



End-of-life preferences of the general public: Results from a Japanese national survey

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ABSTRACT

Purpose: To determine under different End-of-Life (EoL) scenarios the preferences of the general public for EoL care setting and Life-sustaining-Treatments (LST), and to develop a new framework to assess these preferences.

Method: Using a 2-stage, geographical cluster sampling method, we conducted a postal survey across Japan of 2000 adults, aged 20+. Four EoL scenarios were used: cancer, cardiac failure, dementia and persistent vegetative state (PVS).

Results: We received 969 valid responses (response rate 48.5%). Preference for EoL care setting varied by illness with those wishing to spend EoL at home only 39% for cancer, 22% for cardiac failure, and 10–11% for dementia and PVS. Preference for LST differed by scenario and treatment type. In cancer, cardiac failure and dementia, about half to two thirds expressed a preference for antibiotics and fluid drip infusion but few for nasogastric (NG) tube feeding, percutaneous endoscopic gastrostomy (PEG), ventilation or cardiopulmonary resuscitation (CPR). Although our models accounted for only 3–9% of the variance, preferences to receive LST were associated with preference to spend EoL in hospital for cancer and cardiac failure but not dementia.

Conclusions: Few people preferred to die at home, while a preference for hospital was largely determined by factors other than preference for LST.

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1. Introduction

The questions of *where* the public wish to spend End-of-Life (EoL) and *what* they wish to receive by way of Life-Sustaining-Treatments (LSTs) at EoL have not been addressed sufficiently by researchers but have become a major policy concern in many countries [1–3]. A recent

review by Gomes et al. identified significant heterogeneity among the published studies, reporting that of the high quality studies they identified, the percentage of people who preferred EoL care at home ranged from 5% to 100% [4]. Most studies in this area examined the views and preferences of small patient populations or caregivers [4,5], usually of palliative care cancer patients. There are few peer-reviewed general public surveys, and of those that do exist, most have been conducted by those who work in palliative care. These surveys, reflecting the concerns of such researchers, focus explicitly on cancer EoL scenarios [6–8]. Of those that purport to examine general EoL care preferences rather than cancer-specific EoL care

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preferences, many offer a hospice or palliative care unit as an EoL care setting, suggesting cancer to the lay respondent [9–11]. Others provide no description of the EoL scenario at all to the respondent [12] or only a brief general description that focuses on pain, sickness or physical deterioration with no mention of cognitive function, suggesting a cancer or organ failure EoL illness rather than the increasingly common dementia EoL scenario [13–15]. We could find no peer-reviewed study that rigorously investigates the preferences of the general public for EoL care setting under different EoL scenarios, nor could we find a study that rigorously investigates the preferences of the general public for LSTs at EoL. Yet despite the general lack of published evidence on the preferences of the general public for EoL care in scenarios other than terminal cancer, there has been an assumption in health policy circles that EoL at home with minimal invasive LSTs is their preferred option [1,3,16].

Government-funded national surveys in Japan have shown that EoL preferences differ according to scenario [16]. However, the 4th National Survey had problems in the setting of the scenarios and in how the various LST options were presented. These limitations were recognized in a report by the 4th National Survey on End of Life Health Care Committee, which called for the development of an improved survey tool for the 5th National Survey [19]. Our study was funded for conducting a pilot study for the 5th National Survey. Our mandate was to incorporate new perspectives based on the literature and expert opinion, but to allow basic comparisons with past studies.

Following our pilot, the 5th National Survey was conducted in 2013 and published last year [20]. Due to reasons of data protection formalities, the data from this National Survey will not be available for analysis for 2 years from publication, which is why our analysis is limited to the data from our pilot study. Parenthetically, the 5th National Survey questionnaire and methodology were very similar to our study, and direct comparison of the raw data shows that our pilot data and the 5th National Survey data are consistent.

Our objective was to provide a generic framework for examining preferences for the site of EoL care and for types of LST according to discrete scenarios. However, apart from differences in social and cultural values, the following factors should be taken into consideration when interpreting our results. First, Japan has universal health coverage so that out-of-pocket costs are not a major concern in accessing hospital care: Although a proportion of the health care costs billed by providers must be paid by the individual as co-payment, the rate is reduced to 1% when it exceeds the ceilings set according to income levels, effectively providing catastrophic coverage [17]. Second, Japan also has public long-term care insurance that has made costs affordable to all care home residents [17]. As a result, financial concerns are not a major driver of EoL care preferences.

2. Methods

2.1. Subjects

The population examined by this survey was all individuals in Japan on the Basic Residents Register, aged 20+

years old on 1st October 2011. We used a 2-step geographical cluster sampling method. Japan is divided into 1897 municipalities, and municipalities are each subdivided into several hundred 'national census enumeration districts,' giving a total of 1,010,340 districts across Japan. In the first step of our sampling method, 100 districts were randomly extracted from the total of 1,010,340 districts, after stratification for region and urbanization. In the second step, for each district selected, 20 subjects were extracted from the Basic Residents Register held by the district's municipality using a simple random sampling method. In total, our sample consisted of 2000 adults. The sampling period ran from 8th September 2011 to 14th October 2011.

The survey was undertaken as a postal survey, with questionnaire packs posted on 19th October 2011. As well as the questionnaire, the packs sent out by post also included explanatory letters from our department and from the MHLW, and stamped, addressed envelopes for the questionnaire return. Reminders (which would be words of gratitude for those who had responded) were sent on 31st October 2011. The closing date for returns was 16th January 2012. Returns were low for 20–39 year old age group so additional questionnaires for this 20–39 year old age group were sent 18th November 2011.

2.2. Ethics approval

The study design and survey were approved by the Keio University School of Medicine Ethics committee, registration number 2011-180.

2.3. Questionnaire

In line with the pilot brief of our funding body, the survey instrument used in the previous 4th National Survey's on End of Life Care was used as a starting point as we were constrained by the need for the 5th National Survey to be comparable to previous surveys. We conducted a systematic literature search of both the English and Japanese evidence base using respectively PubMed and Igaku Chuo Zasshi, identifying 57 relevant articles. Further articles of interest including some not published in the peer-reviewed literature were identified by examination of the references of notable articles and by contacting experts. The questionnaire was developed by a survey instrument development group, supervised by an expert panel including a legal expert, emergency medicine and palliative care specialists.

The 4th National Survey on End of Life care had used 3 scenarios investigating EoL care preferences. At the request of the MHLW, in order to be able to make comparisons with the past National Surveys, we retained the cancer and PVS scenarios. However, we divided the cerebrovascular disease or dementia 'frailty' scenario into 2 new scenarios: end-stage cardiac failure and end-stage dementia. This was based on a conceptual framework suggested by Coppola [21] to examine contrasts between physical impairment and cognitive impairment. Further, we retained but expanded the LSTs, and changed the focus from treatment discontinuation to treatment initiation. Please refer to the Appendix for a translation of all the relevant survey questions.

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