RESEARCH PAPER

Functional disability trajectories at the end of life among Japanese older adults: findings from the Japan Gerontological Evaluation Study (JAGES)

Junko Saito[1,†], Hiroshi Murayama[2,†], Takayuki Ueno[3], Masashige Saito[4,5], Maho Haseda[6], Tami Saito[7], Katsunori Kondo[3,5,8], Naoki Kondo[6]

[1]Division of Behavioral Sciences, National Cancer Center Institute for Cancer Control, Tokyo, Japan
[2]Research Team for Social Participation and Community Health, Tokyo Metropolitan Institute of Gerontology, Tokyo, Japan
[3]Center for Preventive Medical Sciences, Chiba University, Chiba, Japan
[4]Faculty of Social Welfare, Nihon Fukushi University, Aichi, Japan
[5]Center for Well-being and Society, Nihon Fukushi University, Aichi, Japan
[6]Department of Social Epidemiology, Graduate School of Medicine and School of Public Health, Kyoto University, Kyoto, Japan
[7]Department of Social Science, Research Institute, National Center for Geriatrics and Gerontology, Aichi, Japan
[8]Center for Gerontology and Social Science, Research Institute, National Center for Geriatrics and Gerontology, Aichi, Japan

Address correspondence to: Naoki Kondo, Department of Social Epidemiology, Graduate School of Medicine and School of Public Health, Kyoto University, Kyoto, Japan. Email: kondo.naoki.0s@kyoto-u.ac.jp
[†]Junko Saito and Hiroshi Murayama are co-first authors

Abstract

Background: this study aimed to identify distinct subgroups of trajectories of disability over time before 3 years of death and examine the factors associated with trajectory group membership probabilities among community-dwelling Japanese older adults aged 65 years and above.

Methods: participants included 4,875 decedents from among community-dwelling Japanese older adults, aged ≥ 65 years at baseline (men: 3,020; women: 1,855). The certified long-term care levels of the national long-term care insurance (LTCI) system were used as an index of functional disability. We combined data from the 2010 Japan Gerontological Evaluation Study and data from the 2010 to 2016 LTCI system. Group-based mixture models and multinominal logistic regression models were used for data analysis.

Results: five distinct trajectories of functional disability in the last 3 years of life were identified: 'persistently severe disability' (10.3%), 'persistently mild disability' (13.0%), 'accelerated disability' (12.6%), 'catastrophic disability' (18.8%) and 'minimum disability' (45.2%). Multinominal logistic regression analysis found several factors associated with trajectory membership; self-rated health was a common predictor regardless of age and gender. The analysis also showed a paradoxical association; higher education was associated with trajectory group membership probabilities of more severe functional decline in men over 85 years at death.

Conclusions: individual perception of health was a strong predictor of trajectories, independent of demographic factors and socio-economic status. Our findings contribute to the development of policies for the long-term care system, particularly for end-of-life care, in Asian countries.

Keywords: disability, Japan, trajectory, older people

Key Points

- Understanding the heterogeneity of the disablement process over time is informative for disability prevention strategies.
- Using long-term care insurance data and nationwide survey samples, we identified five disability patterns at end of life.
- Self-rated health was a strong predictor of such trajectories, independent of demographic factors and socio-economic status.

Introduction

Functional disability is a critical public health issue in an increasingly ageing society. Functional disability, defined as difficulty in performing tasks needed for independent living [1], is generally measured by activities of daily living (ADL) [2–4] and instrumental ADL [5]. Functional disability in older adults affects their quality of life and health status, and impacts the health care system with long-term hospitalisation and care needs [6, 7]. Thus, exploring the potential factors for the prevention and postponement of functional disability is necessary.

The theory of compression of morbidity proposes that, if the onset of chronic illness and disability can be postponed, the lifetime burden of illness and disability can be compressed into a shorter average period before death [8]. This theory is informative for population-based disability prevention strategies; however, the disablement is an individual-level phenomenon. For the development of clinical strategies for end-of-life care and support from family members, it is more useful to understand the systematic heterogeneity of the disablement process over time for community-dwelling older people at the end-of-life stage.

Although several studies have revealed trajectory patterns of functional disability in old age [9–13], research on disability trajectories at the end of life is sparse. Gill *et al.* [14] found five distinct trajectories of disability in the last year of life among community-dwelling older residents—no disability, catastrophic disability, accelerated disability, progressive disability and persistently severe disability. Lunney *et al.* [15] also identified similar trajectory patterns of mobility limitation at end of life (3 years before death) in community-dwelling older people. However, these two studies were based on data from the United States; no study from Asian countries, including Japan, has explored these patterns at end of life. Functional trajectories are relevant to diagnosis and the delivery of health services and long-term care, which vary across countries [16, 17]. Furthermore, these studies did not specifically examine the determinants of trajectories by age group, which may be particularly informative for policy implications.

To better understand the patterns of functional disability at end of life in older adults, this study analysed data from the Japan Gerontological Evaluation Study (JAGES), a questionnaire-based nationwide study targeting community-dwelling older people aged ≥ 65 years who are functionally independent. First, it aimed to identify distinct subgroups of trajectories of disability over time 3 years before death. Second, it examined the factors associated with trajectory group membership probabilities by age group.

Methods

Study participants

Baseline data were obtained from the 2010 JAGES and combined with individual long-term care insurance (LTCI)

data for 6 years (2010–16) from 14 municipalities in seven prefectures across six regions in Japan. Of the 121,398 adults recruited in the JAGES 2010 survey, 72,440 responded (response rate 59.7%). Among them, 70,697 participants' data matched with the LTCI database, whereas 7,943 had died during the follow-up period until 2016. Among them, 4,875 decedents were eligible for LTCI trajectories with >36 months' follow-up (Figure 1).

The JAGES protocol was approved by the Ethics Committee for Research on Human Subjects at Nihon Fukushi University (No. 10-05), and the use of the JAGES data was approved by the Ethics Committee of the Faculty of Medicine, The University of Tokyo (No. 10555).

This study is a continuation of our previous work that identified the trajectory patterns, using the same combined databases of JAGES 2010 and individual LTCI data for 6 years [10]. While the previous study identified three trajectory patterns from the 'onset' of the functional disability, this study focuses on functional disability at 'end of life' in older adults, which can contribute directly to the development of end-of-life care and support from family members.

