

Preferences in end of life care substantially differ between the Netherlands and Japan

Results from a cross-sectional survey study

A. Stef Groenewoud^{a,*}, Noriko Sasaki, MD, PhD^b, Gert P. Westert, PhD^a, Yuichi Imanaka, PhD^b

Abstract

Strategies to increase appropriateness of EoL care, such as shared decision making (SDM), and advance care planning (ACP) are internationally embraced, especially since the COVID-19 pandemic. However, individuals preferences regarding EoL care may differ internationally. Current literature lacks insight in how preferences in EoL care differ between countries and continents. This study's aim is to compare Dutch and Japanese general publics attitudes and preferences toward EoL care, and EoL decisions. Methods: a cross-sectional survey design was chosen. The survey was held among samples of the Dutch and Japanese general public, using a Nationwide social research panel of 220.000 registrants in the Netherlands and 1.200.000 in Japan. A quota sampling was done (age, gender, and living area). N=1.040 in each country.

More Japanese than Dutch citizens tend to avoid thinking in advance about future situations of dependence (26.0% vs 9.4%; $P=.000$); say they would feel themselves a burden for relatives if they would become dependent in their last phase of life (79.3% vs 47.8%; $P=.000$); and choose the hospital as their preferred place of death (19.4% vs 3.6% $P=.000$). More Dutch than Japanese people say they would be happy with a proactive approach of their doctor regarding EoL issues (78.0% vs 65.1% JPN; $P=.000$).

Preferences in EoL care substantially differ between the Netherlands and Japan. These differences should be taken into account a) when interpreting geographical variation in EoL care, and b) if strategies such as SDM or ACP – are considered. Such strategies will fail if an international “one size fits all” approach would be followed.

Abbreviations: ACP = advance care planning, EoL = end of life, GP = general practitioner, JPN = Japan, NL = the Netherlands, SDM = shared decision making.

Keywords: advance care planning, Japan, Netherlands, palliative care, small-area variation, terminal care

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This study was approved by both the Ethics Committee of Kyoto University Graduate School and Faculty of Medicine, Japan (R0478).

The study was also approved by the Ethics Committee of Radboud University Medical Center Nijmegen, the Netherlands (2019–5284). This committee also declared that no judgment by a regional committee was needed, since survey participants are not asked to be subject to activities or treatments that fall within the scope of the Medical Research Involving Human Subjects Act.

Informed consent was received from all participants prior to the survey. The consent procedure consisted of 2 steps. First, panel members received an e-mail with information about the aim and the contents of the questionnaire. Second, they were asked to participate in the survey, by providing them with the following text: “The survey includes questions which ask you for your attitudes toward the end-of-life care. Please make sure that you are willing to participate in this survey. If you do not agree to answer these questions, please click the “quit” button. You will not participate in this survey. If you do want to participate, you can choose the “proceed” button to start the survey. Answers to the questions are anonymized, and only utilized for the research in the interest of social benefit”.

All authors have seen and approved the final version of this manuscript, and are aware of and agree to this submission to BMC Palliative Care.

Data can be obtained via the corresponding author. The institutions are bound by confidentiality agreements which prevent compliance with this data sharing policy.

The authors declare that there is no conflict of interest.

The datasets generated during and/or analyzed during the current study are available from the corresponding author on reasonable request.

^a Scientific Institute for Quality of Healthcare, Radboud University Medical Center, Nijmegen, the Netherlands, ^b Department of Healthcare Economics and Quality Management, Kyoto University, Graduate School of Medicine, Kyoto, Japan.

* Correspondence: Stef Groenewoud, Scientific Institute for Quality of Healthcare, Radboud University Medical Center, 114 IQ Healthcare, Po Box 9101, 6500 HB Nijmegen, The Netherlands (e-mail: stef.groenewoud@radboudumc.nl).

