Article

The association between activities of daily living and long hours of care provided by informal caregivers using a nationally representative survey in Japan

Hiroaki Ueshima [a,b], Arito Yozu [a,c,*], Hideto Takahashi [d], Haruko Noguchi [e], Nanako Tamiya [a,f]

[a] Health Services Research & Development Center, University of Tsukuba, Japan, 1-1-1 Tenno-dai, Tsukuba, Ibaraki, 305-8575, Japan
[b] Division of Medical Information Technology and Administration Planning, Kyoto University Hospital, 54 Kawaharacho, Shogoin, Sakyo-ku, Kyoto, 606-8507, Japan
[c] Center for Medical Sciences, Ibaraki Prefectural University of Health Sciences, 4669-2 Ami, Ami-machi, Inashiki, Ibaraki, 300-0394, Japan
[d] National Institute of Public Health, Japan, 2-3-6 Minami, Wako, Saitama, 351-0197, Japan
[e] Faculty of Political Science and Economics, Waseda University, 1-6-1 Nishi-Waseda, Shinjuku-ku, Tokyo, 169-8050, Japan
[f] Department of Health Services Research, Faculty of Medicine, University of Tsukuba, Japan, 1-1-1 Tenno-dai, Tsukuba, Ibaraki, 305-8575, Japan

Introduction

The population in Japan is ageing rapidly, leading to the inevitable increase in the number of elders with disabilities living at home. Hence, Japanese government introduced the public long-term care insurance (LTCI) system in 2000. When individuals apply for certification for the LTCI services, municipalities evaluate their needs based on the information on activities of daily living (ADLs) and/or instrumental activities of daily living (IADLs) surveyed from them and their attending physicians. Thereafter, municipalities assign them to one of the eight care-need levels, which include independent, support-required (scale of 1–2) and severe care-required (scale of 1–5) levels. Applicants who are certified to be at either support-required or care-required level are eligible to use the LTCI services. Since the LTCI system was started in Japan, the number of LTCI service users has been increasing (the Ministry of Health, 2016).

Meanwhile, informal caregivers, such as family members or friends, have an important role in the continuity of living at home for older people with disabilities. Some previous studies suggested that heavy caregiver burden is a predictor of the admission of care recipients to a nursing care institution (Bilotta, Nicolini, & Vergani, 2009; Kuzuya et al., 2011). This burden should be reduced, so that elderly patients can avoid institutionalization and continue living at home.

In this study, we focused on the time spent on care that might reflect the burden on primary informal caregivers (PICs). Providing long hours of care is associated with negative consequences in PICs, such as a high risk of non-fatal coronary heart disease (Miyawaki et al., 2017), depressive symptoms (Cannuscio et al., 2002), highly subjective burden (Kim, Chang, Rose, & Kim, 2012), low health-related quality of life (Thomas, Saunders, Roland, & Paddison, 2015), low happiness ratings (van Campen, de Boer, & Iedema, 2013), retiring (Jacobs, Laporte, Van Houtven, & Coyte, 2014) and low self-reported health status(Legg, Weir, Langhorne, Smith, & Stott, 2013). Therefore, the number of hours spent on care provided by PICs should be shortened to reduce their burden.

Some research on the factors associated with long hours of care provided by PIC has been performed. In terms of the characteristics of the care recipients, male (Katz, Kabeto, & Langa, 2000), depression (Langa, Valenstein, Fendrick, Kabeto, & Vijan, 2004), stroke (Skolarus, Freedman, Feng, Wing, & Burke, 2016), or dementia (K M Langa et al., 2001; Nordberg, von Strauss, Kåreholt, Johansson, & Wimo, 2005) were associated with long hours of care by PIC. In terms of the characteristics of PICs, unmarried daughters of care recipients (Brody, Litvin, Albert, & Hoffman, 1994) or unemployed (Coleman, 1993, p. 221) were associated with long hours of care by PIC. Other previous studies reported that the number of hours of caregiving differed among different ethnic groups (Joo, Fang, Losby, & Wang, 2015), and that PICs living in urban areas provided more hours of care than those living in rural ones (Coleman, 1993, p. 221; Wimo et al., 2017).

The level of the ADLs of care recipients is an important factor associated with long hours of care provided by PICs. Some found that a low score of ADL was associated with long hours of care provided by PICs (Haro et al., 2014; Li, 2005). However, the specific assistance in ADL elements which is associated with long hours of care provided by PICs is unclear. Therefore, it is also unknown which specific ADL assistance by formal caregivers (FC) (e.g. visiting nurse services, home rehabilitation services, home care services, etc.) can effectively reduce the number of hours of care provided by PICs. Hence, this study aimed to determine the particular assistance by PIC in ADL elements associated with long hours of care provided by PICs, considering the presence of assistance by FCs.

* Corresponding author. Center for Medical Sciences, Ibaraki Prefectural University of Health Sciences, 4669-2 Ami, Ami-machi, Inashiki, Ibaraki, 300-0394, Japan
E-mail address: yodu-jscn@umin.net (A. Yozu).

Data and methods

Data

We used the Comprehensive Survey of Living Conditions (CSLC), which is a nationally representative cross-sectional survey conducted by the Statistical Act (Act No. 53 of May 23, 2007) of Japan. This survey comprises five questionnaires stated as follows: 1) Household Questionnaire, 2) Income Questionnaire, 3) Savings Questionnaire, 4) Health Questionnaire and 5) Long-term Care Questionnaire. Out of these questionnaires, we used the individual-based data of Household Questionnaire and Long-term Care Questionnaire in 2010 and 2013, with an official permission from the Ministry of Health, Labour and Welfare. Household Questionnaire was performed to survey all households living in roughly 5500 districts, which were randomly selected from the nationwide districts determined in the Japanese census. Each district has approximately 50 households. Consequently, Household Questionnaire surveyed approximately 750,000 household members in 290,000 households. Long-term Care Questionnaire was answered by approximately 7000 persons who were certified to be at either support-required or care-required level and lived in 2500 randomly selected districts out of the districts for the Household Questionnaire. All persons who were administered the Long-term Care Questionnaire were also given the Household Questionnaire. Therefore, we could merge the data obtained from Household Questionnaire and Long-term Care Questionnaire.

The Household Questionnaire in 2010 and 2013 surveyed 289,363 and 295,367 households, of which the response rates were 79.1% (228,864 households) and 79.4% (234,383 households), respectively. Meanwhile, the Long-term Care Questionnaire in the same time periods surveyed 7192 and 7270 people, of which the response rates were 82.2% (5910 responses) and 87.2% (6430 responses), respectively. The Household Questionnaire included several areas of question, such as the amount of monthly household expenditure in May in each survey year, family structure, types of health insurance, working status and the number of children in the household. Long-term Care Questionnaire included the care level, primary disease causing the disability and hours spent on care provided by PICs. This study was approved by the ethics committee of the University of Tsukuba (approval number: 1166).