Functional disability

We used the certified long-term care levels of the national LTCI system as an index of functional disability. According to the LTCI system, individuals are classified into seven care levels based on a home visit survey by a trained interviewer and an examination by a primary care physician: support levels 1–2 and care levels 1–5 [18], where care level 5 indicates the highest functional disability. In principle, the long-term care level certification is valid for 12 months, and a maximum of 24 months (with the exception of 6 months for the initial certification). Older adults or their family members need to renew the certification before expiry, and may apply for re-evaluation of the care level based on the progress of the disability even during the validity period. Each municipality, as the insurer, makes the final decision to certify the care level based on nationally standardised evaluation items. We scored individual functional disability using an 8-point Likert scale: 8 = independent, 7 = support level 1, 6 = support level 2, 5 = care level 1, 4 = care level 2, 3 = care level 3, 2 = care level 4 or 1 = care level 5. In the current analysis, we used the care levels during the last 36 months before death.

Sociodemographic factors

We assessed participants' marital status and socio-economic status (SES; including education, annual equivalised household income and working status) from the 2010 JAGES survey. Marital status was divided into 'married' or 'not married'. Education was measured by years of schooling and categorised into '≤9 years' or '≥10 years'. Annual equivalised household income was adjusted for household size, dividing the income by the square root of the number of people in the household, and categorised into '< 3 million
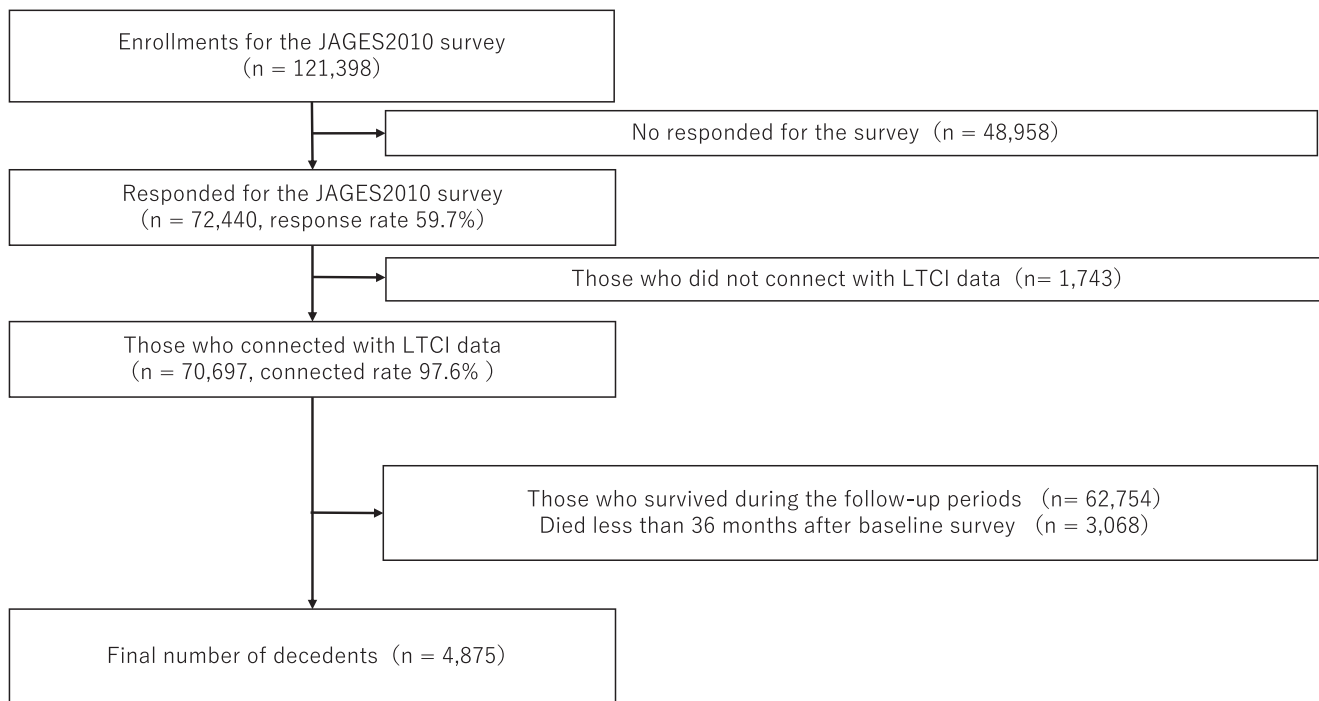
Figure 1. Flow diagram for participant selection.

yen' or '≥3 million yen'. Working status was categorised into 'currently working' or 'currently not working'.

Health status

Health status included self-rated health and number of current medical treatments, from the 2010 JAGES data. Self-rated health was assessed by: 'How do you feel about your current health status: excellent, good, fair, or poor?' Responses were categorised into dichotomous variables (good [excellent/good] or poor [fair/poor]). The number of current medical treatments was calculated for 14 diseases (i.e. cancer, heart disease, stroke, high blood pressure, diabetes, obesity, hyperlipidaemia, osteoporosis, joint disease/neuralgia, injury/fracture, respiratory disease, gastrointestinal disease, liver disease and mental disease) in three categories (1 = no disease, 2 = 1 disease or 3 = ≥2 diseases).

Covariates

Duration from the baseline survey to death (days) and population density were used as covariates. We evaluated the last 3 years of life during the 6 follow-up years from 2010, encompassing 1,095–2,339 days. Municipality population density of inhabitable area was categorised as follows: metropolitan (≥4,000 people/km²), urban (1,500–3,999 people/km²), semi-urban (1,000–1,499 people/km²) and rural (≤999 people/km²).

Statistical analysis

First, we used group-based mixture models (GBMM) with maximum likelihood estimation, using *traj* STATA package

[19], to identify distinct trajectories of functional disability before death among older decedents. GBMM focuses on between-class differences in intercepts and slopes; individuals within each group start at the same value [20]. We used GBMM since our study focuses on trajectory group identification, rather than distinct populations within subgroups. In addition, GBMM results are simple and easy to interpret compared with other models, such as the growth mixture model, because the model provides clearer identification of latent classes and simpler computations [20]. The level of functional disability per month in the last 36 months before death (i.e. 36 time points) was modelled as a normal distribution. We identified trajectories based on the number of groups (2–5) and the shape of their trajectory (1: linear, 2: quadratic or 3: cubic) and selected the best fit using the Bayesian information criterion, the Akaike information criterion, substantial number of participants in each group (at least 5%) and the study objective (identification of distinct and interpretable trajectories of functional disability). To determine the final model's validity, we confirmed that the average posterior probability of each class was above 0.70, which indicated good discrimination. There were no missing data for the group-based trajectory analysis, since functional disability information was collected from a public (LTCI) database.

