

Letters to the editor

Gender differences in wishes and feelings regarding end-of-life care among Japanese elderly people living at home

Yoshihisa Hirakawa¹, Yupeng He¹, Chifa Chiang¹, and Atsuko Aoyama¹

¹ Department of Public Health and Health Systems, Nagoya University Graduate School of Medicine, Japan

Abstract

Objective: This study aimed to explore the gender differences in wishes and feelings regarding end-of-life care among Japanese elderly people requiring home care services.

Patient/Materials and Methods: This study was a secondary analysis of the qualitative data previously compiled from a total of 102 elderly people living at home. The data was retrospectively collected from the participants' nursing records, which included a designated advance care planning (ACP) form completed between January and July 2015. Out of the 102 participants, 86 men and women who were either living alone or with a spouse were selected for the present analysis. We reviewed the participants' ACP forms based on which of the sentiments on the following checklist were expressed: anxiety about the future, abandonment of control, clinging to current daily life, inadequate support from spouse, and a tendency to delegate decision-making.

Results: The most commonly expressed feeling was abandonment of control, among both men and women. Among elderly people living alone, women were more likely to want to be surrounded by good, caring people when approaching the end of their lives. Among elderly people living with a spouse, women were more likely to want to delegate decision-making to others.

Conclusion: Our results pointed to a gender difference in the attitudes of elderly people toward interactions with the people surrounding them during the end-of-life decision-making process. In order to provide better overall care, health care professionals must come to realize the importance of this gender difference, as it has an impact on the ACP choices made by elderly people living in the community.

Key words: gender differences, advance care planning, elderly

(*J Rural Med 2019; 14(1): 148–151*)

Received: September 26, 2018

Accepted: January 24, 2019

Correspondence: Yoshihisa Hirakawa, Department of Public Health and Health Systems, Nagoya University Graduate School of Medicine, 65 Tsuruma-cho, Showa-ku, Nagoya City, Aichi 466-8550, Japan
E-mail: y.hirakawa@med.nagoya-u.ac.jp

This is an open-access article distributed under the terms of the Creative Commons Attribution Non-Commercial No Derivatives (by-nc-nd) License <<http://creativecommons.org/licenses/by-nc-nd/4.0/>>.

Introduction

Advance care planning (ACP) is a process that allows individuals to formulate their wishes about end-of-life care before the onset of life-threatening conditions^{1–3}. ACP is used to describe the particular wishes and feelings of a person regarding end-of-life options such as place of care, to list the advance directives for or against specific treatments, and to designate proxies for when that person no longer has the capacity to make personal decisions^{1–3}.

Previous studies have indicated that community health care professionals (i.e. physicians, nurses, care managers and social workers) in Japan are not properly trained to discuss end-of-life care preferences with elderly people and their families^{3–5}. Community health care professionals would be better able to engage in meaningful communication with their clients and tailor their services to their needs if they could understand the factors influencing the choices made by elderly people regarding end-of-life care.

However, little information is available about the values and preferences of elderly people regarding end-of-life care in real-world settings. We previously conducted a qualitative study on ACP content using data from 102 elderly people needing daily assistance; we discovered that elderly people tend to leave end-of-life care decisions to other people, and that their decisions tend to change as they approach death³.

This secondary data analysis aimed to explore the gender differences in wishes and feelings regarding end-of-life care among Japanese elderly people requiring home care services. While older age groups have so far been dominated by women⁶, more elderly men are now living alone due to men's improved life expectancy. A number of studies have suggested that elderly men are more likely to be susceptible to social loneliness and to die prematurely than are women, due to their generally lower aptitude for self-support and self-care^{6–9}. Whether or not gender influences elderly people's wishes and feelings regarding the end of their lives is

Table 1 Subjects' characteristics (N=86)