Study subjects

From CSLC, we extracted care recipients who responded to both Household Questionnaire and Long-term Care Questionnaire, and their PICs who responded to the Household Questionnaire. We included samples if PICs were living with their care recipients. Then we excluded samples if there were one or more members in their household who were six years of age or older and who needed some help in addition to the care recipients. Thereafter, we identified the pairs of PIC and care recipient living together. Then, we included the pairs of PIC and care recipient if the age of the care recipients were older than 65 years and if their certified levels were care-required (scale of 1–5). Finally, we excluded the pairs of PIC and care recipient who met one of the following criteria: 1) care recipients were not provided any care by PIC, other caregivers, or FC; 2) children before admission to elementary school were living in the household; 3) care recipients had a job at the time of the survey; 4) care recipients were living in a group home for elderly people with dementia; 5) no information on the age of PICs or the number of hours of care provided by PICs was found; 6) no information on the primary disease causing the disability was found; or 7) the presence of assistance were unknown for at least one ADL as follows: oral cleansing, facial cleansing, changing of positions, feeding, taking of medicine, wiping of the body, toileting, bathing, washing of the hair, and dressing (Figure 1).

Dependent variable

The dependent variable indicated the length of time spent on care provided by PICs. The original questionnaire contained categorical variables such as 'almost all day', 'around half of the day', '2 to 3 h', 'help only when needed' and 'others'. Previous studies defined caregiving of more than 20 h per week, namely, approximately 3 h per day, as an intensive level of caregiving (Colombo, Llena-Nozal, Mercier, & Tjadens, 2011; Miyawaki et al., 2017). Additionally, in the original questionnaire, nearly half of study subjects were occupied 'almost all day' and 'around half of the day'. Hence, we made a dichotomous variable composed of 'longer hours' ('almost all day' or 'around half of the day') and 'shorter hours' ('2 to 3 h', 'help only when needed', or 'others') as the dependent variable.

Key independent variables

The key independent variables were the situations of assistance in each ADL element. Original Long-term Care Questionnaire included items on 16 activities, namely, oral cleansing, facial cleansing, changing of positions, feeding, taking of medicine, wiping of the body, toileting, bathing, washing of the hair, dressing, food preparation, walking outside, housekeeping, laundry, shopping, and conversation. Meanwhile, the Lawton–Brody ADL Scale (Lawton & Brody, 1969), which is a well-known IADL scale, includes the ability to use the telephone, shopping, food preparation, housekeeping, laundry, mode of transportation, responsibility for own medications, and ability to handle finances. Therefore, we excluded food preparation, walking outside, housekeeping, laundry, and shopping from the independent variables. However, we regarded taking of medicine as an independent variable because a previous study demonstrated that medication management could reduce the possibility of nursing home admission (Schulz, Porter, Lane, Cornman, & Branham, 2011). Conversation can be an ADL element, but it is not applicable to the LTCI services in Japan. Thus, we excluded conversation from the independent variables and focused on the physical aspects of ADL.

Therefore, the independent variables in this study included the assistance in oral cleansing, facial cleansing, changing of positions, feeding, taking of medicine, wiping of the body, toileting, bathing, washing of the hair, and dressing.

Regarding the assistance in each ADL element, the questionnaire asked who supported the care recipients. These individuals who provided the support was the PIC, FC, or other informal caregivers (e.g. friends and other family members aside from PIC). Based on this question, we constructed the following categorical variables for each ADL element by the presence or absence of care by PIC: 1) 'PIC did not assist' and 2) 'PIC assisted'. Then, we divided 2) 'PIC assisted' into two categories by the presence or absence of care from FC: 2-1) 'PIC assisted and FC did not assist' and 2-2) 'PIC and FC assisted' (Figure 2). We ignored ADL assistance by other informal caregivers because the number of care recipients in this category was limited (approximately 5% of all subjects in each ADL element). Instead, we included the number of informal caregivers except PIC as a control variable because this number reflects the ability of caregiving in households and can be associated with the hours of care by PIC.

Control variables

We included several control variables, namely, age, gender, working status, potential number of informal caregivers except PIC in his/her family and educational attainment, into our regression analyses. For care recipients, the control variables included the age, gender, care level, primary disease causing the disability and educational attainment.

Statistical analysis

We showed the descriptive statistics of the dependent and independent variables. Continuous variables were expressed as mean ± SD, whereas the categorical variables were expressed as numbers and percentages. Hence, we used the chi-square test or *t*-test to analyze the significant differences in the characteristics of PIC and care recipients between the dependent variables 'longer hours' and 'shorter hours'. Then, we used the single logistic regression analysis to examine the relationship between the assistance in each ADL element ('PIC assisted and FC did not assist' or 'PIC and FC assisted' versus 'PIC did not assist') and 'longer hours' of caregiving without adjustment.

Thereafter, we examined the associations between the assistance in each ADL element and 'longer hours' of caregiving adjusted by control variables, using two multiple logistic regression models, namely, the PIC model and the PIC and FC model. The PIC model included the situation of assistance in each ADL element by PICs as binary variables: 1) 'PIC did not assist' and 2) 'PIC assisted'. Meanwhile, the PIC and FC model included the situation of assistance in each ADL element by PIC and FC as the variables with the following three situations: 1) 'PIC did not assist' (as a reference), 2-1) 'PIC assisted and FC did not assist', and 2-2) 'PIC and FC assisted' (Figure 2). However, we excluded the facial cleansing and washing of the hair from the PIC model and the PIC and FC model because facial cleansing highly correlated with oral cleaning and washing of the hair highly correlated with bathing (Spearman's correlation coefficients > 0.6). Other correlations between independent variables were not strong (correlation coefficients < 0.6).

Furthermore, we conducted multiple logistic regression analysis using the PIC and FC model stratified by the gender of care recipients. We also conducted multiple logistic regression analysis using the PIC

and FC model stratified by the working situation because the working situation obviously reflects the availability of PICs to provide care and a previous study showed that having no job was a PIC-related factor associated with long hours of caregiving (Coleman, 1993, p. 221).

All models were adjusted for the dummy of the survey year, characteristics of PICs (age, gender, working status, the number of other informal caregivers and educational attainment) and characteristics of care recipients (age, gender, care level, primary disease causing the disability and educational attainment). The results of the multiple logistic regression analysis were expressed as odds ratios (OR) with 95% confidence interval (CI). We considered P < 0.05 as statistically significant. Our analyses were conducted by Stata 14 (StataCorp, College Station, TX, USA).

Results

Descriptive analysis

We identified 3758 pairs of PIC and care recipients as study subjects (Figure 1). For the 3758 PICs, the mean age was 64.9 years (SD 11.2 years). Among these PICs, 985 (26.2%) were male, and 2773 (73.8%) were female. A total of 1715 PICs (45.6%) spent 'longer hours' on care, and they tended to be significantly older, less likely to be working, and less likely to achieve a higher educational attainment compared with those who spent 'shorter hours' on informal care (Table 1).