We then used multinomial logistic regression analysis to calculate the relative risk ratios (RRR) and 95% confidence intervals (CIs), stratified by gender and three age-at-death groups—young–old (67–79 years), middle–old (80–84 years) and old–old (≤85 years)—as research on older Japanese adults has shown that the factors associated with functional disability differ by gender [21, 22].
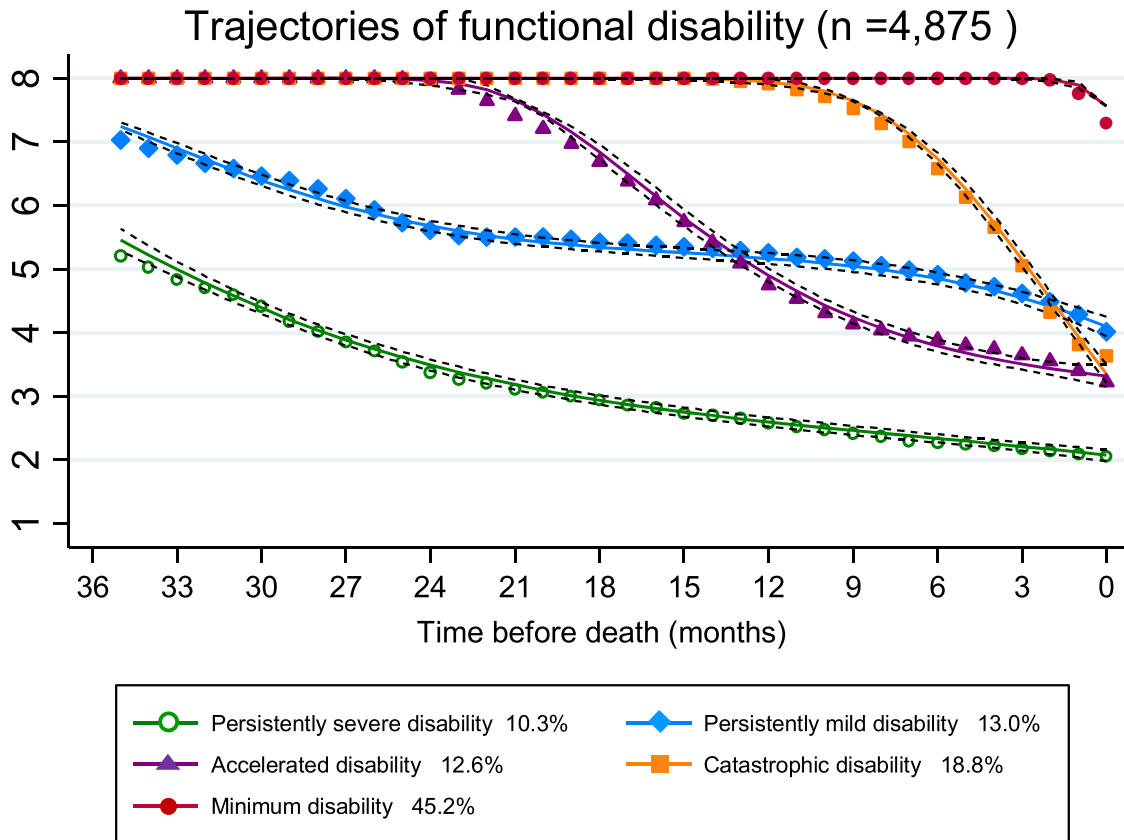
Trajectories of functional disability (n =4,875)

Figure 2. Trajectories of functional disability in the last 3 years of life among decedents. Functional disability indicated the certified long-term care levels of the national LTCI system by an 8-point Likert scale: 8 = independent, 7 = support level 1, 6 = support level 2, 5 = care level 1, 4 = care level 2, 3 = care level 3, 2 = care level 4 and 1 = care level 5. The solid lines show the estimated values of functional disability for members in the groups. The plots show the observed level of functional disability among members in the groups. Dashed lines in black colour show the 95% CIs.

Sociodemographic variables, health status, municipality population density and duration from baseline survey to death (days) were added in the model. In addition, we examined the heterogeneity in the association between age-at-death and trajectory patterns by gender including interaction terms. To mitigate potential biases because of missing data in the JAGES, we used the multiple imputation (MI) by chained equations approach under the missing at random assumption. We built 20 imputed data sets and combined the results using the standard Rubin's rule [23]. We conducted a sensitivity analysis without MI, applying the missing indicator method [24]. All analyses were conducted using STATA 14.2 (Stata Corp, College Stations, TX, USA).

Results

The best-fitting model of functional disability trajectories before death was a five-trajectory model, shaped '3-3-3-3-1'. Figure 2 illustrates the trajectories of functional disability in the last 3 years of life for deceased participants: persistently severe disability (504 [10.3%]), persistently mild disability (635 [13.0%]), accelerated disability (616 [12.6%]),

catastrophic disability (915 [18.8%]) and minimum disability (2,205 [45.2%]).

Table 1 shows the baseline characteristics of the decedents by the five trajectories. For both men and women, the 'minimum disability' and 'catastrophic disability' groups, respectively, had the highest (49.2% and 38.8%, respectively) and second highest proportions (18.8% and 18.8%). The average age-at-death differed across the trajectories for men and women; the 'persistently mild disability' group showed the oldest age-at-death (85.5 years) for men and the 'persistently severe disability' group showed the oldest age-at-death (88.8 years) for women, whereas the 'minimum disability' group showed the youngest age-at-death (80.0 and 81.2 years, respectively). These groups had different sociodemographic characteristics, including marital status and SES. During the follow-up period, 59.1% of men (*n* = 1,784) and 68.9% of women (*n* = 1,278) had certified long-term care needs. The mean functional ability (the mean certified long-term care level) at 36 months before death was 7.68 for men and 7.44 for women, and these decreased to 5.27 and 4.89, respectively, in the last month of life (data not shown). These results demonstrate that functional disability at the end of life is more severe in women than in men. The detailed

Table 1. Characteristics of decedents at baseline according to functional disability trajectory group with imputed data.

