The personal cost of dementia care in Japan: A comparative analysis of residence types

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中部　貴央

The personal cost of dementia care in Japan: a comparative analysis of residence types

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Key points

- The personal cost of dementia care across different residence types was quantified.
- Institutionalized patients still received informal care from voluntary caregivers.
- Total costs were higher in community-dwelling patients than those in institutions.

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Abstract

Objective: We aimed to quantify the personal economic burden of dementia care in Japan according to residence type.

Methods: A cross-sectional online survey was conducted on 3841 caregivers of people with dementia. An opportunity cost approach was used to calculate informal care costs. All costs and the observed/expected (OE) ratio of costs were adjusted using patient sex, age, and care-needs levels; and compared among the residence types.

Results: The mean daily informal care time was 8.2 hours, and the mean monthly informal care costs for community-dwelling people with dementia were US$1559. The OE ratio for informal care costs in community-dwelling patients was higher than in institutionalized patients.

Conclusion: The inclusion of informal care costs reduced the differences in total personal costs among the residence types. The economic burden of informal care should be considered when quantifying dementia care costs.

Introduction

The increasing global prevalence of dementia has immense social and economic consequences [1]. The *World Alzheimer Report 2015* estimated that 46.8 million people were living with dementia in 2015, and this number is expected to rise to 131.5 million by 2050 [1]. In Japan, the number of people with dementia has been steadily increasing as its population ages at an unprecedented rate. The systemic provision of dementia care is therefore a particularly important health policy issue in Japan.

Informal care, which is voluntarily provided by a patient's family and friends, constitutes a critical component of dementia care. This type of care can account for the majority of dementia care in many cases, and is usually provided free of charge to the patient. Nevertheless, informal care places a heavy economic burden on both the caregivers and patients, and many cost-of-illness studies of dementia have incorporated informal care cost estimates [2–4]. However, these studies have generally focused on countries in North America and Europe, and few analyses including informal care costs have been conducted in Asia [5]. In Japan, the annual societal cost of dementia (including informal care) in the community setting was estimated to be approximately 140 billion yen (US$14 billion) [6,7].

Both healthcare and long-term care (LTC) costs can strain public finances, and it is

necessary to estimate their collective impact on society. Under the Japanese insurance system, people pay 10% to 30% (according to income and age) of total healthcare expenses as out-of-pocket payments for services covered by insurance. Raising the out-of-pocket rate may alleviate the burden on public finances, but the personal economic burden of caring for people with dementia must first be quantified to support the development of sustainable dementia care systems. However, the personal cost of dementia care that includes informal care in Japan remains unclear.

Under the limited resources and finances for health and long-term care, the Japanese government has established a strong policy to transfer patients from institutionalized to home care settings, and from healthcare to long-term care. The policy also pushes to use more services not covered by the public insurance systems. This would reduce the fiscal burden on the public insurance systems for health and long-term care, but would increase the burden on their families or communities. For people with dementia, various combinations of these care and services are crucial, and residential types (social care types) affect the burden's total volume and the balance between burden on persons and on the insurance systems. Measuring and clarifying the total burden and its components, including informal care for people with dementia in each residential type, will provide necessary information to design a well-balanced and efficient healthcare and LTC system.

Furthermore, people with dementia live both in the community and in specialized institutions. However, few studies have compared the costs of dementia between the community and institutional settings [2]. Moreover, to the best of our knowledge, no studies have clarified the differences in the costs of dementia among the types of institution, such as group homes and LTC facilities. In order to design and implement an integrated community care system, it is important to ascertain the relative costs between home care and care provided in various institutional types.

The objective of this study was to quantify the personal economic burden of dementia care as informal care costs and out-of-pocket payments according to residence type.

2. Methods

2.1. Web-based survey for data collection on people with dementia and their caregivers

In this cross-sectional study, we conducted a web-based questionnaire survey from March 3 to March 14, 2016 in cooperation with a commercial research company (Automatic Internet Research System, Macromill, Inc., Japan). Potential participants fulfilled the following criteria: (1) aged 30 years or older, (2) non-professional caregiver of people with dementia, (3) caring for only one person with dementia, and (4) have no conflicts of interest with advertising or marketing research entities. We excluded

caregivers under 30 years old because they comprise only 2% of all caregivers in Japan [8], and also it is difficult to consider such young caregivers provide care .A total of 3600 participants were recruited from the research company's registrants and divided into different age groups (850 participants each in the 30–39 year, 40–49 year, 50–59 year, and 60–69 year groups; 200 participants in the ≥70 year group). We set the sample size to equal amounts per age group (except those 70 or over) to avoid a bias only to young caregivers. The use of a web-based survey enables rapid large-scale data collection and erroneous responses, and is low cost. In consideration of these advantages, we elected to use a web-based survey for this study.