For the care recipients, the mean age was 83.8 years (SD 7.8 years). A total of 1343 (35.7%) were male, and 2415 (64.3%) were female. Major cause of the disability was stroke for 950 care recipients (25.3%), followed by dementia for 788 care recipients (21.0%). Care recipients whose PICs spent 'longer hours' on care were more likely to be male,
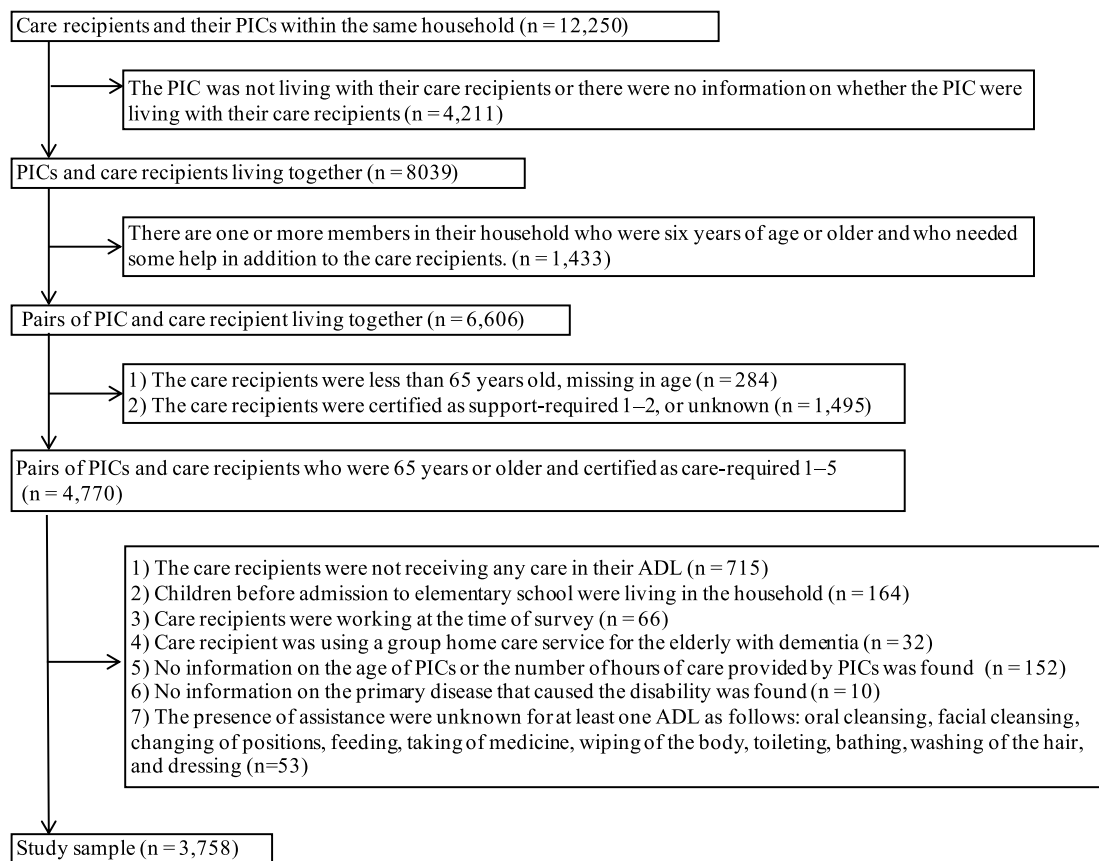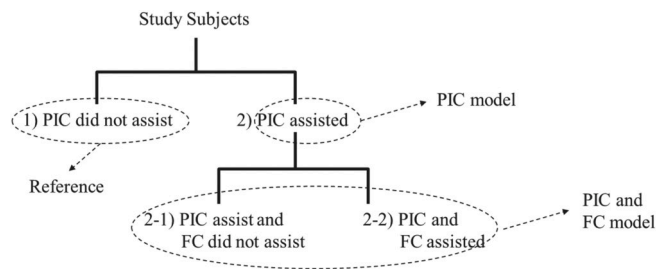
Care recipients and their PICs within the same household (n = 12,250)

→ The PIC was not living with their care recipients or there were no information on whether the PIC were living with their care recipients (n = 4,211)

PICs and care recipients living together (n = 8039)

→ There are one or more members in their household who were six years of age or older and who needed some help in addition to the care recipients. (n = 1,433)

Pairs of PIC and care recipient living together (n = 6,606)

→ 1) The care recipients were less than 65 years old, missing in age (n = 284)
2) The care recipients were certified as support-required 1–2, or unknown (n = 1,495)

Pairs of PICs and care recipients who were 65 years or older and certified as care-required 1–5 (n = 4,770)

→ 1) The care recipients were not receiving any care in their ADL (n = 715)
2) Children before admission to elementary school were living in the household (n = 164)
3) Care recipients were working at the time of survey (n = 66)
4) Care recipient was using a group home care service for the elderly with dementia (n = 32)
5) No information on the age of PICs or the number of hours of care provided by PICs was found (n = 152)
6) No information on the primary disease that caused the disability was found (n = 10)
7) The presence of assistance were unknown for at least one ADL as follows: oral cleansing, facial cleansing, changing of positions, feeding, taking of medicine, wiping of the body, toileting, bathing, washing of the hair, and dressing (n=53)

Study sample (n = 3,758)

Fig. 1. Flow chart of the study subjects. Abbreviations: PIC, Primary informal caregivers; CSLC, Comprehensive Survey of Living ConditionsFlow chart of the study subjects. Abbreviations: PIC, Primary informal caregivers; CSLC, Comprehensive Survey of Living Conditions.

Fig. 2. The categories of the assistance of each ADL element and the relationship between these categories and regression model. Abbreviations: PIC, Primary informal caregivers; FC, Formal Caregivers.

categorized into severer care level, disabled due to stroke, and achieve a higher educational attainment compared with those whose PICs spent 'shorter hours' on informal care (Table 2). In the single logistic regression analysis, the assistance ('PIC assisted and FC did not assist' or 'PIC and FC assisted' versus 'PIC did not assist') in all ADL elements was

significantly associated with 'longer hours' of care provided by PICs (Table 3).