	Men (n=39)	Women (n=47)
Age (years)	75.6 (\pm 7.9)	80.8 (\pm 7.9)
Basic activities of daily living		
Independent	18 (46.2%)	21 (44.7%)
Housebound	13 (33.3%)	18 (38.3%)
Chairbound	6 (15.4%)	5 (10.6%)
Bed-ridden	2 (5.1%)	1 (2.1%)
Unknown	0 (0.0%)	2 (4.3%)
Dementia (care manager's assessment)	21 (53.8%)	23 (48.9%)
Marital status		
Married	31 (79.5%)	16 (34.0%)
Widowed	2 (5.1%)	28 (59.6%)
Divorced	3 (7.7%)	0 (0.0%)
Single	3 (7.7%)	1 (2.1%)
Unknown	0 (0.0%)	2 (4.3%)
Household type		
One-person	8 (20.5%)	32 (68.1%)
Couple	31 (79.5%)	15 (31.9%)

Number (%) or mean (\pm SD) is shown in table.

still unclear because, so far, very little research has been done to shed light on this topic¹⁰.

Methods

This study was part of a larger qualitative study on the end-of-life wishes and decision-making process of Japanese elderly people requiring home care services; data collection details are described elsewhere³. In brief, we collected the qualitative data from a total of 102 elderly people (47 men, 55 women) from 6 home care support offices belonging to a medical cooperative. The clients' wishes and feelings about end-of-life care were recorded at initial interviews at the home care support offices between January and July 2015. This data was retrospectively collected from the participants' nursing records, which included a designated ACP form filled out according to semi-structured interviews. The interview form contained questions about the participants' wishes and feelings; living arrangements; desired place of death; and future treatment and care options, in case they were no longer able to communicate their wishes, as well as demographic information.

Out of the 102 participants, 86 men and women living alone or with their spouse were included in the present analysis (Table 1). We specifically chose to focus on these two groups because they are growing in number and importance to public health policy. We then reviewed their ACP forms using a checklist of responses, recording a positive answer if personal wishes and feelings regarding end-of-life were clearly mentioned. The items on the checklist, which were

decided on the basis of a review of the previous qualitative study³, were as follows: anxiety about the future (fear of loneliness, dislike of hospitalization, fear of decline), abandonment of control, clinging to current daily life (surrounded by good, caring people, attachment to house, maintaining average living standards, desire for freedom, desire for autonomy), inadequate support from spouse, and delegating decision-making. In order to identify the gender differences in wishes and feelings about end-of-life care among the participants, we separated the elderly men and women living alone from those living with a spouse, considering the effects of household type on the gender differences. The quantitative data was statistically analyzed using the Fisher's test, performed with IBM SPSS Statistics 24. A p-value of less than 0.05 was considered statistically significant.

This study was approved by the Bioethics Review Committee of the Nagoya University School of Medicine before the investigation (approval number 2014-0411). Written and verbal informed consent was obtained from the participants by their care managers. Interviews were conducted privately and participants' transcripts were anonymized.

Results

Regardless of gender, cognitive impairment (as assessed by care managers), and independence level for activities of daily living were similar among the participants (Table 1). Women were more likely than men to be widowed (59.6% vs. 5.1%). As shown in Table 2, the most commonly expressed feeling among both men and women was abandonment of

Table 2 Elderly subjects' wishes and feelings regarding end-of-life (N=86)

	Living alone			Living with a spouse		
	Men (n=8)	Women (n=32)	p-value	Men (n=31)	Women (n=15)	p-value
Abandonment of control	5	10	0.126	16	5	0.346
Fear of decline	5	9	0.102	7	2	0.696
Attachment to house	0	7	0.309	11	6	1.000
Surrounded by good, caring people	0	16	0.013	5	3	1.000
Dislike of hospitalization	1	1	0.364	3	3	0.372
Fear of loneliness	2	3	0.257	1	2	0.244
Desire for autonomy	0	1	1.000	2	0	1.000
Delegating decision-making	1	2	0.498	0	4	0.008
Maintaining average living standard	0	1	1.000	1	0	1.000
Desire for freedom	0	5	0.563	1	1	1.000
Inadequate mutual support	0	0	-	0	0	-
Clinging to current daily life	0	0	-	0	0	-

p-values by Fisher's test.

control. Among elderly people living alone, women were more likely to want to be surrounded by good, caring people when approaching the end of their lives, as shown by declarations such as: "I am grateful that my children, daughter-in-law, and day service center staff kindly take turns caring for me", "I hope to spend the last days of my life at home, enjoying good relations with friends, neighbors and family", and "I would be happy if my son and his family came back to live with me in the future". Among elderly people living with a spouse, women were more likely to want to delegate decision-making to others, as evidenced by statements such as: "I want to delegate my care to my family because they are looking after me very well".

