Readiness for Decision Making towards End-of-Life Care among Unmarried or Divorced Middle-aged and Elderly Men in Japan

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Abstract

BACKGROUND: Previous research has found that 70% of patients are unable to express their end-of-life (EOL) preferences. Hospitals in Japan often ask the patient's family members to guess and express the patient's will and take decisions on his/her behalf, but never-married and divorced men often have no relatives to fulfill such functions. METHODS: An internet survey was conducted on February 14-24, 2020. The sample size was 3,224 and it was balanced among 3 layers: gender, age (50s, 60s, 70s+), and marital status (never-married, divorced, widowed, married). The sample included 471 never-married men and 472 divorced men. RESULTS: Overall, it was found that 3.1% had no support in the event of hospitalization. Among all participants, the never-married or divorced men had little contact with relatives, few friends, and little communication with their neighbors; 20% of them had no one to support them when hospitalized. Sixty percent of all participants never discussed their advanced care planning (ACP) with their families or friends, and this number was around 84% among nevermarried or divorced men. Among all participants, 11.7% had written an "ending note" to communicate their will regarding end-of-life and after-death decisions. This number was much lower for never-married men at 3.6%. CONCLUSIONS: As never-married and divorced men have little chance to share their thoughts with others, they are more likely to have difficulties in making and communicating EOL decisions. The number of never-married elderly men is increasing rapidly, and a solution to help them express their EOL decisions is needed.

Keywords: Loneliness, Family, Advance Care Planning, Advance Directives, Dementia, Hospitalization

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Introduction

Previous research¹ has found that 70% of patients cannot express their will at the end of their life. "Final years of life" may vary as per the life expectancy in each country. I focused on the peak age range for the occurrence of death. For Japanese men, the number of deaths at ages 85–89 is 133000, which is 19% of the total deaths. This percentage is higher than that in any other 5-year-age group. By the same calculation, the most common age range at death for men is 80–84 in Singapore, 75–79 in Korea, 70–74 in Indonesia, and 65–69 in Thailand (Figure 1).

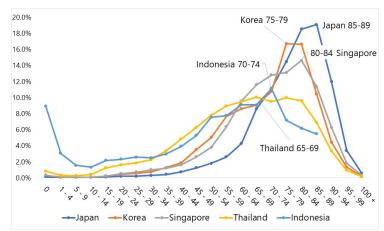


Figure 1: Most Common Ages at Death for Males in Asian Countries²

As the most common age at death is 85–89 years for men in Japan, the last decade of life is estimated to be between 75 and 84 years. In total, 11.6% of men between 75 and 79 and 23.0% of men between 80 and 84 were certified for long-term care by the long-term care insurance committee(Kaigo-nintei-shinsakai) (Figure 2). Approximately 2.7% of men between 75 and 79 and 3.8% of men between 80 and 84 were hospitalized on the date of the survey (MHLW 2020). As the average length of hospital stay was 19 days among patients aged 60 and over (JILI 2019), the majority of men aged 75–84 years are likely to be hospitalized more than once in the last decade of their life.

¹ Ministry of Health, Welfare, and Labor of Japan Advance care planning (Jinsei-kaigi) promotion. Retrieved from: https://www.mhlw.go.jp/stf/newpage 02783.html (2021, March 7)

² UN Demographic Yearbook 2019 (Table 19). Deaths by age, sex, and age-specific death rates by sex: latest available year, 2010–2019.

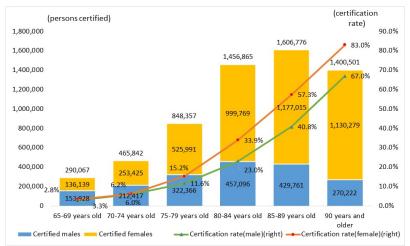


Figure 2: Number of People Certified for Long-term Care and Certification Rate³

Hospitals in Japan often demand that patients' family members come and guess the will of the patient and speak for him/her. Even if the patient is not living with dementia and can express his/her own will, most of the hospitals demand the patient's family or relatives, which is often the patient's spouse or children, to come to the hospital to make and communicate the necessary decisions on behalf of the patient. However, never-married and divorced men often have no relatives who are willing to fulfill such functions.