Multiple logistic regression analysis

In the multiple logistic regression analysis using the PIC model, which included the assistance by PICs ('PIC did not assist' or 'PIC assisted') in each ADL element, the ADL elements that were significantly associated with 'longer hours' of care provided by PICs ('PIC assisted') were oral cleansing (OR: 1.28, 95% CI: 1.02–1.60), changing of positions (OR: 1.41, 95% CI: 1.11–1.80), feeding (OR: 1.34, 95% CI: 1.10–1.64), taking of medicine (OR: 1.49, 95% CI: 1.22–1.82), wiping of the body (OR: 1.60, 95% CI: 1.30–1.97), toileting (OR: 1.49, 95% CI: 1.21–1.85), and dressing (OR: 1.33, 95% CI: 1.08–1.63) (Table 4). Subsequently, in the multiple logistic regression analysis using the PIC and FC model, which included the assistance by PIC and FC ('PIC did not assist', 'PIC assisted and FC did not assist' or 'PIC and FC assisted') in each ADL element, the assistances by PIC ('PIC assisted and FC did not assist') in changing of positions (OR: 1.65, 95% CI: 1.27–2.14), feeding (OR: 1.37, 95% CI: 1.10–1.70), taking of medicine (OR: 1.53, 95% CI: 1.25–1.88),

Table 1
The descriptive statistics of the PIC characteristics.

Variable		All subjects (n = 3,758)		Longer hours (n = 1,715)		Shorter hours (n = 2,043)		P value*
		n	(%)	n	(%)	n	(%)	
Survey year	2010	1,777	(47.3)	804	(46.9)	973	(47.6)	0.648
	2013	1,981	(52.7)	911	(53.1)	1,070	(52.4)	
Age	Mean ± SD	64.9 ± 11.2		66.5 ± 10.8		63.5 ± 11.3		<0.001
Sex	Men	985	(26.2)	434	(25.3)	551	(27.0)	0.248
	Women	2,773	(73.8)	1,281	(74.7)	1492	(73.0)	
Working situations	Not working	2,373	(63.1)	1,263	(73.6)	1,110	(54.3)	<0.001
	Working	1,385	(36.9)	452	(26.4)	933	(45.7)	
Number of informal caregivers except the PIC	0	1,766	(47.0)	794	(46.3)	972	(47.6)	0.689
	1	1,354	(36.0)	630	(36.7)	724	(35.4)	
	more than 2	432	(11.5)	202	(11.8)	230	(11.3)	
	missing	206	(5.5)	89	(5.2)	117	(5.7)	
Education[a]	Low	852	(22.7)	433	(25.3)	419	(20.5)	0.002
	Middle	1,840	(49.0)	812	(47.3)	1,028	(50.3)	
	High	792	(21.1)	338	(19.7)	454	(22.2)	
	Missing	274	(7.3)	132	(7.7)	142	(7.0)	

*Difference between "longer hours" and "shorter hours"; p values from χ^2 test (categorical variables) or t-test (continuous variables).
[a] Low: graduated junior high school middle: graduated the high school high: Bachelor, Master, Doctor, professional school, and technical college.

Table 2
The descriptive statistics of the care recipients characteristics.

Variable		All subjects (n = 3,758)		Longer hours (n = 1,715)		Shorter hours (n = 2,043)		P value*
		n	(%)	n	(%)	n	(%)	
Age	Mean ± SD	83.8 ± 7.8		83.6 ± 8.1		83.9 ± 7.6		0.14
Sex	Male	1,343	(35.7)	692	(40.3)	651	(31.9)	<0.001
	Female	2,415	(64.3)	1023	(59.7)	1,392	(68.1)	
Care level	Care-required 1	893	(23.8)	196	(11.4)	697	(34.1)	<0.001
	Care-required 2	1,096	(29.2)	388	(22.6)	708	(34.7)	
	Care-required 3	806	(21.5)	420	(24.5)	386	(18.9)	
	Care-required 4	561	(14.9)	391	(22.8)	170	(8.3)	
	Care-required 5	402	(10.7)	320	(18.7)	82	(4.0)	
The primary disease that caused the disability	Frailty	537	(14.3)	188	(11.1)	349	(17.1)	<0.001
	Stroke	950	(25.3)	498	(29.0)	452	(22.1)	
	Heart disease	115	(3.1)	54	(3.1)	61	(3.0)	
	Respiratory disease	81	(2.2)	38	(2.2)	43	(2.1)	
	Dementia	788	(21.0)	373	(21.7)	415	(20.3)	
	Fracture or fall	398	(10.6)	172	(10.0)	226	(11.1)	
	Other diseases	889	(23.7)	392	(22.9)	497	(24.3)	
Education[a]	Low	2,019	(53.7)	860	(50.2)	1,159	(56.7)	<0.001
	Middle	1,092	(29.1)	545	(31.8)	547	(26.8)	
	High	266	(7.1)	143	(8.3)	123	(6.0)	
	Missing	381	(10.1)	167	(9.7)	214	(10.5)	

*Difference between "longer hours" and "shorter hours"; p values from χ^2 test (categorical variables) or t-test (continuous variables).
[a] Low: graduated junior high school middle: graduated the high school high: Bachelor, Master, Doctor, professional school, and technical college.

Table 3

Results of the single logistic regression analysis including the situation of assistance by PIC and FC in each ADL element.

		All subjects (n = 3,758)			
		OR		95%CI	
				Lower	Upper
Oral cleansing	PIC did not assist	1.00		(Reference)	
	PIC assisted and FC did not	4.79	**	4.09	5.62
	PIC and FC assisted	4.82	**	3.50	6.63
Facial cleansing	PIC did not assist	1.00		(Reference)	
	PIC assisted and FC did not	5.01	**	4.29	5.85
	PIC and FC assisted	5.11	**	3.73	7.02
Changing of positions	PIC did not assist	1.00		(Reference)	
	PIC assisted and FC did not	6.11	**	5.14	7.26
	PIC and FC assisted	4.43	**	3.38	5.81
Feeding	PIC did not assist	1.00		(Reference)	
	PIC assisted and FC did not	4.08	**	3.52	4.74
	PIC and FC assisted	4.44	**	3.46	5.70
Taking of medicine	PIC did not assist	1.00		(Reference)	
	PIC assisted and FC did not	2.74	**	2.34	3.21
	PIC and FC assisted	3.47	**	2.73	4.41
Wiping of the body	PIC did not assist	1.00		(Reference)	
	PIC assisted and FC did not	3.37	**	2.89	3.94
	PIC and FC assisted	4.77	**	3.60	6.31
Toileting	PIC did not assist	1.00		(Reference)	
	PIC assisted and FC did not	4.73	**	4.07	5.51
	PIC and FC assisted	5.20	**	4.23	6.40
Bathing	PIC did not assist	1.00		(Reference)	
	PIC assisted and FC did not	1.08		0.93	1.26
	PIC and FC assisted	1.69	**	1.28	2.24
Washing of the hair	PIC did not assist	1.00		(Reference)	
	PIC assisted and FC did not	1.49	**	1.27	1.74
	PIC and FC assisted	1.92	**	1.38	2.69
Dressing	PIC did not assist	1.00		(Reference)	
	PIC assisted and FC did not	3.86	**	3.33	4.48
	PIC and FC assisted	5.51	**	4.42	6.87

*P < 0.05, **P < 0.01 Abbreviations: PIC, Primary informal caregiver; FC, Formal caregiver.

Table 4

Results of multivariate binary logistic regression analysis which included the situation of assistance in each ADL element from the PIC as binary variables (PIC model).