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1. Introduction

1.1. Background

There is substantial variation in the utilization and the intensity of health care at the End of Life (EoL)* both within and between countries. For example, the “percentage of deaths occurring in hospitals”, which is often used as an indicator, was 46.9% in England in 2016; with a 35.2% to 63.1% range between Care Commissioning Groups (CCGs).^[1] Studies in 2013 and 2016 reported an average of 38% in Switzerland, with a considerable variation between cantons^[2,3]. Also the complementary indicator: “the percentage of people who die at home” considerably varies between cantons: from 22.1% in Ticino (TI) to 33.3% in Aargau (AG).^[3]

The average for Germany was 38.3% and even higher proportions inhabitants die in hospitals in Norway (44.7%), Belgium (51.2%), and Canada (52.1%).^[4] The USA have the lowest proportion of inhabitants dying in hospitals^[4]: 22.9% (varying from 12% (Minot, ND) to 46% (Manhattan, NY)),^[5] followed by the Netherlands: 24% (varying from 18.1% palliative care network North East Friesland to 32.2% palliative care network Roermond).^[6] The country with the highest percentage of decedents in hospitals is Japan.^[7,8] Most recent statistics report an average of 85.4% dying “hospitalized” encompassing clinics, health services and facilities/homes for the elderly. For “clinics” only, the average percentage is 74.3%, varying between 64.5 (city of Sendai) and 84.0% (city of Kitakyusyu).^[9]

Geographical differences in patterns of healthcare utilization often lead to discussions about the appropriateness of EoL care and the need to understand the causes of the variation.^[10,11] If we want to understand regional, and cross-country variation in health care utilization, we should look at 3 things.^[12]

- a) professional beliefs about treatment;
- b) variation in the demand for health care, which may in turn be influenced by
 - i) incidence of a disease (i.e. death), and
 - ii) patients’ willingness to receive care;
- c) the degree into which patient preferences are incorporated into professional decisions.

The literature already does provide us with a certain body of knowledge about how physicians attitudes toward EoL care differ within^[14–17] and between^[18–24] countries. It lacks however insight in international differences in preferences and attitudes of the general public regarding EoL-care. At the same time, concepts such as Shared Decision Making,^[25,26] and Advance Care Planning^[27,28] are internationally embraced and implemented in order to diminish unwarranted variation in EoL-care. The recent COVID-19 pandemic has further catalysed this movement, and ACP and SDM initiatives are now even encouraged on a global scale.^[29] Before concepts for the improvement of appropriate EoL care, such as ACP can be successfully implemented in a local situation however, it is important to understand differences in preferences people may have regarding health care at the EoL. Moreover, we believe that such knowledge is crucial for the successful implementation of interventions for the improvement of EoL care.

1.2. Objectives

To survey, compare, and explore (differences in) the general public preferences for EoL-care within and between in the

country with the highest percentage of people dying in hospitals (Japan), and the country with one of the lowest percentages (the Netherlands), enabling strategies for the reduction of unwarranted variation in EoL-care in these 2 countries, and other, similar countries to be implemented in a better way.

* It is not our aim to define the “End of Life (EoL)” very precise here, but – in line with current relevant literature – we discern 2 relevant aspects:

1. a disease-centered perspective based on a period of irreversible decline before death and
2. a time-based perspective, which is somewhere between 6 months or 1 year before the expected death.^[13]