	All	Persistently severe disability	Persistently mild disability	Accelerated disability	Catastrophic disability	Minimum disability	P-value
	% or mean (SD)	% or mean (SD)	% or mean (SD)	% or mean (SD)	% or mean (SD)	% or mean (SD)	
Men							
	(n = 3,020; 100%)	(n = 255; 8.4%)	(n = 331; 11.0%)	(n = 382; 12.7%)	(n = 567; 18.8%)	(n = 1,485; 49.2%)	
Age at death	82.0 (6.6)	85.0 (6.6)	85.5 (6.1)	83.8 (6.3)	82.6 (6.2)	80.0 (6.2)	<0.001
Years of education, ≥10 years	45.0	44.5	46.4	39.7	46.1	45.8	<0.001
Equivalised household income, ≥3 million yen	24.7	21.6	25.1	23.7	25.6	25.1	<0.001
Working status, currently working	19.3	10.7	12.9	15.7	19.3	23.2	<0.001
Marital status, married	82.4	81.4	74.4	84.0	82.5	83.9	<0.001
Number of medical treatments							<0.001
0	23.7	23.4	17.3	23.3	23.5	25.3	
1	39.9	39.3	40.2	41.8	37.3	40.5	
≥2	36.5	37.3	42.5	34.9	39.2	34.3	
Self-rated health, good	66.8	55.9	50.3	61.6	66.4	73.9	<0.001
Women							
	(n = 1,855; 100%)	(n = 249; 13.4%)	(n = 304; 16.4%)	(n = 234; 12.6%)	(n = 348; 18.8%)	(n = 720; 38.8%)	
Age at death	84.1 (7.0)	88.8 (6.5)	86.5 (6.2)	85.5 (6.2)	84.0 (6.6)	81.2 (6.6)	<0.001
Years of education, ≥10 years	35.8	29.8	36.5	36.1	35.9	37.6	<0.001
Equivalised household income, ≥3 million yen	25.6	22.6	25.3	30.5	25.9	25.0	<0.001
Working status, currently working	12.0	5.7	8.2	10.8	12.1	16.1	<0.001
Marital status, married	40.9	32.3	35.5	39.2	34.9	49.5	<0.001
Number of medical treatments							<0.001
0	19.1	16.8	17.9	21.3	17.2	20.6	
1	38.7	41.7	42.2	36.2	38.7	37.0	
≥2	42.2	41.6	39.9	42.5	44.1	42.5	
Self-rated health, good	65.9	59.2	56.7	59.4	66.4	74.0	<0.001

SD, standard deviation. The results of one-way factorial ANOVA for age-at-death and chi-square test for other variables.

proportions of each variable by trajectories and age-at-death subgroups are shown in Supplementary Tables S1 and S2.

Tables 2 and 3 show the results of the multinomial logistic regression analysis stratified by age (young–old, middle–old and old–old) and gender. For men, poor self-rated health was generally associated with memberships in the 'persistently severe disability', 'persistently mild disability', 'accelerated disability' and 'catastrophic disability' (only for young–old) trajectories. In particular, among old–old men, higher education was associated with 'persistently mild disability' and 'catastrophic disability'; however, these associations were not observed in other age-at-death groups. Marital status was also inversely associated with membership in the 'persistently mild disability' trajectory. For women, poor self-rated health was associated with memberships in the same three trajectories as men. For other variables, common associations with multiple trajectory groups were not found. The interaction between age-at-death (three categories) and gender in the model of all samples showed that the effect of age for women aged ≥85 years and belonging to the 'persistently severe disability' trajectory was significantly larger compared with

their male counterparts; however, such an interaction was not observed in other trajectory patterns.

Supplementary tables show the results of interaction terms in multinominal logistic regression analysis of all samples (Supplementary Table S3), baseline characteristics without imputed data (Supplementary Table S4) and sensitivity analysis without MI and the missing indicator method (Supplementary Tables S5 and S6).

Discussion

This study analysed data on functional disability during the last 3 years of life in a nationwide sample of older Japanese decedents and generated two key findings. First, it identified five distinct trajectories of end-of-life (here, last 3 years before death) functional disability: 'persistently severe disability', 'persistently mild disability', 'accelerated disability', 'catastrophic disability' and 'minimum disability'. Second, it found several factors, including self-rated health and education, associated with trajectory membership. In particular, self-rated health was consistently associated with trajectory membership in both men and women.

Table 2. Multinominal logistic regression analysis on the trajectory membership of functional disability in the age-at-death subgroups in men.