It was found that among men aged 75–84, 2.7% were never-married and 3.0% were divorced. This number is higher than that in Korea or Indonesia, but not as high as in the U.S. or European countries (Figure 3).

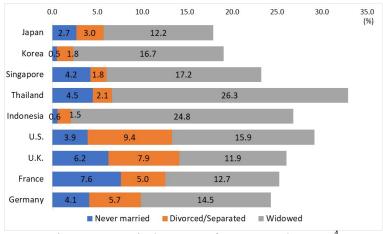


Figure 3: Marital Status of Men Aged 75–84⁴

Never-married or divorced old men had been a minority in Japan until the 2010s. However, their population is expected to increase rapidly. Sixteen percent of men aged 70 and over are estimated to be never-married or divorced by 2040 (Figure 4). The number of never-married or divorced men aged 70 and over is estimated to be approximately 2 million by 2040 (Figure 5).

³ Cabinet Office of Japan, Gender Equality Bureau (2018) White Paper on Gender Equality 2018, p. 15 Figure I-SF-43.

⁴ United Nations Statistics Division Demographic Statistics Database | Retrieved from: http://data.un.org/Data.aspx?d=POP&f=tableCode:23 (2021, March 7)

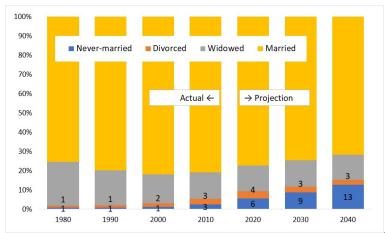


Figure 4: Marital Status of Men Aged 70 and Over in Japan⁵

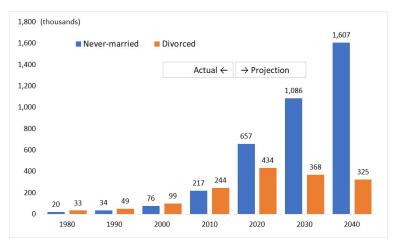


Figure 5: Number of Never-married or Divorced Men Aged 70 and Over⁶

Methodology

An Internet survey was conducted on February 14–24, 2020. The total sample size was 3,224 individuals. The sample was balanced among the three layers: sex (male, female); age (50s, 60s, 70s+); and, marital status (unmarried, divorced, widowed, married).

The sample included 471 unmarried men and 472 divorced men. The ratios in the sample size did not reflect the actual ratios in the Japanese population; therefore, the ratios of gender, age, and marital status were calculated based on the Japan Census 2015, to get a clearer and complete picture regarding "unmarried men in their 50s and older."

The survey items were as follows:

- Basic attributes (gender, age, marital status, occupation)
- Relationships with family members, relatives, friends, and neighbors
- People to support you when you are hospitalized or need help

⁵ National Institute of Population and Social Security Research (2018) *Household Projections for Japan : 2015-2040*, Table 4 The breakdown of divorced and widowed was calculated based on the composition in Japan Census 2015

⁶ State of Maryland Office of the Attorney General (2019) A Guide to Maryland Law on Health Care Decisions, August 2019. Retrieved from:

https://www.marylandattorneygeneral.gov/Health%20Policy%20Documents/adirective.pdf

- Communication regarding preferences for long-term care or EOL care
- Anxiety about decision-making in the last years of life
- Preparation in terms of advance care planning and "ending note"

Outcomes

It was found that 36.5% of never-married men and 37.0% of divorced men in their 70s and over have no relatives within the third degree of kinship (Figure 6). Consanguine family members within the third degree of kinship often have a legal duty to support each other, before the Public Assistance Act is applied (in case of need). Hospitals are likely to ask patients' relatives to come and help, and this is often a family member in the third degree of kinship. They usually inherit the estate of the deceased person. That is to say, if the patient dies due to a medical error, those relatives are the heirs to inherit the right to claim damages. Hospitals ask the patient's relative to sign a consent form before the surgery to reduce the likelihood of them suing the hospital if the surgery is unsuccessful.