2. Methods

2.1. Study design, setting and participants

Between March and April 2016, we performed a cross-sectional survey among representative samples of the Dutch and Japanese general public. Figure 1 visualises the sampling strategy. We used a nationwide social research panel of approximately 1.2 million registrants in Japan and 220.000 registrants in the Netherlands. The panel is owned by an online research company: Macromill, Inc, Tokyo, Japan. Respondents were recruited by randomly sending emails to its registrants, using an informed “opt-in” approach. We used a quota sampling method by age, gender and living areas. Recruitment emails were sent step-by-step until the intended number of participants in each stratum below had been fulfilled. A total of 1.040 respondents who live in Japan and have the Japanese nationality, and a total of 1.040 respondents who live in the Netherlands and have the Dutch nationality participated: 260 urban male, 260 urban female, 260 rural male, and 260 rural female. Each stratum consisted of the same age category volume (i.e., 52 male and 52 female in 20–39, 40–49, 50–59, 60–69, and 70 years or older age groups). This was done because we wanted explore the preferences in each of the groups (and thus needed enough power per group). In our view this was more important (given our aim to explore preferences in sub-groups) than creating age groups that mirror the demographic structure of the overall population. Urban area and rural area were defined as follows: Province of North Holland and South Holland were assigned as urban area, while rest of the provinces as rural area in the Netherlands. For Japan, the prefectures of Tokyo, Kanagawa, Chiba, Saitama, Kyoto, Osaka, and Hyogo were assigned as urban area, while rest of the prefectures were seen as rural area in Japan. We excluded 2 Japanese respondents whose answers were unreliable, and the final sample size was n=1040 in the Netherlands and n=1038 in Japan.

2.2. Variables

Table 1 contains the characteristics of the study sample, whereas Table 2 presents the main outcomes; the questions regarding preferences at the EoL, that were asked in de survey.

2.3. Statistical methods

We used IBM SPSS Statistics 22 for descriptive statistics for both respondents characteristics and the answers they gave to questions.

If numbers of respondents per answer category were too small, and if categories could reasonably be merged, we put them

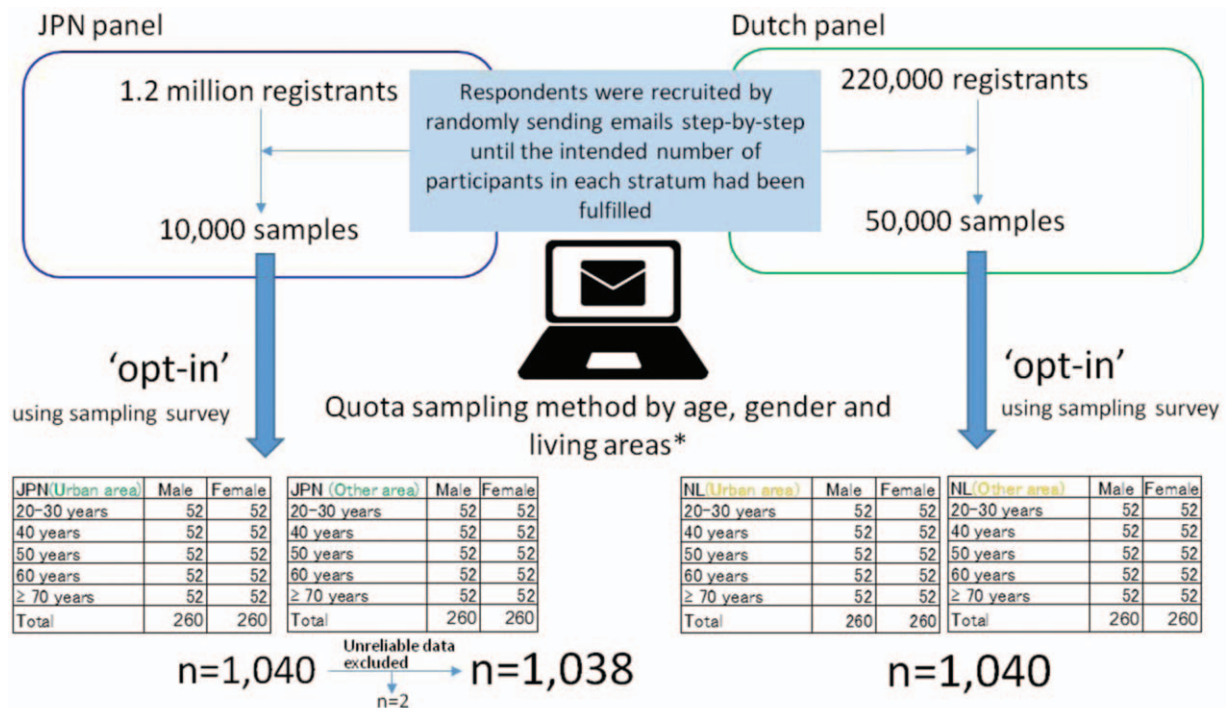


Figure 1. shows the (quota) sampling strategy for the Japanese (JPN) panel at the left, and the Dutch (NL) panel at the right.