	Men (n = 3,020)		
	67–79 years (n = 1,096)	80–84 years (n = 809)	85 years (n = 1,115)
Persistently severe disability	RRR (95% CI)	RRR (95% CI)	RRR (95% CI)
Years of education, ≥10 years	1.08 (0.59–2.00)	1.42 (0.80–2.53)	1.26 (0.81–1.95)
Equivalised household income, ≥3 million yen	0.70 (0.29–1.66)	0.75 (0.34–1.63)	0.88 (0.52–1.49)
Employment status, currently working	0.65 (0.30–1.41)	0.37 (0.13–1.04)	0.52 (0.24–1.15)
Marital status, married	0.95 (0.41–2.18)	0.95 (0.42–2.16)	0.91 (0.56–1.50)
Number of medical treatments			
1	0.59 (0.29–1.20)	0.91 (0.42–1.96)	1.08 (0.59–1.96)
≥2	0.57 (0.28–1.17)	0.79 (0.36–1.76)	1.05 (0.58–1.92)
Self-rated health, good	**0.31 (0.17–0.57)**	**0.37 (0.20–0.70)**	**0.50 (0.32–0.79)**
Population density (ref: metropolitan)			
Urban	1.02 (0.42–2.49)	0.79 (0.38–1.62)	1.33 (0.79–2.25)
Semi-urban	1.99 (0.92–4.33)	1.49 (0.72–3.08)	1.30 (0.74–2.28)
Rural	1.91 (0.69–5.33)	0.88 (0.36–2.16)	1.56 (0.74–3.29)
Duration from the baseline survey to death (days)	**1.001 (1.001–1.002)**	**1.001 (1.000–1.002)**	**1.002 (1.001–1.003)**
Persistently mild disability			
Years of education, ≥10 years	0.94 (0.52–1.69)	1.02 (0.61–1.71)	**1.86 (1.27–2.72)**
Equivalised household income, ≥3 million yen	0.54 (0.22–1.30)	0.90 (0.44–1.84)	1.16 (0.75–1.80)
Employment status, currently working	0.60 (0.27–1.32)	1.11 (0.59–2.09)	0.51 (0.25–1.05)
Marital status, married	0.56 (0.29–1.10)	**0.48 (0.26–0.88)**	0.69 (0.45–1.06)
Number of medical treatments			
1	**3.08 (1.05–9.08)**	0.94 (0.47–1.88)	1.10 (0.65–1.88)
≥2	2.40 (0.82–7.06)	0.88 (0.44–1.77)	1.27 (0.74–2.17)
Self-rated health, good	**0.22 (0.12–0.40)**	**0.31 (0.19–0.51)**	**0.44 (0.30–0.65)**
Population density (ref: metropolitan)			
Urban	1.29 (0.54–3.07)	0.59 (0.32–1.09)	0.74 (0.46–1.19)
Semi-urban	2.02 (0.89–4.58)	1.54 (0.85–2.80)	1.04 (0.63–1.69)
Rural	2.49 (0.96–6.45)	**0.33 (0.13–0.87)**	1.55 (0.87–2.77)
Duration from the baseline survey to death (days)	1.001 (1.000–1.002)	1.001 (1.000–1.001)	**1.001 (1.000–1.001)**
Accelerated disability			
Years of education, ≥10 years	0.65 (0.41–1.02)	1.03 (0.64–1.64)	1.04 (0.71–1.53)
Equivalised household income, ≥3 million yen	1.14 (0.65–1.99)	0.83 (0.42–1.67)	0.95 (0.60–1.51)
Employment status, currently working	0.72 (0.42–1.24)	0.65 (0.33–1.29)	0.89 (0.51–1.56)
Marital status, married	1.27 (0.67–2.40)	0.65 (0.37–1.15)	1.59 (0.97–2.59)
Number of medical treatments			
1	1.29 (0.64–2.62)	1.09 (0.58–2.02)	0.85 (0.52–1.40)
≥2	1.51 (0.77–2.97)	0.61 (0.32–1.17)	0.85 (0.49–1.45)
Self-rated health, good	**0.44 (0.27–0.70)**	**0.45 (0.28–0.72)**	0.75 (0.49–1.14)
Population density (ref: metropolitan)			
Urban	1.08 (0.61–1.91)	0.85 (0.48–1.51)	0.65 (0.41–1.03)
Semi-urban	0.71 (0.39–1.31)	1.12 (0.60–2.09)	0.92 (0.57–1.49)
Rural	1.90 (0.96–3.74)	1.14 (0.58–2.25)	0.86 (0.47–1.60)
Duration from the baseline survey to death (days)	1.000 (1.000–1.001)	1.000 (1.000–1.001)	1.000 (1.000–1.000)
Catastrophic disability			
Years of education, ≥10 years	0.93 (0.66–1.29)	1.26 (0.83–1.91)	1.26 (0.89–1.79)
Equivalised household income, ≥3 million yen	1.09 (0.72–1.65)	1.17 (0.72–1.92)	0.92 (0.61–1.38)
Employment status, currently working	0.94 (0.64–1.37)	1.00 (0.60–1.67)	0.80 (0.48–1.34)
Marital status, married	1.20 (0.73–1.96)	0.86 (0.49–1.51)	0.97 (0.64–1.45)
Number of medical treatments			
1	0.95 (0.60–1.53)	1.05 (0.57–1.92)	0.91 (0.57–1.43)
≥2	0.93 (0.58–1.50)	1.50 (0.84–2.67)	1.04 (0.66–1.64)
Self-rated health, good	**0.62 (0.43–0.90)**	0.73 (0.47–1.14)	0.76 (0.53–1.11)
Population density[a] (ref: metropolitan)			
Urban	0.78 (0.51–1.20)	0.65 (0.39–1.09)	0.84 (0.56–1.27)
Semi-urban	0.79 (0.52–1.21)	0.84 (0.48–1.47)	0.94 (0.60–1.47)
Rural	0.99 (0.57–1.70)	0.75 (0.40–1.42)	1.02 (0.58–1.78)
Duration from the baseline survey to death (days)	1.000 (1.000–1.001)	1.000 (1.000–1.001)	1.000 (1.000–1.001)

RRR, relative risk ratio. [a]Municipality population density of inhabitable area was categorised as metropolitan (≥4,000 people/km^2), urban (1,500–3,999 people/km^2), semi-urban (1,000–1,499 people/km^2) and rural (≤999 people/km^2). Bold values (RRR and 95% CIs) reached statistical significance, <0.05.

Table 3. Multinominal logistic regression analysis on the trajectory membership of functional disability in the age-at-death subgroups in women.