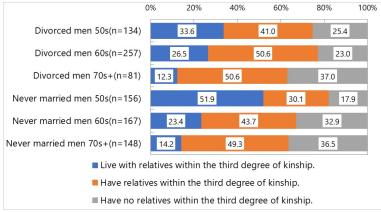


Figure 6: Relatives within the Third Degree of Kinship

In total, 92.8% of men and women aged 50 and older have someone who can support them when they are hospitalized; in case of never-married men the number is much lower at 65.7%. About 20% of divorced or never-married men have absolutely no one to help them with EOL decisions (Figure 7).

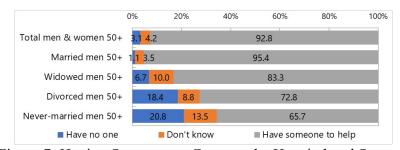


Figure 7: Having Someone to Come to the Hospital and Support

There is a polarization between those who are connected with both relatives and friends and those who are not connected to anyone. Of the men and women aged 50 and over, 21.9% answered that they had no friends to talk to or ask for advice. This rate was higher in never-married men (40.2%). Among never-married men with no relatives within the third degree of kinship, those in their 50s had the least number of friends (Figure 8).

As the number of never-married and divorced men increases in the future, the gap between those who have plenty of relatives and friends and those who do not is likely to widen.

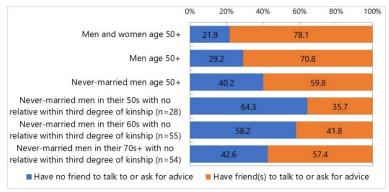


Figure 8: Having Friends to Talk to and Ask for Advice

Men in their 50s and over have anxiety about communication and expressing their intent for the final years of life. Further, 55.9% of men aged 50 and over are anxious about developing dementia and losing the ability to take decisions by themselves when they get older. Over 40% are anxious that they will be moved to a nursing home or undergo medical treatment or surgery they do not want (Figure 9). The level of anxiety is not influenced by whether they are married and have relatives, or are single with few relatives. The risk of developing dementia is the same, and even if they have family members who can speak for them, this fact does not make them any less anxious (Figure 10).

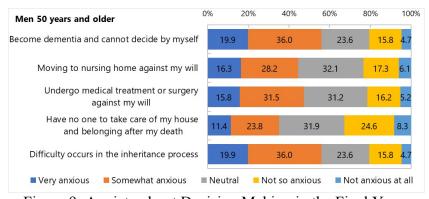


Figure 9: Anxiety about Decision Making in the Final Years

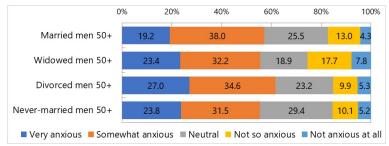


Figure 10: Anxiety about Dementia and Not Being Able to Take Independent Decisions

Anxiety about decision-making about EOL care does not drive them to prepare in advance. About 14.8% of men and women aged 50 and over have told someone about how they want to be treated in their final days, or be cared for in the final years of their life (Figure 11). This rate is lower in divorced and never-married men. Divorced men and divorced women were in contrast. Only 5.9% of divorced men have told someone about their will, but 15% of divorced

women have told someone. This may be because mothers often get custody after divorce and the children care about their single mother, but fathers tend to become estranged from the children after divorce. As for the never-married, 5.2% of never-married men and 10.3% of never-married women have told someone about their will. Never-married men and women are both likely to have few relatives, but women have more acquaintances than men.

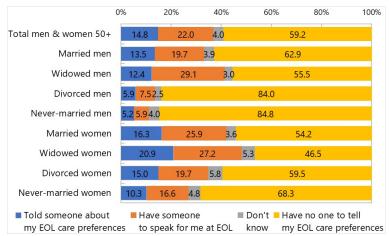


Figure 11: Told Someone about ACP or EOL Care Preferences

Since it is difficult to "tell" someone how one wants to be treated at the end of life, a tool called "ending note" was created recently, which is now widely known in Japan. It is usually a notebook with many write-in columns and questions to answer. The ending note often includes items such as DNR order, whether you want to be cared for at home or in a facility, list of properties, insurance, debts, or personal history. Many local governments are distributing "ending notes" free of charge, encouraging the elderly to express their wishes for EOL care in advance and to write down administrative correspondence about what they want to be done after their death.