together. We did this for spousal caregiver categories “parents”, “family”, “friends”; we merged categories of care settings: “nursing home”, and “home for the elderly”; as well as “home for the elderly” and “other”. We merged categories of responses to ACP: “too confronting” with “give more hope together”, as well as “clear message” with “openness”. We merged categories of preferred care in the terminal phase: “stopping active treatment, such as artificial respiration” with “stop eating and drinking”; as well as “suicide”, “physician assisted suicide”, and “euthanasia”. We merged categories of answers to the question: “would you feel a burden for your relatives?”: “no, I would have done the same”, with “no, I paid premiums for that”; as well as “yes I would be afraid of asking too much from my family” with “yes, I would be afraid of asking too much from society”.

We explored differences within Japan and the Netherlands, and tested if differences in distribution over answer categories in the 47 different prefectures (JPN) and 12 different provinces (NL) were statistically significant, using a Pearson Chi-Squared test.

We then looked at differences (percentages) between both countries, and tested if differences in distribution over answer categories were statistically significant, using a Pearson Chi-Squared test in SPSS.

3. Results

3.1. Participants and descriptive data

A total number of 1,040 surveys in the Netherlands and 1,038 in Japan were completed. Table 1 shows that in spite of the quota sampling strategy, the distribution over subjective.

Suburban and rural areas slightly differ: more people live in suburban regions in Japan than in the Netherlands. The Dutch sample has slightly more people living together while they are not

married, or living alone. Regarding occupation, the Japanese sample there are some more people working for themselves (on a freelance basis), are house wife, or unemployed, while in the Dutch sample more pensioners are represented. The Dutch sample has some more high and moderate educated people, resulting into slightly a higher representation in higher income classes, compared to the Japanese sample.

3.2. Outcome data and main results

We found no statistically significant regional differences in peoples preferences regarding EoL care within both countries. Preferences did not statistically significant differ between provinces (NL) or prefectures (JPN). We also compared rural with more urbanised areas, and found no statistically significant differences as well. There was however one exception: in the Netherlands, people from suburban areas more often report that it is very likely that they will move to another area in case they would become dependent of health care (25.6% vs 18.7% urban and 16.8% rural), and less people from suburban areas state that this would be very unlikely (51.9% suburban vs 61.0% urban and 67.3% rural); $P = .003$.

We did find however, some considerable differences in the general publics EoL-care preferences between the 2 countries. If asked who they expect to be their most important care giver in case they would suffer from dementia and become dependent, Japanese people more often refer to their children (9.2%) than the Dutch (51%). Also, Japanese people more often admit they have not thought about that yet (26.0% vs 9.4%). Dutch citizens more often expect nursing professionals to be their primary care givers in that case (50.8% vs 33.0%).

Regarding the preferred place of receiving care in case of dependency, the Dutch seem to avoid nursing homes (2.7% vs

Table 1
Sample characteristics.