	Women (n = 1,855)		
	67–79 years (n = 487)	80–84 years (n = 443)	85 years (n = 925)
Persistently severe disability	RRR (95% CI)	RRR (95% CI)	RRR (95% CI)
Years of education, ≥10 years	0.94 (0.33–2.64)	1.97 (0.86–4.49)	**0.62 (0.40–0.98)**
Equivalised household income, ≥3 million yen	0.30 (0.04–2.18)	0.99 (0.36–2.71)	1.28 (0.71–2.33)
Employment status, currently working	0.31 (0.04–2.60)	0.74 (0.19–2.85)	0.50 (0.17–1.46)
Marital status, married	1.99 (0.63–6.25)	0.95 (0.46–1.95)	0.84 (0.51–1.37)
Number of medical treatments			
1	0.90 (0.21–3.87)	1.42 (0.46–4.38)	1.13 (0.59–2.16)
≥2	1.12 (0.25–4.90)	0.67 (0.22–2.03)	0.71 (0.38–1.33)
Self-rated health, good	0.41 (0.15–1.09)	**0.44 (0.20–0.97)**	**0.48 (0.31–0.76)**
Population density (ref: metropolitan)			
Urban	1.17 (0.30–4.55)	1.67 (0.64–4.31)	0.91 (0.56–1.50)
Semi-urban	1.85 (0.48–7.10)	2.05 (0.74–5.70)	1.05 (0.61–1.82)
Rural	**5.44 (1.12–26.36)**	1.02 (0.23–4.63)	0.69 (0.33–1.45)
Duration from the baseline survey to death (days)	**1.002 (1.000–1.003)**	**1.001 (1.000–1.003)**	**1.001 (1.001–1.002)**
Persistently mild disability			
Years of education, ≥10 years	1.16 (0.57–2.35)	1.35 (0.71–2.55)	0.90 (0.58–1.38)
Equivalised household income, ≥3 million yen	1.06 (0.42–2.70)	1.08 (0.54–2.16)	1.29 (0.68–2.43)
Employment status, currently working	0.90 (0.33–2.47)	0.94 (0.37–2.40)	0.49 (0.18–1.32)
Marital status, married	0.69 (0.33–1.44)	0.82 (0.45–1.50)	0.90 (0.55–1.46)
Number of medical treatments			
1	1.09 (0.37–3.21)	1.26 (0.52–3.03)	1.09 (0.60–1.96)
≥2	0.88 (0.32–2.42)	0.76 (0.33–1.78)	0.62 (0.34–1.13)
Self-rated health, good	**0.14 (0.07–0.31)**	**0.41 (0.21–0.78)**	**0.52 (0.33–0.82)**
Population density (ref: metropolitan)			
Urban	0.83 (0.35–1.95)	1.37 (0.61–3.06)	1.08 (0.65–1.78)
Semi-urban	0.95 (0.40–2.26)	**2.65 (1.18–5.96)**	1.51 (0.87–2.62)
Rural	0.97 (0.28–3.35)	2.42 (0.86–6.81)	1.07 (0.54–2.12)
Duration from the baseline survey to death (days)	**1.001 (1.000–1.002)**	**1.002 (1.001–1.002)**	**1.001 (1.000–1.002)**
Accelerated disability			
Years of education, ≥10 years	0.95 (0.44–2.08)	1.02 (0.53–1.94)	1.00 (0.62–1.60)
Equivalised household income, ≥3 million yen	1.04 (0.37–2.94)	1.23 (0.60–2.53)	**1.89 (1.06–3.37)**
Employment status, currently working	0.84 (0.27–2.58)	0.85 (0.32–2.26)	0.84 (0.34–2.12)
Marital status, married	0.82 (0.39–1.71)	0.94 (0.51–1.70)	1.04 (0.60–1.80)
Number of medical treatments			
1	0.98 (0.30–3.23)	1.40 (0.51–3.80)	0.66 (0.34–1.29)
≥2	1.56 (0.51–4.85)	1.31 (0.50–3.44)	**0.40 (0.21–0.76)**
Self-rated health, good	**0.33 (0.16–0.69)**	**0.50 (0.27–0.91)**	**0.55 (0.33–0.91)**
Population density (ref: metropolitan)			
Urban	0.53 (0.20–1.41)	0.76 (0.37–1.57)	0.91 (0.53–1.57)
Semi-urban	1.27 (0.54–2.99)	1.19 (0.55–2.57)	1.22 (0.67–2.23)
Rural	1.64 (0.54–5.04)	0.41 (0.13–1.30)	0.44 (0.19–1.01)
Duration from the baseline survey to death (days)	1.001 (1.000–1.002)	1.000 (1.000–1.001)	1.000 (1.000–1.001)
Catastrophic disability			
Years of education, ≥10 years	1.10 (0.67–1.81)	1.23 (0.67–2.25)	0.81 (0.52–1.26)
Equivalised household income, ≥3 million yen	0.74 (0.39–1.43)	1.80 (0.92–3.54)	1.29 (0.74–2.24)
Employment status, currently working	0.83 (0.43–1.59)	0.85 (0.33–2.18)	1.04 (0.45–2.42)
Marital status, married	0.66 (0.40–1.07)	0.69 (0.38–1.27)	0.80 (0.47–1.35)
Number of medical treatments			
1	0.73 (0.37–1.46)	1.37 (0.56–3.30)	1.36 (0.71–2.63)
≥2	0.78 (0.40–1.53)	1.01 (0.43–2.36)	1.08 (0.58–2.02)
Self-rated health, good	0.67 (0.38–1.18)	0.84 (0.44–1.62)	**0.63 (0.40–0.98)**
Population density[a] (ref: metropolitan)			
Urban	0.86 (0.47–1.60)	0.65 (0.32–1.32)	**0.56 (0.34–0.91)**
Semi-urban	1.07 (0.56–2.02)	0.73 (0.33–1.59)	0.79 (0.46–1.35)
Rural	1.75 (0.83–3.69)	0.71 (0.27–1.84)	**0.39 (0.19–0.79)**
Duration from the baseline survey to death (days)	1.000 (1.000–1.001)	1.001 (1.000–1.002)	1.000 (1.000–1.000)

[a]Municipality population density of inhabitable area was categorised as metropolitan (≥4,000 people/km²), urban (1,500–3,999 people/km²), semi-urban (1,000–1,499 people/km²) and rural (≤999 people/km²). Bold values (RRR and 95% CIs) reached statistical significance, <0.05.

These five trajectories are similar to previous studies in the United States [14, 15], indicating little cultural and racial/ethnical differences in end-of-life trajectory patterns among older adults. We also found that approximately half of the decedents maintained high functional independence before death (i.e. belonged to the 'minimum disability' group). This proportion is higher than that in previous studies. For example, Gill *et al.* [14] reported that ∼17% of older decedents in the United States belonged to the 'no disability' trajectory group. These findings from western countries are based on data from the 1990s. Of late, older adults have been found to show healthier trajectories of functional ability [25, 26]; thus, it is possible that a cohort effect might have influenced the present results. Another reason for this result could be the method of assessing functional disability. We used data from the certified care levels of the Japanese LCTI system to assess functional disability. In this system, the care level is changed only when individuals or their family members apply for an evaluation or when certification is renewed after its expiry [18]. Therefore, the care levels of the present sample might have been underestimated, leading to a high proportion of people in the 'minimum disability' trajectory.

Poor self-rated health was inversely associated with membership in the 'minimum disability' trajectory for both men and women. Self-rated health is a culturally dependent measure that reflects both functional and psychosocial status and may improve with age [27, 28]; it has been found to be a good predictor of mortality and morbidity among older adults in both western and Asian countries [29–31]. The present study indicates that even at the end of life, better perception of one's own health can predict individual functional ability across all age groups after adjustment of actual disease conditions and socio-economic factors. A possible explanation is that self-rated health may represent an individual's comprehensive evaluation of their own health over objective measures [29] or that self-rated health may reflect either psychosocial resources that an individual possesses or health behaviours that influence changes in functional ability [32, 33].

Marital status was inversely associated with membership in the 'persistently mild disability' trajectory, exclusively in men; this association is consistent with previous research [34] and a possible explanation is the marital resource model [35]. Marriage provides important resources, including social, psychological and economic support, which may help sustain an individual's health and well-being. Especially, as older men tend to have narrower social networks than women [36], the proportion of resources provided by a spouse may be larger. Another explanation involves the psychological mechanisms after a spouse's death. The majority of unmarried older men in this study were widowed rather than single or divorced. The loss of a spouse is one of the most stressful life events [37] and may cause more psychological distress and exacerbate functional disability, especially in men [38].