		All subjects (n = 3,173)			
		OR		95%CI	
				Lower	Upper
Oral cleansing	PIC did not assist	1.00		(Reference)	
	PIC assisted	1.28	*	1.02	1.60
Changing of positions	PIC did not assist	1.00		(Reference)	
	PIC assisted	1.41	**	1.11	1.80
Feeding	PIC did not assist	1.00		(Reference)	
	PIC assisted	1.34	**	1.10	1.64
Taking of medicine	PIC did not assist	1.00		(Reference)	
	PIC assisted	1.49	**	1.22	1.82
Wiping of the body	PIC did not assist	1.00		(Reference)	
	PIC assisted	1.60	**	1.30	1.97
Toileting	PIC did not assist	1.00		(Reference)	
	PIC assisted	1.49	**	1.21	1.85
Bathing	PIC did not assist	1.00		(Reference)	
	PIC assisted	1.08		0.89	1.31
Dressing	PIC did not assist	1.00		(Reference)	
	PIC assisted	1.33	**	1.08	1.63

*p < 0.05, **p < 0.01 Abbreviations: PIC, Primary Informal Caregiver; FC, Formal Caregiver The model was adjusted for the dummy of the survey year, characteristics of PICs (age, gender, working status, the number of other informal caregivers and educational attainment) and characteristics of care recipients (age, gender, care level, primary disease causing the disability and educational attainment).

wiping of the body (OR: 1.50, 95% CI: 1.19–1.88), toileting (OR: 1.44, 95% CI: 1.14–1.81), and dressing (OR: 1.28, 95% CI: 1.03–1.59) were significantly associated with 'longer hours' of care provided by PICs. Moreover, in the PIC and FC model, the assistance by PIC and FC ('PIC and FC assisted') in wiping of the body (OR: 2.06, 95% CI: 1.37–3.11), toileting (OR: 1.72, 95% CI: 1.19–2.50), and dressing (OR: 1.58, 95% CI: 1.09–2.29) were significantly associated with 'longer hours' of care

provided by PICs (Table 5).

In the stratified analysis using the PIC and FC model among male care recipients, the assistance by PIC and FC ('PIC and FC assisted') in toileting (OR: 2.33, 95% CI: 1.15–4.73) was significantly associated with 'longer hours' of care provided by PICs. Meanwhile, in such an analysis among female care recipients, the assistance by PIC and FC ('PIC and FC assisted') in wiping of the body (OR: 2.08, 95% CI: 1.27–3.41), toileting

Table 5
Results of multivariate binary logistic regression analysis which included the situation of assistance in each ADL element from the PIC and FC as the variables with three situations (PIC and FC model).

		All subjects (n = 3,173)			
		OR		95%CI	
				Lower	Upper
Oral cleansing	PIC did not assist	1.00		(Reference)	
	PIC assisted and FC did not	1.25		0.99	1.59
	PIC and FC assisted	1.34		0.84	2.14
Changing of positions	PIC did not assist	1.00		(Reference)	
	PIC assisted and FC did not	1.65	**	1.27	2.14
	PIC and FC assisted	0.74		0.47	1.17
Feeding	PIC did not assist	1.00		(Reference)	
	PIC assisted and FC did not	1.37	**	1.10	1.70
	PIC and FC assisted	1.24		0.82	1.89
Taking of medicine	PIC did not assist	1.00		(Reference)	
	PIC assisted and FC did not	1.53	**	1.25	1.88
	PIC and FC assisted	1.24		0.84	1.83
Wiping of the body	PIC did not assist	1.00		(Reference)	
	PIC assisted and FC did not	1.50	*	1.19	1.88
	PIC and FC assisted	2.06	*	1.37	3.11
Toileting	PIC did not assist	1.00		(Reference)	
	PIC assisted and FC did not	1.44	*	1.14	1.81
	PIC and FC assisted	1.72	*	1.19	2.50
Bathing	PIC did not assist	1.00		(Reference)	
	PIC assisted and FC did not	1.07		0.86	1.33
	PIC and FC assisted	1.17		0.80	1.70
Dressing	PIC did not assist	1.00		(Reference)	
	PIC assisted and FC did not	1.28	*	1.03	1.59
	PIC and FC assisted	1.58	*	1.09	2.29

*p < 0.05, **p < 0.01Abbreviations: PIC, Primary Informal Caregiver; FC, Formal CaregiverThe model was adjusted for the dummy of the survey year, characteristics of PICs (age, gender, working status, the number of other informal caregivers and educational attainment) and characteristics of care recipients (age, gender, care level, primary disease causing the disability and educational attainment).

Table 6
Results of multivariate binary logistic regression analysis which included the situation of assistance in each ADL element from the PIC and FC as the variables with three situations (PIC and FC model) stratified by gender.

		Male (n = 1,146)				Female (n = 2,027)			
		OR		95%CI		OR		95%CI	
				Lower	Upper			Lower	Upper
Oral cleansing	PIC did not assist	1.00		(Reference)		1.00		(Reference)	
	PIC assisted and FC did not	1.01		0.68	1.49	1.38	*	1.01	1.87
	PIC and FC assisted	1.69		0.63	4.55	1.22		0.70	2.12
Changing of positions	PIC did not assist	1.00		(Reference)		1.00		(Reference)	
	PIC assisted and FC did not	1.95	**	1.27	2.97	1.51	*	1.07	2.12
	PIC and FC assisted	1.37		0.56	3.31	0.59		0.33	1.05
Feeding	PIC did not assist	1.00		(Reference)		1.00		(Reference)	
	PIC assisted and FC did not	1.40		0.98	2.00	1.34	*	1.01	1.77
	PIC and FC assisted	1.68		0.74	3.81	1.04		0.63	1.71
Taking of medicine	PIC did not assist	1.00		(Reference)		1.00		(Reference)	
	PIC assisted and FC did not	1.95	**	1.37	2.76	1.39	*	1.07	1.81
	PIC and FC assisted	1.07		0.52	2.22	1.29		0.80	2.08
Wiping of the body	PIC did not assist	1.00		(Reference)		1.00		(Reference)	
	PIC assisted and FC did not	1.90	**	1.33	2.72	1.25		0.92	1.70
	PIC and FC assisted	2.23		0.98	5.09	2.08	**	1.27	3.41
Toileting	PIC did not assist	1.00		(Reference)		1.00		(Reference)	
	PIC assisted and FC did not	1.67	**	1.15	2.41	1.31		0.97	1.77
	PIC and FC assisted	2.33	*	1.15	4.73	1.58	*	1.00	2.49
Bathing	PIC did not assist	1.00		(Reference)		1.00		(Reference)	
	PIC assisted and FC did not	0.80		0.56	1.13	1.32		0.99	1.76
	PIC and FC assisted	1.45		0.76	2.75	1.05		0.64	1.70
Dressing	PIC did not assist	1.00		(Reference)		1.00		(Reference)	
	PIC assisted and FC did not	1.05		0.73	1.51	1.47	**	1.11	1.94
	PIC and FC assisted	1.29		0.67	2.48	1.82	*	1.13	2.94

*p < 0.05, **p < 0.01Abbreviations: PIC, Primary Informal Caregiver; FC, Formal CaregiverThe model was adjusted for the dummy of the survey year, characteristics of PICs (age, gender, working status, the number of other informal caregivers and educational attainment) and characteristics of care recipients (age, gender, care level, primary disease causing the disability and educational attainment).