	NL N = 1,040 N (%)	JPN N = 1,038 N (%)
Male	520 (50.0)	519 (50.0)
Age		
20–39 years	208 (20.0)	207 (19.9)
40–49 years	208 (20.0)	208 (20.0)
50–59 years	208 (20.0)	207 (19.9)
60–69 years	208 (20.0)	208 (20.0)
≥70 years	208 (20.0)	208 (20.0)
Objective area of residence*		
Urban	520 (50.0)	520 (50.0)
Non-urban	520 (50.0)	520 (50.0)
Subjective area of residence		
Urban	444 (42.7)	342 (32.9)
Suburban	293 (28.2)	584 (56.3)
Rural	303 (29.1)	112 (10.8)
Marital status		
Married	570 (54.8)	678 (65.3)
Unmarried	342 (32.9)	327 (31.5)
Living together (with/without official registration)	128 (12.3)	33 (3.2)
Family composition & Living arrangements		
Single living alone	252 (24.2)	174 (16.7)
Occupation		
Company employee	314 (30.2)	284 (27.3)
Medical/nursing professional	20 (1.9)	21 (2.0)
Civil servant	37 (3.6)	24 (2.3)
Self-employed (own firm with/without personnel)	99 (9.5)	73 (7.0)
Freelance worker	7 (0.7)	163 (15.7)
Teacher/Research & Development	36 (3.5)	11 (1.1)
Housewife/ house-husband	85 (8.2)	230 (22.2)
Pensioner	310 (29.8)	66 (6.4)
Student	27 (2.6)	10 (1.0)
Unemployed	71 (6.8)	142 (13.7)
Other	75 (7.2)	14 (1.3)
Final academic background		
High	459 (44.1)	429 (41.3)
Moderate	374 (36.0)	253 (24.4)
Low	201 (19.3)	350 (33.7)
None of the above	6 (0.6)	6 (0.6)
Annual income		
<€7000	32 (3.1)	97 (9.3)
€7000–€35,000	352 (33.9)	482 (46.4)
€35,000–€75,000	347 (33.4)	237 (22.8)
€75,000≤	63 (6.1)	69 (6.6)
Don't know	246 (23.7)	153 (14.7)

* Detailed definition is described in the manuscript.

15.9% of the Japanese) and to favor home care (19.7% vs 13.0%). When asked for their preferred place of death however, Japanese people more often choose the hospital (19.4% vs 3.6%) whereas the Dutch prefer home care combined with outpatient care (66.0%) more than the Japanese (49.5%).

If asked how they would feel if their doctor would pro-actively confront them with their future death, and talk with them about goals in life (which is usually done in Advance Care Planning^[27,30]), Dutch people more often say they would be happy with such an approach (78.0% vs 65.1%). More Japanese people than Dutch people say that ACP is too confronting and that they would expect their doctor to give them more hope (18.4% vs 11.3%).

When asked if they would experience themselves to be a burden for those surrounding them if they would become dependent in their last phase of life, far more Japanese admit they would do so (79.3% vs 47.8%). Far more Dutch than Japanese people explicitly say this would not be the case (40.9% vs 6.8%).

Asked for their preferred medical decision at the end of life if they would become terminally ill, the Dutch more often prefer the actively ending of life (42.9%) than the Japanese (18.0%).

Japanese people prefer a more passive approach (forgo active treatment or stop eating and drinking) more often (20.9%) than the Dutch (6.6%).

4. Discussion

4.1. Key results

Our data show that Japanese and Dutch peoples preferences for EoL-care substantially differ. If people from the Netherlands and people from Japan are asked for their preferences in case they would become dependent, palliative or even terminally ill, they have very different ideas about what they can ask from other people, who should preferably take care of them, where this care should be given, and when curative treatments should (pro-actively or not) be replaced for what type of end-of-life decisions. Finally, even the preferred place of death substantially differs between the 2 countries.

4.2. Contrasting results with current body of literature

There is some literature on peoples preferences regarding care at the end of life, however, most studies focus on very specific target groups. To the best of our knowledge no comparisons between countries have been made thus far.

For example, a study among Mori and non-Mori in New Zealand showed that top priority for groups at end of life was “not being a burden to my family”. Interestingly, a home death was not a high priority for either group. End of life preferences also differed by gender.^[31] This study underpins that we chose a relevant variable for our survey on end of life (care) preferences, namely: if people would feel themselves a burden to their families.

A recent survey about EoL (care) preferences among the general public in Japan showed that the proportion of the general public who wanted “chemotherapy or radiation”, “ventilation”, and “cardiopulmonary resuscitation” was significantly higher than the frequency of these options being recommended by physicians, nurses, and care staff. It concluded that regarding a hypothetical scenario for advanced cancer, the general public preferred more aggressive treatment and more frequent life sustaining treatment than that recommended by healthcare providers.^[32] This study is in line, and therefore strengthens our findings that Japanese people are less inclined to accept that their doctor would start talking about (alternative) goals at the EoL, and that they expect their doctors to give them hope instead.