In addition, we found an association between low educational level and membership in the 'minimum disability'

trajectory among men aged over 85 years at death. This is paradoxical, but consistent with previous findings regarding childhood SES and functional decline or mortality among older Japanese people [39, 40]. This finding may represent a survival bias—men who endured hardships in their early life and survived tend to have less functional disability in old age [41]; this includes people aged ≥85 at death during 2013–16, who were aged ≥14 years at the end of the World War II (1939–45). People in this cohort, who were of draft-eligible age during the war, were more likely to be drafted (and to die) if they belonged to families with a lower SES and more likely to be subjected to harsher conditions after the war [42, 43]. Therefore, men with low educational levels who survived the war until the age of 85 or above may have been very strong, both physically and mentally.

We also found an age–gender effect in the additional analysis, which suggests that although older adults enjoy a longer life expectancy, functional disability towards end of life becomes more severe with age; particularly, for those aged ≥85, it is more severe in women than in men. One reason for this could be that women tend to live longer. As functional disability increases with age in older populations [44] and women had a higher average age in the old–old group compared with men in this study, they needed relatively advanced levels of care in the last 3 years of life. Moreover, potential biological effects suggest that women are more susceptible to diseases (e.g. arthritis, depression, dementia and falls) that result in increased functional disability compared with men [45, 46].

Our findings can contribute to the development of policies in Japan's LTCI system. For example, by understanding the pattern of trajectories, their proportions and determinants by age group, we can predict the demand for end-of-life and medical care, and the impact of interventions that influence these determinants. The use of a statutory measure of functional disability, the level of long-term care needs, as in this study, emphasizes the significance for policy implications. Furthermore, we can evaluate end-of-life policies in terms of effectiveness, efficiency and equity by describing the cost estimates for each pattern and the percentage distribution of each pattern by subgroups, such as region and SES. The findings can also contribute to improving end-of-life care at the clinical level; for example, by predicting future changes in physical functioning, health professionals involved in care may be able to prepare the patient and their family for the end of life.

A major strength of this study is that it focused on end-of-life functional disability patterns among community-dwelling older adults using a retrospective cohort design with large panel data, a somewhat-neglected area of research, and thus, contributed significantly to the literature. Additionally, previous studies on this topic have been based in western countries. Since social and cultural backgrounds may influence attitudes towards end of life [47], evidence from non-western populations is needed. To our knowledge, this is the first study to investigate end-of-life functional disability trajectories in an Asian country.

However, this study has some limitations. First, data on long-term care levels were only obtained from individuals who applied for LTCI. Individuals who had functional disability but did not use the public LTCI because they had access to private nursing care or for other reasons are considered independent in the analysis. Although Japanese citizens aged ≥40 years are insured by the LTCI, we assumed that some individuals did not apply for it despite needing LTCI. Second, this study did not consider hospitalisation data, since we did not merge medical records data with LTCI data. Trajectory patterns that account for hospitalisation may better reflect actual functional decline at end of life among older adults [48]. Third, reverse causation remains possible in the association between sociodemographic factors and trajectory group membership. However, we confirmed that the results are similar in the sensitivity analysis, by excluding decedents who had reported being dependent in the baseline survey, even if not certified for long-term care needs yet (data are not shown in the table).

Conclusions

Using data from a nationwide study in Japan, we identified five distinct trajectories of functional disability among community-dwelling older adults at the end of life. We also found several factors associated with trajectory membership; in particular, self-rated health was a strong predictor of functional decline independent of demographic factors and SES, regardless of age and gender. We also found a paradoxical association between higher education and trajectory group membership probabilities of more severe functional decline in men aged ≥85 years at death, potentially reflecting the effects of surviving the World War II. Our findings can contribute to the development of new long-term care policies, particularly for end-of-life care in Asian countries.

References

1. Rodrigues MA, Facchini LA, Thumé E, Maia F. Gender and incidence of functional disability in the elderly: a systematic review. Cad Saude Publica 2009; 25: S464–76.
2. Katz S, Ford AB, Moskowitz RW, Jackson BA, Jaffe MW. Studies of illness in the aged. The index of ADL: a standardized measure of biological and psychosocial function. JAMA 1963; 185: 914–9.
3. Mahoney FI, Barthel DW. Functional evaluation: the Barthel index. Md State Med J 1965; 14: 61–5.
4. Data management service of the Uniform Data System for Medical Rehabilitation and the Center for Functional Assessment Research: Guide for use of the uniform data set for medical rehabilitation. version 3.1,State University of New York at Buffalo, 1990.
5. Lawton MP, Brody EM. Assessment of older people: self-maintaining and instrumental activities of daily living. Gerontologist 1969; 9: 179–86.
6. Guralnik JM, Fried LP, Salive ME. Disability as a public health outcome in the aging population. Annu Rev Public Health 1996; 17: 25–46.
7. Fried TR, Bradley EH, Williams CS, Tinetti ME. Functional disability and health care expenditures for older persons. Arch Intern Med 2001; 161: 2602–7.
8. Fries JF. Aging, natural death, and the compression of morbidity. N Engl J Med 1980; 303: 130–5.
9. Murayama H, Liang J, Shaw BA *et al.* Socioeconomic differences in trajectories of functional capacity among older Japanese: a 25-year longitudinal study. J Am Med Dir Assoc 2020; 21: 734–739.e1.
10. Saito J, Kondo N, Saito M *et al.* Exploring 2.5-year trajectories of functional decline in older adults by applying a growth mixture model and frequency of outings as a predictor: a 2010–2013 JAGES longitudinal study. J Epidemiol 2019; 29: 65–72.
11. Zimmer Z, Martin LG, Jones BL, Nagin DS. Examining late-life functional limitation trajectories and their associations with underlying onset, recovery, and mortality. J Gerontol B Psychol Sci Soc Sci 2014; 69: 275–86.
12. Yu H-W, Chen D-R, Chiang T-L, Tu Y-K, Chen Y-M. Disability trajectories and associated disablement process factors among older adults in Taiwan. Arch Gerontol Geriatr 2015; 60: 272–80.

13. Han L, Allore H, Murphy T, Gill T, Peduzzi P, Lin H. Dynamics of functional aging based on latent-class trajectories of activities of daily living. Ann Epidemiol 2013; 23: 87–92.

14. Gill TM, Gahbauer EA, Han L, Allore HG. Trajectories of disability in the last year of life. N Engl J Med 2010; 362: 1173–80.