(OR: 1.58, 95% CI: 1.00–2.49), and dressing (OR: 1.82, 95% CI: 1.13–2.94) were significantly associated with 'longer hours' of care provided by PICs (Table 6).

In the stratified analysis using the PIC and FC model among the PICs who had a job, the assistance by PIC and FC ('PIC and FC assisted') in wiping of the body (OR: 3.57, 95% CI: 1.80–7.06) and toileting (OR:

Table 7
Results of multiple logistic regression analysis which included the situation of assistance in each ADL element by PIC and FC as the variables with three situations (PIC and FC model) stratified by working situation of PIC.

		Having a job (n = 1,152)				Having no job (n = 2,021)			
		OR		95%CI		OR		95%CI	
				Lower	Upper			Lower	Upper
Oral cleansing	PIC did not assist	1.00		(Reference)		1.00		(Reference)	
	PIC assisted and FC did not	1.48		0.98	2.25	1.12		0.83	1.49
	PIC and FC assisted	1.78		0.90	3.56	1.06		0.55	2.06
Changing of positions	PIC did not assist	1.00		(Reference)		1.00		(Reference)	
	PIC assisted and FC did not	1.75	*	1.09	2.82	1.67	**	1.22	2.30
	PIC and FC assisted	0.46		0.21	0.99	1.00		0.54	1.85
Feeding	PIC did not assist	1.00		(Reference)		1.00		(Reference)	
	PIC assisted and FC did not	1.54	*	1.05	2.27	1.32	*	1.01	1.72
	PIC and FC assisted	1.06		0.55	2.05	1.33		0.76	2.32
Taking of medicine	PIC did not assist	1.00		(Reference)		1.00		(Reference)	
	PIC assisted and FC did not	1.55	*	1.07	2.24	1.54	**	1.19	1.97
	PIC and FC assisted	1.19		0.63	2.24	1.29		0.77	2.17
Wiping of the body	PIC did not assist	1.00		(Reference)		1.00		(Reference)	
	PIC assisted and FC did not	1.65	*	1.08	2.52	1.42	*	1.07	1.88
	PIC and FC assisted	3.57	**	1.80	7.06	1.56		0.93	2.64
Toileting	PIC did not assist	1.00		(Reference)		1.00		(Reference)	
	PIC assisted and FC did not	1.49		0.97	2.28	1.41	*	1.07	1.86
	PIC and FC assisted	1.88	*	1.03	3.43	1.70	*	1.05	2.76
Bathing	PIC did not assist	1.00		(Reference)		1.00		(Reference)	
	PIC assisted and FC did not	1.08		0.72	1.63	1.04		0.80	1.35
	PIC and FC assisted	1.15		0.55	2.38	1.18		0.75	1.86
Dressing	PIC did not assist	1.00		(Reference)		1.00		(Reference)	
	PIC assisted and FC did not	1.09		0.73	1.61	1.38	*	1.06	1.80
	PIC and FC assisted	1.66		0.90	3.04	1.52		0.94	2.46

*p < 0.05, **p < 0.01 Abbreviations: PIC, Primary Informal Caregiver; FC, Formal Caregiver The model was adjusted for the dummy of the survey year, characteristics of PICs (age, gender, working status, the number of other informal caregivers and educational attainment) and characteristics of care recipients (age, gender, care level, primary disease causing the disability and educational attainment).

1.88, 95% CI: 1.03–3.43) was significantly associated with 'longer hours' of care provided by PICs. Meanwhile, in such analysis among the PICs who had no job, the assistance by PIC and FC ('PIC and FC assisted') in toileting (OR: 1.70, 95% CI: 1.05–2.76) was significantly associated with 'longer hours' of care provided by PICs (Table 7).

Discussion

We conducted the analysis by using the nationally representative cross-sectional data of Japan to determine the relationship between the situation of assistance in each ADL element and 'longer hours' of care provided by PICs. In the multiple logistic regression analysis using the PIC model, the assistance provided in seven ADL elements (i.e. oral cleaning, changing of positions, feeding, taking of medicine, wiping of the body, toileting, and dressing) was significantly associated with 'longer hours' of care provided by PICs (Table 4). Meanwhile, in the regression analysis using the PIC and FC model, the assistance in wiping of the body, dressing, and toileting were also significantly associated with 'longer hours' of care provided by PICs, even when the care recipients were assisted by both PIC and FC (Table 5). Moreover, in the regression analysis using the PIC and FC model stratified by the gender of the care recipients, toileting among male care recipients and wiping of the body, toileting, and dressing among female care recipients were significantly associated with 'longer hours' of care provided by PICs, even when both PIC and FC provided the assistance (Table 6). In the regression analysis using the PIC and FC model stratified by the working situation of PIC, wiping of the body among the PICs who had a job and toileting among the PICs who had no job were significantly associated with 'longer hours' of care provided by PICs, even when both PIC and FC provided the assistance (Table 7).

The association between the total ADL scores of care recipients and the hours spent on care provided by PICs has been extensively studied. Some studies showed that increased limitations in ADL are associated with an increase in the number of hours of care provided by PICs (Haro et al., 2014; Li, 2005). Furthermore, impairment in the ADL of care

recipients significantly predicts the subjective burden of caregivers (Ajay, Kasthuri, Kiran, & Malhotra, 2017; Kim et al., 2012). In our result, when PICs assisted care recipients in seven ADL elements (i.e. oral cleansing, changing of positions, feeding, taking of medicine, wiping of the body, and toileting), PICs were significantly more likely to spend 'longer hours' on care (Table 4). Our results are consistent with those of previous studies. In addition, our study clarified the specific ADL elements that were associated with long hours of care provided by PICs. The strength of our study was that it demonstrated the relationship between 'longer hours' of care provided by PICs and the assistance in specific ADL elements.