We found 1 study that compared EoL preferences of different ethnic groups: African American, Hispanics and non-Hispanic whites.^[33] Racial, ethnic, and other factors associated with whether older adults discussed their end-of-life (EOL) care wishes with family, were examined. EoL discussions were less likely for Hispanics. We learn from that study that ethnicity influences EOL care discussion, moderated by family/friend involvement, however, results were considered preliminary by the authors.

Table 2**Main outcomes.**

Variable	JPN N (%)	NL N (%)	P-value
<i>In case you would suffer from dementia, and would not be able to live by yourself anymore, who would be your major care provider?</i>			
a) Spouse	a) 307 (29.6)	a) 309 (29.7)	.000
b) Child (ren)	b) 96 (9.2)	b) 53 (5.1)	
c) Parent (s) / Relatives/Friends	c) 22 (2.1)	c) 52 (5.0)	
d) Institutional nursing care professionals	d) 343 (33.0)	d) 528 (50.8)	
e) Don't know	e) 270 (26.0)	e) 98 (9.4)	
<i>In case you would suffer from dementia, and would not be able to live by yourself anymore; where would you prefer to live?</i>			
a) At home with ambulatory care (e.g. daily activities)	a) 243 (23.4)	a) 238 (22.9)	.000
b) At home with home care	b) 135 (13.0)	b) 205 (19.7)	
c) Communal house	c) 105 (10.1)	c) 262 (25.2)	
d) Nursing home	d) 165 (15.9)	d) 28 (2.7)	
e) Group home	e) 143 (13.8)	e) 38 (3.7)	
f) Hospital	f) 25 (2.4)	f) 3 (0.3)	
g) I don't know	g) 217 (20.9)	g) 99 (9.5)	
h) Other	h) 5 (0.5)	h)167 (16.1)	
<i>Imagine you are diagnosed with a life threatening disease, and you would only have 12 months left; how would you feel if your doctor would confront you with this and ask you what life goals you still have and how health care may fit/ support goals?</i>			
a) I would consider such an approach too confronting; my doctor should wait for me to take the initiative to discuss End of Life issues. In the meanwhile, I would expect a hope-giving attitude from my doctor	a) 191 (18.4)	a) 118 (11.3)	.000
b) I would appreciate such openness and a clear message: it makes clear what is going to happen	b) 676 (65.1)	b) 811 (78.0)	
c) I do'nt know/other	c)171 (16.5)	c)111 (10.7)	
<i>If you were diagnosed with a life threatening disease with a prognosis of approximately 3 to 6 months, with no likelihood of recovery, what type of treatment strategy would you wish to adopt?.</i>			
a) Active treatment	a) 91 (8.8)	a) 114 (11.0)	.000
b) Palliative care	b) 647 (62.3)	b) 704 (67.7)	
c) Do nothing	c) 132 (12.7)	c) 64 (6.2)	
d) Don't know	d) 158 (15.2)	d) 107 (10.3)	
e) Other	e) 10 (1.0)	e) 51 (4.9)	
<i>If you were diagnosed with a life threatening disease with a prognosis of approximately 3 to 6 months, with no likelihood of recovery, what would be your preferred place of death?</i>			
a) Home with ambulatory care	a) 174 (16.8)	a) 252 (24.2)	.000
b) Home with homecare	b) 339 (32.7)	b) 438 (42.1)	
c) Inpatient (non hospital) care	c) 36 (3.5)	c) 20 (1.9)	
d) Hospital care	d) 201 (19.4)	d) 37 (3.6)	
e) Communal house (with care)	e) 27 (2.6)	e) 32 (3.1)	
f) Nursing home	f) 16 (1.5)	f) 8 (0.8)	
g) Hospice	g) 47 (4.5)	g)141 (13.63)	
h) Don't know	h) 183 (17.6)	h) 82 (7.9)	
<i>If you were diagnosed with a life threatening disease with a prognosis of approximately 3 to 6 months, with no likelihood of recovery, that deprives you of your dignity, and results in constant unbearable pain, what would you prefer most?</i>			
a) Apply and persevere any form of treatment that may give any hope for cure	a) 40 (3.9)	a) 88 (8.5)	.000
b) Refrain from active, life prolonging treatment and/or stop eating and drinking	b) 217 (20.9)	b) 69 (6.6)	
c) Intensify pain treatment, even if this would have life-shortening consequences	c) 317 (30.5)	c) 214 (20.6)	
d) Terminate life myself/physician assisted suicide / euthanasia	d) 187 (18.0)	d) 446 (42.9)	
e) Other/don't know	e) 277 (26.7)	e) 223 (21.4)	
<i>When you would become dependent on the help of others during the last phase of your disease, would you perceive yourself as a burden for those around you?</i>			
a) No	a) 71 (6.8)	a) 425 (40.9)	.000
b) Yes	b) 823 (79.3)	b) 497 (47.8)	
c) Don't know	c) 144 (13.9)	c) 118 (11.3)	