15. Lunney JR, Albert SM, Boudreau R *et al.* Mobility trajectories at the end of life: comparing clinical condition and latent class approaches. J Am Geriatr Soc 2018; 66: 503–8.

16. Harris P, Wong E, Farrington S *et al.* Patterns of functional decline in hospice: what can individuals and their families expect? J Am Geriatr Soc 2013; 61: 413–7.

17. Murtagh FE, Addington-Hall JM, Higginson IJ. End-stage renal disease: a new trajectory of functional decline in the last year of life. J Am Geriatr Soc 2011; 59: 304–8.

18. Tsutsui T, Muramatsu N. Care-needs certification in the long-term care insurance system of Japan. J Am Geriatr Soc 2005; 53: 522–7.

19. Jones BL, Nagin DS. A note on a Stata plugin for estimating group-based trajectory models. Sociol Methods Res 2013; 42: 608–13.

20. Frankfurt S, Frazier P, Syed M, Jung KR. Using group-based trajectory and growth mixture modeling to identify classes of change trajectories. Couns Psychol 2016; 44: 622–60.

21. Noguchi T, Kondo K, Saito M, Nakagawa-Senda H, Suzuki S. Community social capital and the onset of functional disability among older adults in Japan: a multilevel longitudinal study using Japan Gerontological Evaluation Study (JAGES) data. BMJ Open 2019; 9: e029279. https://doi.org/10.1136/bmjopen-2019-029279.

22. Ashida T, Kondo N, Kondo K. Social participation and the onset of functional disability by socioeconomic status and activity type: the JAGES cohort study. Prev Med 2016; 89: 121–8.

23. White IR, Royston P, Wood AM. Multiple imputation using chained equations: issues and guidance for practice. Stat Med 2011; 30: 377–99.

24. Nur U, Shack LG, Rachet B, Carpenter JR, Coleman MP. Modelling relative survival in the presence of incomplete data: a tutorial. Int J Epidemiol 2009; 39: 118–28.

25. Taylor MG. Capturing transitions and trajectories: the role of socioeconomic status in later life disability. J Gerontol B Psychol Sci Soc Sci 2010; 65B: 733–43.

26. Schoeni RF, Liang J, Bennett J, Sugisawa H, Fukaya T, Kobayashi E. Trends in old-age functioning and disability in Japan, 1993–2002. Popul Stud 2006; 60: 39–53.

27. Ishizaki T, Yoshida H, Suzuki T, Shibata H. The association between self-rated health status and increasing age among older Japanese living in a rural community over a 6-year period: a longitudinal data analysis. Gerontology 2009; 55: 344–52.

28. Dening TR, Chi LY, Brayne C, Huppert FA, Paykel ES, O'Connor DW. Changes in self-rated health, disability and contact with services in a very elderly cohort: a 6-year follow-up study. Age Ageing 1998; 27: 23–33.

29. Idler EL, Benyamini Y. Self-rated health and mortality: a review of twenty-seven community studies. J Health Soc Behav 1997; 38: 21–37.

30. Lee Y, Shinkai S. A comparison of correlates of self-rated health and functional disability of older persons in the Far East: Japan and Korea. Arch Gerontol Geriatr 2003; 37: 63–76.

31. Lee Y. The predictive value of self-assessed general, physical, and mental health on functional decline and mortality in older adults. J Epidemiol Community Health 2000; 54: 123–9.

32. Xu J, Roberts RE. The power of positive emotions: it's a matter of life or death—subjective well-being and longevity over 28 years in a general population. Health Psychol 2010; 29: 9–19.

33. Halford C, Ekselius L, Anderzen I, Arnetz B, Svärdsudd K. Self-rated health, life-style, and psychoendocrine measures of stress in healthy adult women. Ups J Med Sci 2010; 115: 266–74.

34. Feng L, Ng XT, Yap P *et al.* Marital status and cognitive impairment among community-dwelling Chinese older adults: the role of gender and social engagement. Dement Geriatr Cogn Dis Extra 2014; 4: 375–84.

35. Williams K, Umberson D. Marital status, marital transitions, and health: a gendered life course perspective. J Health Soc Behav 2004; 45: 81–98.

36. McLaughlin D, Vagenas D, Pachana NA, Begum N, Dobson A. Gender differences in social network size and satisfaction in adults in their 70s. J Health Psychol 2010; 15: 671–9.

37. Holmes TH, Rahe RH. The social readjustment rating scale. J Psychosom Res 1967; 11: 213–8.

38. Lee GR, DeMaris A, Bavin S, Sullivan R. Gender differences in the depressive effect of widowhood in later life. J Gerontol B Psychol Sci Soc Sci 2001; 56: S56–61.

39. Tani Y, Kondo N, Nagamine Y *et al.* Childhood socioeconomic disadvantage is associated with lower mortality in older Japanese men: the JAGES cohort study. Int J Epidemiol 2016; 45: 1226–35.

40. Murayama H, Fujiwara T, Tani Y *et al.* Long-term impact of childhood disadvantage on late-life functional decline among older Japanese: results from the JAGES prospective cohort study. J Gerontol A Biol Sci Med Sci 2018; 73: 973–9.

41. Zimmer Z, Martin LG, Nagin DS, Jones BL. Modeling disability trajectories and mortality of the oldest-old in China. Demography 2012; 49: 291–314.

42. Watanabe T. Who became the soldiers? Part 1: inequality in pre-war Showa period military service cohorts. Kwansei Gakuin Sociol Depart Stud 2014; 119: 1–18.

43. Watanabe T. Inequality in mortality risk during the Asia-Pacific war. Kwansei Gakuin Sociol Depart Stud 2016; 123: 85–101.

44. Herr M, Arvieu JJ, Robine JM, Ankri J. Health, frailty and disability after ninety: results of an observational study in France. Arch Gerontol Geriatr 2016; 66: 166–75.

45. Newman AB, Brach JS. Gender gap in longevity and disability in older persons. Epidemiol Rev 2001; 23: 343–50.

46. Carmel S. Health and well-being in late life: gender differences worldwide. Front Med 2019; 10: 218. https://doi.org/10.3389/fmed.2019.00218.

47. Kagawa-Singer M, Blackhall LJ. Negotiating cross-cultural issues at the end of life: 'you got to go where he lives'. JAMA 2001; 286: 2993–3001.

48. Gill TM, Gahbauer EA, Han L, Allore HG. The role of intervening hospital admissions on trajectories of disability in the last year of life: prospective cohort study of older people. BMJ 2015; 350: h2361. https://doi.org/10.1136/bmj.h2361.