Moreover, we demonstrated the relationship between 'longer hours' of care provided by PICs and the assistance provided in each ADL element, with consideration of the FCs. In our regression analyses, the assistances in ADL elements by PIC significantly associated with 'longer hours' of care in the PIC model ('PIC assisted') were oral cleaning, changing of positions, feeding, taking of medicine, wiping of the body, toileting, and dressing. Even in the PIC and FC model, the assistances in changing positions, feeding, taking of medicine, wiping of the body, toileting, and dressing by PIC ('PIC assisted and FC did not assist') were also significantly associated with 'longer hours' of care by PIC. Our regression analyses showed that the assistance in oral cleaning was significantly associated with 'longer hours' of care in the PIC model (OR: 1.28, 95% CI: 1.02–1.60), but the assistance by PIC ('PIC assisted and FC did not assist') in oral cleaning was not significantly associated with 'longer hours' of care in the PIC and FC model (OR: 1.25, 95% CI: 0.99–1.59). However, the point estimates and 95% CI were similar between the PIC model and the PIC and FC model. Therefore, the discrepancy may be due to the size of the study population. Increasing the study population numbers might result in a significant association. Thus, those results were consistent.

When a PIC assisted his/her care recipient and FC did not assist in changing of positions, feeding and taking of medicine, he/she was likely to spend 'longer hours' on care. However, when both PIC and FC assisted in these three ADL elements, the PIC was not likely to spend on 'longer

hours' on care. To our knowledge, the relationship between the number of hours spent on care provided by PICs and the assistance in changing of positions, feeding and taking of medicine has not yet been studied. Considering that these three ADL elements are required to be performed at a fixed time each day, the FC can easily provide additional help in these ADL elements. That is why the FC may be able to decrease the burden 'PIC did not assist' in these three ADL elements.

When a PIC assisted his/her care recipient and FC did not assist in wiping of the body or dressing, he/she was likely to spend 'longer hours' on care. Moreover, even when both PIC and FC provided the assistance in this ADL element, the PIC remained likely to spend on 'longer hours' on care. The relationship between the assistance in wiping of the body or dressing and the time spent on care provided by PICs has not been reported. Perhaps, care recipients might refuse to be unclothed in front of the FC. Hence, the FC might be difficult to provide care in wiping of the body, and the PIC should execute it. Therefore, the PIC was likely to spend long hours on care. So, the FCs may need to manage the resistance to care recipient's being unclothed. For example, FC with the same gender as the care recipients may be suitable to provide the assistance in wiping of the body. In the stratified analysis among female (OR: 2.08, 95% CI: 1.27–3.41) care recipients, the assistance in wiping of the body was significantly associated with 'longer hours' of care provided by the PIC, even when both PIC and FC assisted. Meanwhile, in the analysis among male care recipients, the association between the assistance by both PIC and FC in wiping of the body and the time spent on care provided by the PIC was not significant (OR: 2.23, 95% CI: 0.98–5.09), but the point estimates were close to those of female care recipients. Therefore, the gender difference among care recipients was small. On the other hand, the assistance by both PIC and FC in dressing among female care recipients was significantly associated with "longer hours' of care provided by the PIC, even when both PIC and FC assisted (OR: 1.82, 95% CI: 1.13–2.94). However, among male care recipients, the assistance in dressing was not significantly associated with 'longer hours' of care provided by the PIC, when both PIC and FC assisted (OR: 1.29, 95% CI: 0.67–2.48). Male care recipients may be less likely to be resistant to being undressed in front of the FC compared with female care recipients.

When a PIC assisted his/her care recipient and FC did not assist in toileting, he/she was significantly likely to spend 'longer hours' on care. Moreover, even when both PIC and FC assisted in toileting, the PIC was still likely to spend 'longer hours' on care. Previous studies showed that assistance in toileting, or incontinence, is associated with time spent on care provided by PICs, or the admission to a nursing home. Furthermore, the number of hours of care provided by a PIC is longer in older people with incontinence than those without such condition (Langa, Fultz, Saint, Kabeto, & Regula Herzog, 2002). Incontinence also increases the risk of nursing home placement in subjects without dementia (Andel, Hyer, & Slack, 2007). Our results are consistent with those of previous studies. However, the previous studies did not consider the situation of assistance in toileting provided by the FC. Our study showed that assistance in toileting was significantly associated with 'longer hours' of care provided by PICs, even when both PIC and FC assisted. Caregivers cannot predict when care recipients require assistance in toileting. Furthermore, toileting assistance might be needed at midnight. Therefore, the FC might be difficult to provide enough assistance and PICs are likely to spend long hours on care. So the intervention to reduce dependence in toileting activity such as installing handrails may be needed. Moreover, considering the use of other types of services, such as respite care or day care services, may be better. In the stratified analysis among male care recipients, assistance in toileting was significantly associated with 'longer hours' of care provided by PICs (OR: 2.33, 95% CI: 1.15–4.73), even when both PIC and FC assisted. The analysis among female care recipients also revealed the significant association between 'longer hours' of care provided by PICs and the assistance in toileting from both PIC and FC (OR: 1.58, 95% CI: 1.00–2.49). These results suggest that the relationship between the assistance in toileting and long

hours of caregiving is regardless of gender of care recipient.

In the stratified analysis among the PICs who had no job, the assistance by PIC and FC in toileting was significantly associated with 'longer hours' of care provided by PICs. In the analysis among the PICs who had a job, the assistances by PIC and FC in wiping of the body and toileting were significantly associated with 'longer hours' of care provided by PICs and the assistance by PIC and FC. The assistance in wiping of the body from PIC and FC were not significantly associated with the 'longer hours' of care by PIC among the PICs who had no job, however, there was some tendency to significance (OR: 1.56, 95% CI: 0.93–2.64). Thus, each analysis had similar results. Therefore, the relationship between the assistance in ADL elements and the long hours of care by PIC were not really affected by the working situation of the PIC.

Our findings suggested that FCs should pay more attention to PICs who are assisting in the wiping of the body, dressing or toileting of care recipients. If PICs are assisting care recipients in changing of positions, feeding, taking of medicine, or dressing, considering the help of FC may be better. Moreover, policymakers may consider adding some incentives to the FC services that include wiping of the body, dressing toileting or some situations that need frequent care, require a heavy physical load, or are accompanied with intimate contact with the care recipient.

This study has some limitations. Firstly, this study is cross-sectional, making the establishment of causality difficult. Secondly, the time spent on care provided by PICs was regarded as a dichotomous variable, given that the original questionnaire was a discrete variable. Thirdly, 'PIC did not assist' included two situations. In one situation, care recipients were not provided with care in each ADL element; in the other situation, care was provided in each ADL element, but PICs did not assist. Nevertheless, we believe this categorization was reasonable, because the dependent variable was the time spent on care provided by PICs. Fourth, some specific combinations of assistances in ADL elements or generally high care needs in care recipients might be associated with long hours of care provided by PICs, but we did not consider those. Finally, the relationship between time spent on care provided by PICs and the presence of assistance in each ADL element is potentially confounded by the care recipient's needs of care. In this study, we included the care level as a control variable, but we did not have other information that reflects the care recipient's needs of care. Therefore, we should take into consideration that the odds ratio of the presence of assistance in each ADL element in our analysis might have been overestimated.

Conclusions

In summary, our results showed that the assistance in wiping of the body, dressing and toileting was associated with long hours of care provided by PICs, even when both PIC and FC assisted in the care. Therefore, considering the kinds of ADL elements is important when providing care to support the PICs effectively.