Although this study underpins our findings that preferences for EoL (care) differ between ethnic groups, we can conclude that our study importantly adds to the current body of knowledge because cross country, and intercontinental comparisons of EoL (care) preferences have not been made thus far.

4.3. Interpretation

We believe our results should be consciously taken into account if differences in health care (utilisation) at the EoL are interpreted and explained. For example, the actual percentage of people who die in hospitals is much higher in Japan (85.4%)^[9] than in the Netherlands (24%).^[6] It would be too simplistic however, to conclude that EoL care in the Netherlands does better. Adding our data to this discussion shows that the discrepancy between the preferred vs the actual place of death is higher in the Netherlands (24.0%: 3.6%=6.6) than in Japan (85.4%: 19.4%=4.4). This sheds a different light on the situation than merely comparing percentages. Also, since strategies for the reduction of unwarranted variation, and the improvement of appropriateness of care at the EoL, such as SDM or ACP, are adopted nowadays, even on a global scale,^[29] peoples local preferences should be accurately taken into account. We saw that e.g., ACP is valued completely different by Japanese people (too confronting and hope-taking) than by the Dutch (clear, open, and honest).

Furthermore, the following 3 points may explain the differences that we found between the 2 countries. First, since euthanasia is illegal in Japan, traditional Japanese culture tends to prevent people to openly discuss end-of-life decisions. Japanese can only choose very inactive ways of hastened death, such as “not eating and drinking” at most. This sharply contrasts to the Netherlands, where since 2002 the euthanasia act has provided a legal basis for the open discussion of all medical decisions at the end of life. In addition, compared to the Dutch, Japanese peoples hope-cherishing attitude may lead to a greater tendency tend to end ones life at hospital.

Second, ACP has not yet been widely known and adopted in the daily clinical settings in Japan. According to the national survey of EoL care conducted in 2017, only 26% to 35% of healthcare professionals such as physicians, nurses, and paid caregivers actually implement ACP in their daily practices.^[34] Moreover, only 20% to 30% of them referred to the national guidelines for EoL care which has been developed by the government in 2007 and revised in 2015.^[35] An international comparative study on terminal care systems from 8 countries including the Netherlands and Japan, reported that there was no nation-wide consensus for the EoL treatment choices in Japan and that many Japanese specialists had a tendency to emphasize “family opinions” and “length of remaining life” rather than patient preference and his/her quality of life.^[36] In this context, the results from our study that Japanese respondents felt ACP as “too confronting” and preferred rather “hope-taking” may add the reason why ACP has not infiltrated in Japanese culture from the perspective of the patient themselves. However, the EoL activities, so-called “shukatsu”, including inheritance, funeral preparation and online memorials not to make inconvenience with ones surroundings, have been growing across the country for these several decades.^[37] These activities are out of health insurance and public health services, and they may reflect the changing culture of the modern super-aging society in Japan.