A total of 11.7% of men and women aged 50 and older have written or are in the process of composing an "ending note" but only 3.6% of never-married men have done this (Figure 12). Men are more reluctant than women to prepare for EOL care. An individual, whether male or female, is more likely to prepare ending notes if he/she lives alone, away from their family. If an individual is living with relatives, he/she would find it easier to discuss EOL decisions orally or expect relatives to estimate his/her wish based on their conversations and behavior, rather than writing the will down in a notebook. Based on the findings of this study, it is assumed that people with no relatives generally find it hard to write such a note as they cannot think of anyone who would read and execute their will in the right way.

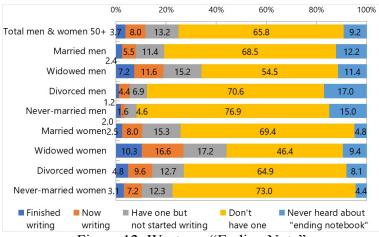


Figure 12: Wrote an "Ending Note"

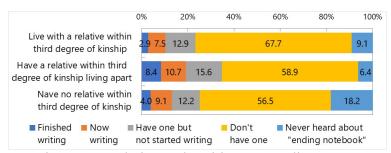


Figure 13: Relative and Writing an "Ending Note"

Even if they neither tell nor write down how they want to be treated at the end of life, they still want to be cared for as per their own preferences, rather than leave the decisions to their family or friends (Figure 12). This tendency is more common among divorced men, but only 5.9% of divorced men have told someone about their EOL care preferences (Figure 11). This makes it very difficult for others to estimate how they want to be cared for.

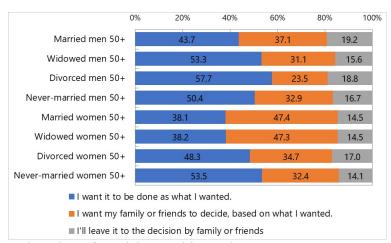


Figure 14: Delegation of Decision Making When I Cannot Express My Thoughts

Even in the U.S., where advance directives are more widespread than Japan, these directives are not executed automatically. Forms distributed by the state government demand naming one's agent who will make healthcare decisions for them^[6]. It is very important not only to express the will in a document, but also to assign someone to execute it.

Of the never-married men in their 50s, 53.9% said their parents or siblings will decide about their medical treatment when they are unable to express their wishes. As for never-married men aged 60 and over, nearly 40% said their siblings will take decisions for them. However, a helpful relative is often likely to be middle-aged or old and frail themselves.

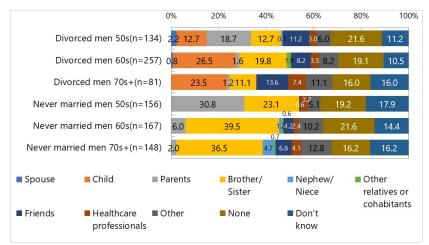


Figure 15: Person Who Takes Decisions about Treatment or Care on Behalf of You

Conclusion

Never-married and divorced men are less likely to have relatives in close kinship, friends, or neighborhood acquaintances whom they can ask for help. If a never-married or divorced man is hospitalized and cannot express his thoughts, there will be no one who can accurately determine or understand what he wants. In order to organize thoughts about how he wants to be cared for in his latest years, he should tell someone, or write it down in a document, such as an "ending-note". Ending note is a tool now widely known in Japan, but it is not a legal document, so it is left to the person who reads the ending note to decide whether to fulfil the writer's wishes or not. Never-married or divorced men without relatives or friends find it hard to imagine who will read their ending notes, which discourages them from writing them. With no thoughts expressed in advance, it gets harder to estimate the EOL preferences. This is like the chicken or egg dilemma. To overcome this issue, one solution is that older individuals must be encouraged to create and maintain connections with people to whom they can entrust the execution of EOL intentions. Another solution is to build a mechanism to estimate and execute intentions semi-automatically even if there is no one available to assume the EOL decision making responsibility.

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