Ethical approval

The ethics committee of the University of Tsukuba approved this study (approval number: 1166).

CRediT authorship contribution statement

Hiroaki Ueshima: Conceptualization, Methodology, Formal analysis, Writing - original draft, Visualization. **Arito Yozu:** Conceptualization, Methodology, Writing - original draft, Supervision. **Hideto Takahashi:** Conceptualization, Methodology, Writing - review & editing, Supervision. **Haruko Noguchi:** Conceptualization, Methodology, Writing - review & editing, Supervision. **Nanako Tamiya:** Conceptualization, Methodology, Resources, Writing - review & editing, Supervision, Project administration, Funding acquisition.

Acknowledgements:

References

Ajay, S., Kasthuri, A., Kiran, P., & Malhotra, R. (2017). Association of impairments of older persons with caregiver burden among family caregivers: Findings from rural South India. *Archives of Gerontology and Geriatrics, 68*, 143–148.

Andel, R., Hyer, K., & Slack, A. (2007). Risk factors for nursing home placement in older adults with and without dementia. *Journal of Aging and Health, 19*, 213–228.

Bilotta, C., Nicolini, P., & Vergani, C. (2009). Quality of private personal care for elderly people in Italy living at home with disabilities: Risk of nursing home placement at a 1-year follow-up. *Health and Social Care in the Community, 17*, 543–547.

Brody, E. M., Litvin, S. J., Albert, S. M., & Hoffman, C. J. (1994). Marital status of daughters and patterns of parent care. *Journal of Gerontology, 49*, S95–S103.

van Campen, C., de Boer, A. H., & Iedema, J. (2013). Are informal caregivers less happy than noncaregivers? Happiness and the intensity of caregiving in combination with paid and voluntary work. *Scandinavian Journal of Caring Sciences, 27*, 44–50.

Cannuscio, C. C., Jones, C., Kawachi, I., Colditz, G. A., Berkman, L., & Rimm, E. (2002). Reverberation of family illness: A longitudinal assessment of informal caregiver and mental health status in the nurses' health study. *American Journal of Public Health, 92*, 305–1311.

Coleman, P. D. R. (1993). *Determinants of the supply of informal care to the frail elderly*. Syracuse University. p-221 pp.

Colombo, F., Llena-Nozal, A., Mercier, J., & Tjadens, F. (2011). *Help wanted?*.

Haro, J. M., Kahle-Wrobleski, K., Bruno, G., Belger, M., Dell'Agnello, G., Dodel, R., et al. (2014). Analysis of burden in caregivers of people with Alzheimer's disease using self-report and supervision hours. *The Journal of Nutrition, Health & Aging, 18*, 677–684.

the Ministry of Health, L., and Welfare. (2016). *Long-term care insurance system of Japan*.

Jacobs, J. C., Laporte, A., Van Houtven, C. H., & Coyte, P. C. (2014). Caregiving intensity and retirement status in Canada. *Social Science & Medicine, 102*, 74–82.

Joo, H., Fang, J., Losby, J. L., & Wang, G. (2015). Cost of informal caregiving for patients with heart failure. *American Heart Journal, 169*, 142–148. e142.

Katz, S. J., Kabeto, M., & Langa, K. M. (2000). Gender disparities in the receipt of home care for elderly people with disability in the United States. *Journal of the American Medical Association, 284*, 3022–3027.

Kim, H., Chang, M., Rose, K., & Kim, S. (2012). Predictors of caregiver burden in caregivers of individuals with dementia. *Journal of Advanced Nursing, 68*, 846–855.

Kuzuya, M., Hasegawa, J., Hirakawa, Y., Enoki, H., Izawa, S., Hirose, T., et al. (2011). Impact of informal care levels on discontinuation of living at home in community-dwelling dependent elderly using various community-based services. *Archives of Gerontology and Geriatrics, 52*, 127–132.

Langa, K. M., Chernew, M. E., Kabeto, M. U., Herzog, A. R., Ofstedal, M. B., Willis, R. J., et al. (2001). National estimates of the quantity and cost of informal caregiving for the elderly with dementia. *Journal of General Internal Medicine, 16*, 770–778.

Langa, K. M., Fultz, N. H., Saint, S., Kabeto, M. U., & Regula Herzog, A. (2002). Informal caregiving time and costs for urinary incontinence in older individuals in the United States. *Journal of the American Geriatrics Society, 50*, 733–737.

Langa, K. M., Valenstein, M. A., Fendrick, A. M., Kabeto, M. U., & Vijan, S. (2004). Extent and cost of informal caregiving for older Americans with symptoms of depression. *American Journal of Psychiatry, 161*, 857–863.

Lawton, M. P., & Brody, E. M. (1969). Assessment of older people: Self-maintaining and instrumental activities of daily living. *The Gerontologist, 9*, 179–186.

Legg, L., Weir, C. J., Langhorne, P., Smith, L. N., & Stott, D. J. (2013). Is informal caregiving independently associated with poor health? A population-based study. *Journal of Epidemiology & Community Health, 67*, 95–97.

Li, L. W. (2005). Longitudinal changes in the amount of informal care among publicly paid home care recipients. *The Gerontologist, 45*, 465–473.

Miyawaki, A., Tomio, J., Kobayashi, Y., Takahashi, H., Noguchi, H., & Tamiya, N. (2017). Impact of long-hours family caregiving on non-fatal coronary heart disease risk in middle-aged people: Results from a longitudinal nationwide survey in Japan. *Geriatrics and Gerontology International, 17*, 2109–2115.

Nordberg, G., von Strauss, E., Kåreholt, I., Johansson, L., & Wimo, A. (2005). The amount of informal and formal care among non-demented and demented elderly persons – results from a Swedish population-based study. *International Journal of Geriatric Psychiatry, 20*, 862–871.

Schulz, R. M., Porter, C., Lane, M., Cornman, C., & Branham, L. (2011). Impact of a medication management system on nursing home admission rate in a community-dwelling nursing home–eligible medicaid population. *The American Journal of Geriatric Pharmacotherapy, 9*, 69–79.

Skolarus, L. E., Freedman, V. A., Feng, C., Wing, J. J., & Burke, J. F. (2016). Care received by elderly US stroke survivors may Be underestimated. *Stroke, 47*, 2090–2095.

Thomas, G. P. A., Saunders, C. L., Roland, M. O., & Paddison, C. A. M. (2015). Informal carers' health-related quality of life and patient experience in primary care: Evidence from 195,364 carers in England responding to a national survey. *BMC Family Practice, 16*, 62.

Wimo, A., Elmstahl, S., Fratiglioni, L., Sjlolund, B. M., Skoldunger, A., Fagerstrom, C., et al. (2017). Formal and informal care OF community-living older people: A population-based study from the Swedish national study ON aging and care. *The Journal of Nutrition, Health & Aging, 21*, 17–24.