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Keio University

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Thesis Title

End-of-life preferences of the general public: Results from a Japanese national survey
(終末期医療に対する一般国民の選好についての全国調査)

Thesis Summary

The thesis was a piece of primary quantitative research whose purpose was 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. To do this, we used a 2-stage, geographical cluster sampling method, to conduct a postal survey across Japan of 2000 adults, aged 20 or more. Four EoL scenarios were used: cancer, cardiac failure, dementia and persistent vegetative state (PVS).

We received 969 valid responses (response rate 48.5%). Preference for EoL care setting varied by illness with only a minority of respondents in each scenario preferred to spend EoL at home: 39% in the cancer scenario, 22% in the cardiac failure scenario, and 10-11% in the dementia and PVS scenarios. In 3 of the 4 scenarios half or more of respondents preferred to spend EoL in hospital: 50% in the cancer scenario, 53% in the cardiac failure scenario and 78% in the PVS scenario compared to 34% in the dementia scenario. In contrast, in the dementia scenario, a care home was the preferred place of EoL care with 55% of respondents expressing a preference for this. Preferred EoL care setting differed significantly by scenario when tested with McNemar`s test at $p<0.05$ level.

Preference for LST differed by both scenario and treatment type. LST preference differed by scenario for antibiotics, fluid drip infusion, total parenteral nutrition and CPR, with preference for treatment being most common in cancer and cardiac failure, less common in dementia, and least common for PVS. In contrast, preference for NG tube, PEG and ventilation did not differ significantly by scenario. LST preference also differed by treatment type. In the cancer, cardiac failure and dementia scenarios, about half to two thirds expressed a preference for antibiotics (49-67%) and fluid drip infusion (44-61%), but few for NG tube feeding, PEG, ventilation or CPR (7-19%).

Bivariate analysis found no interaction between preferred EoL care setting and LST preference at EoL. Our multivariate models accounted for only 3-9% of the variance, but preferences to receive LST were associated with preference to spend EoL in hospital for cancer and cardiac failure but not

dementia.

On multivariate analysis, age and income were associated with preference to receive LST at EoL, and sex, age and income were associated with preferred EoL care setting.

We drew 4 conclusions from this research:

1. Contrary to the assumption seen in health policy circles that the public want to die in their homes and do not want LSTs, we found that the proportion of the public who wish to spend EoL at home across all scenarios is low and public preferences regarding LSTs are more nuanced: although few wish to receive nasogastric tube, PEG, ventilation and CPR, for cancer, cardiac failure and dementia, half to two thirds wish to receive LST such as fluid drip infusion and antibiotics at EoL.

2. We found that where people prefer to spend EoL and what LST they want is strongly influenced by EoL scenario. Studies that attempt to draw conclusions about EoL care preference without reference to EoL scenario or that just focus on one scenario may result in misleading conclusions. We called for future studies of EoL care preference to take into account the fact that preferences differ according to EoL scenario.

3. Our analysis of demographic factors in the cancer, heart failure and dementia scenarios revealed some contradictions: that older people wish to be in hospital but not to receive LST at EoL, whereas younger people prefer not to be in hospital, but prefer to receive LST. Similarly, for cancer and dementia, those from households with lower income prefer to be in hospital but not to receive LST, and those from households with higher income prefer not to be in hospital, but prefer to receive LST. Our results are consistent with those of other studies suggesting these contradictions are not unique to Japan.

4. Among those who do not express a preference to receive LST at EoL, almost half in cancer and cardiac failure and almost a third in dementia would still prefer to spend EoL in hospital. Although multivariate analysis did show that there is an association between preference to spend EoL in hospital, and preference to receive LST at EoL for cancer and cardiac failure the multivariate models only explained a very small proportion of the variance in EoL care setting preference. Our results suggest preference to spend EoL in hospital is largely determined by factors other than LST preferences.