ages and chronic diseases.[1] Based on this world population shift, aging nations have growing needs for end-of-life care.[2] Japan, in particular, has demographically become the oldest country in the world since 2004 (19.5% at age 65+ in 2004), and this fast-aging trend is estimated to continue in the future (39.6% at age 65+ by 2050).[3]

The Japanese Ministry of Health, Labor and Welfare has supported institutional palliative care services, which have been covered by National Medical Insurance since 1991. Accordingly, the number of palliative care units (PCUs) increased from five in 1991 to 222 in 2010. To be approved as a PCU, institutions must fulfill requirements regarding staff numbers, facilities, and equipment. Most PCUs belong to general hospitals and have interdisciplinary teams, including physicians, nurses, and other specialists. The PCU has become the most commonly available palliative care service in Japan. PCUs with religious associations are sometimes called "hospices," but both PCUs and hospices aim to provide symptom control and end-of-life care mainly for cancer patients and their families.[4] By comparison, the growth of home palliative care services in Japan still lags behind that in Western countries.[5] However, the trends in the aging of the Japanese population dictate that more end-of-life care must be provided at home. As home-based palliative care teams were not covered by Japanese National Medical Insurance until recently, the government started to provide assistance in 2006 for specialized home palliative care support clinics. These clinics are expected to offer home palliative care for terminally ill patients provided by community physicians and nurses on a 24-hour basis. The clinics can obtain additional remuneration when patients die at home.[6]

The Japanese government also established the Cancer Control Act in 2007, which states the necessity of promoting qualified home palliative care and increasing the home death rate among terminally ill patients (40% in 2012). However, the home death rate has remained around 15%, and more than 80% of terminal patients die in general hospital wards.[7]

Interestingly, a recent report from Taiwan pointed out that the overuse of supply-sensitive services, such as aggressive care in hospital at the end of life, may result from the characteristics of universal insurance coverage, almost unlimited comprehensive services, and pay-for-service reimbursement rules, and this may be a more obvious problem for hospitals with abundant health care resources.[8] In Japan, there is a similar system, such as free access to hospitals by patients without any referral system and a fee-for-service payment system.[9] Besides, the number of inpatient beds per population in Japan is the highest among Organisation for Economic Co-operation and Development countries.[10] Because these systems may be a barrier to promoting home care services in Japan, it is essential to explore Japanese people's perceptions of appropriate health care services related to end-of-life care, including cost and the general public's knowledge of available home care services, which have been suggested to influence preferences for place of care and death.[11–13] Furthermore, their preferences could be influenced by the experiences of service uses and the type of disease with or without troublesome symptoms.[14]

As for the global perspective, despite aggressive efforts to facilitate and encourage death at home in developed countries during the past two decades, most people die in the hospital,[2,14,15] and a persistent fall in the proportion of people who die at home has been reported.[16] Especially in the U.K., the falling home death rate has continued despite the increased number of community palliative care services.[12] This led the World Health Organization to develop international recommendations on planning end-of-life care, which should be responsive to patient choice for place of care and death.[17–19] Recent studies suggest that, for this choice to be meaningful, home, hospice, hospital, and nursing home should be among the options.[12–14,20]