Third, regarding the result that far more Japanese feel themselves burdensome to their surroundings, we have to take into account that the home-based palliative care is not yet well established in Japanese society as it is in the Netherlands. As a result, there is a tendency in Japan that family members are increasingly obliged to take care of EoL patients both physically and financially. The scheme set by the government in Japan is a community-based integrated care system which provides health-care services for aging residents at regional level, and which may lead to reduce the burden of the surrounding families in the future.^[38]

4.4. Limitations

Our study is unique for its data (both the number of respondents in the sample, and the richness of its contents), however there are some limitations as well. First, the number of respondents is too small to make any relevant sub-analyses for regional variation within the 2 countries. We think however, that considerable regional differences in preferences in EoL care exist within both countries. For example, the incidence of euthanasia varies between regions in the Netherlands, which is believed to be caused at least partially by differences in preferences (eg., religion, culture, etc.).^[39] We recommend that future research will study these regional differences and its causes. Second, the quota-sampling-method did not result into a sample that is representative for the 2 countries in terms of age, urbanisation, education and income. Third, we used a panel instead of recruiting respondents from the public by hand, which may also have biased the results in a certain degree. Fourth, one may wonder why we have not adjusted for multiple comparisons, for example by applying a Bonferroni correction. We decided not to do so, because of the exploratory character of our study. Accepted literature in this field states (regarding the question if adjusting for multiple testing is required) that “Bonferroni correction “is strictly required in confirmatory studies. On the other hand, in exploratory studies, in which data are collected with an objective but not with a prespecified key hypothesis, multiple test adjustments are not strictly required. Between the 2 extreme cases of strictly confirmatory and strictly exploratory studies there is a wide range of investigations representing a mixture of both types. The decision whether an analysis should be made with or without multiplicity adjustments is dependent on the questions posed by the investigator and his purpose in undertaking the study.”^[40] Finally, to understand the reasons behind cultural differences, other designs and data-collection strategies are needed, such as interviewing, (participatory) observations or shadowing. We recommend this to be part of future research in this area.

4.5. Generalisability

Given the available body of literature that underpin our results we think that our findings are highly generalisable, despite the earlier mentioned limited representativeness of the sample. In Japan for example, several studies have shown that – even if patients experience distress about the future – they tend not to think about it too much, and leave EoL decisions to others.^[41,42] It is not that patients and professionals find these issues unimportant, but literature reports a huge discrepancy between what people state and what they actually implement in daily practice.^[14,41] A study by Yotani reported that less than 30% of

the doctors discussed EoL decisions during the last 3 months of life with patients, whereas 70% discussed these issues with family of the patients.^[43] Also the factor 4.4 discrepancy between the percentage of people who prefer and actually die in hospitals is supported by findings in other studies.^[44]

Studies in Western countries, and specifically in the Netherlands, underpin our findings as well. Discussing EoL issues with patients is broadly accepted here; both by professionals, and even more by the public.^[15,20] In the Netherlands, GP-patient discussion of treatment preferences occur in 47% of the cases.^[45] Active termination of life is more and more accepted by the majority of Dutch citizens and many physicians.^[15,46]

5. Conclusion

Based on the results of our study we would like to encourage policy makers, health care managers, and (other) professionals that are involved in programs for the improvement of EoL care, to take into the “couleur locale” of local peoples individuals preferences regarding EoL-care, before they a) interpret regional and international variation in EoL-care utilisation, and b) implement strategies for the reduction of unwarranted variation. These strategies, such as ACP, and SDM, should be tailor made instead of following an international “one size fits all” approach.

Second, we recommend that future research will a) further confirm the explorative work that we have done, and b) look for more relevant geographical differences between preferences at the EoL, also – if possible – by using other (qualitative) methods.

Author contributions

All authors meet the requirements for authorship.

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