Discussion

As suggested in a position statement from the Japan Geriatrics Society 2012¹¹⁾, and as was found in the present study, unlike a European and North American point of view where patient autonomy is highly valued, in Japan both elderly men and women tended to give up maintaining control over their end of life and accept their own circumstances as "fate". The results nevertheless revealed an important gender difference in terms of why Japanese elderly people leave end-of-life care decision-making to other people³⁾: in general, elderly women were eager to maintain good relationships with relatives, neighbors, and friends who would eventually support them at the end of their lives. It should be noted that although localisms, age, and living arrangements may have an impact on people's end-of-life preferences, these factors could not be included in our secondary data analysis. Additional quantitative studies will be needed to confirm and generalize our findings.

Conclusion

The secondary analysis of data from the qualitative study revealed that both elderly men and women were likely to leave end-of-life care decision-making to someone else; however, compared to elderly men, elderly women appeared to focus on maintaining good relationships with relatives, neighbors, and friends. This gender difference should be taken into account when considering the ACP wishes and preferences of elderly people living in the community.

Acknowledgement

This work was supported by the Japan Chukyo Longevity Medicine Research Foundation and the Japan Grants-in-Aid for Scientific Research, Grant Number 26460596.

References

1. Lum HD, Sudore RL, Bekelman DB. Advance care planning in the elderly. *Med Clin North Am* 2015; 99: 391–403. [Medline] [CrossRef]
2. Bischoff KE, Sudore R, Miao Y, *et al.* Advance care planning and the quality of end-of-life care in older adults. *J Am Geriatr Soc* 2013; 61: 209–214. [Medline] [CrossRef]
3. Hirakawa Y, Chiang C, Hilawe EH, *et al.* Content of advance care planning among Japanese elderly people living at home: a qualitative study. *Arch Gerontol Geriatr* 2017; 70: 162–168. [Medline] [CrossRef]
4. Yokoya S, Kizawa Y, Maeno T. Practice and perceived importance of advance care planning and difficulties in providing palliative care in geriatric health service facilities in Japan: a nationwide survey. *Am J Hosp Palliat Care* 2018; 35: 464–472. [Medline] [CrossRef]

5. Nakazawa K, Kizawa Y, Maeno T, *et al.* Palliative care physicians' practices and attitudes regarding advance care planning in palliative care units in Japan: a nationwide survey. *Am J Hosp Palliat Care* 2014; 31: 699–709. [Medline] [CrossRef]
6. Kono A, Tadaka E, Okamoto F, *et al.* [Self-care issues of older men living alone. A qualitative comparison between urban high-rise apartment and suburban farming districts]. *Nippon Koshu Eisei Zasshi* 2009; 56: 662–673 (in Japanese). [Medline]
7. Bergland AM, Tveit B, Gonzalez MT. Experiences of older men living alone: a qualitative study. *Issues Ment Health Nurs* 2016; 37: 113–120. [Medline] [CrossRef]
8. Dykstra PA, Fokkema T. Social and emotional loneliness among divorced and married men and women: comparing the deficit and cognitive perspectives. *Basic Appl Soc Psych* 2007; 29: 1–12. [CrossRef]
9. Kandler U, Meisinger C, Baumert J, *et al.* KORA Study Group Living alone is a risk factor for mortality in men but not women from the general population: a prospective cohort study. *BMC Public Health* 2007; 7: 335. [Medline] [Cross-Ref]
10. Perkins HS, Cortez JD, Hazuda HP. Advance care planning: does patient gender make a difference? *Am J Med Sci* 2004; 327: 25–32. [Medline] [CrossRef]
11. Japan Geriatric Society Position of the Japan Geriatrics Society on terminal care medical treatment for the elderly. (in Japanese) <https://www.jpn-geriat-soc.or.jp/proposal/pdf/jgs-tachiba2012.pdf> (Accessed December 5, 2018).