2.2. Questionnaire

The survey was conducted using the Resource Utilization in Dementia (RUD) 3.0 version [9] questionnaire that had been revised to accommodate the Japanese healthcare and LTC system. The RUD is currently one of the most useful tools for collecting data on resource utilization in dementia [9–11], and its use allows for international comparisons [2]. Table 1 shows the components of the revised questionnaire, which included items from the Japanese translation of the RUD that were concerned with informal care duration, caregivers' situation (e.g., employment and cohabitation statuses), and frequency of

116 utilization of LTC services. Survey items specific to Japan included care-needs levels,
117 residence types, LTC services, and out-of-pocket payments. Discussions were held with
118 the developer of the RUD, and approval for its use was obtained.

119 Eligibility for LTC insurance is categorized into seven distinct care-needs levels:
120 support levels 1 to 2 and care-needs levels 1 to 5. Certifications of care-needs levels are
121 dependent on the clinical diagnosis of dementia and the level of cognitive and functional
122 decline. For instance, care-needs level 1 indicates that people need care for instrumental
123 activities of daily living (IADL) and some activities of daily living (ADL) functions.
124 People with care-needs level 5 cannot live without care, such as bedridden individuals.
125 Therefore, these levels were assessed as a proxy for disease severity.

126 The following residence types were analyzed: (1) community residence, such as the
127 patient's home (including patients who use multi-functional care services in small group
128 homes), (2) elderly housing with care services, (3) fee-based homes for older persons, (4)
129 LTC health facilities, (5) intensive care homes for older persons, (6) group homes for
130 older persons with dementia, and (7) sanatoriums and hospitals [12]. Elderly housing with
131 care services introduced in 2011, is run by the private sector, and required to register with
132 the prefecture. Fee-based homes for the elderly also run by the private sector. These are
133 considered housing rather than social welfare facilities for the elderly. There are two

contract types for these privately run residences: lease contract or license agreement. LTC health facilities are for those requiring rehabilitation or healthcare with a possible tenancy period from several months to about one year. Intensive Care Home for the elderly is a day-care facility those requiring constant nursing care services due to serious physical or mental disabilities. Group homes for the elderly with dementia are small facilities in which dementia patients (5-9 persons) live together. These three residence types are covered under LTC insurance benefits as institutional services [12].

2.3. Cost estimation

Total costs were estimated based on four components: out-of-pocket payments (copayments) for healthcare services, out-of-pocket payments (copayments) for LTC services covered by insurance, out-of-pocket payments for LTC services not covered by insurance, and informal care costs. Under Japan's universal health system, all residents must be enrolled in healthcare and LTC (≥40 years old) insurance. Depending on age and income, enrollees must pay a copayment of 10% to 30% when receiving healthcare and LTC services. Out-of-pocket payments for healthcare services and LTC services were determined through a questionnaire covering the various categories. These costs were substituted by a median of each category, and we calculated the weighted average with the following formula: $\frac{\sum_{i=0}^{k}(median\ of\ category_i)*n_i}{\sum n}$

We also assessed the informal care times for ADL, IADL, and supervision as previously described [5,13–16]. Caregivers were asked how many hours they provide care each for ADL, IADL and supervision in one day. They were also asked how many days they provide care for ADL, IADL and supervision in one month. Those questions were based on the previous four weeks. We assessed the daily informal care time by summing the care time for both ADL and IADL. Supervision time might be included simultaneously other care time for ADL or IADL functions. Caregivers may also supervise people with dementia while doing other activities, such as cooking for their children. Sometimes, total informal care time, including supervision time, could extend to 24 hours [17]. For these reasons, we assessed supervision time separately from informal care time for ADL and IADL.

Caregivers were asked to state their contribution to the total informal care received by the patient as one of the following five options: 1–20%, 21–40%, 41–60%, 61–80%, or 81–100%. Per RUD instructions, we adjusted the informal care times by these contribution levels to treat all caregivers as primary caregivers and estimate the costs associated with all informal care provided to a patient. Total informal care time was adjusted by dividing by the median of each contribution rate category.

The cost of informal care can be estimated using the "opportunity cost" or "replacement

cost" approaches [2–4]. The opportunity cost approach estimates the costs due to loss of productivity, whereas the replacement cost approach assumes the informal care services can be similarly valued as home care services provided by professional caregivers. Similar to previous studies that used the RUD [1,5,18], we selected the opportunity cost approach in order to assess informal care time as forgone wages for caregivers. Costs were valued by the caregivers' monthly mean wage stratified by sex and age[19]. We assessed informal care costs for caregivers who were not working or were over 65 years of age at 30% of the mean wage of employed caregivers [20–23]. Time spent on supervision was assumed to be zero cost for the same reasons why we assess it separately [5,17,18,24]. A maximum daily informal care time of 16 hours was assumed in order to allow for other activities and sleeping time [25–27].

2.4 Inclusion and exclusion criteria

We included all caregivers and people with dementia who responded to the web-based survey. However, we excluded the following respondents; (1) caregivers over 100 years old or with dementia from a decline of cognitive function, (2) those who provided contradictory information regarding the caregiver's relationship with people with dementia, and, (3) those who reported an informal care time for ADL or IADL that exceeded 24 hours per day. For instance, contradictory relationships between caregivers

188 and people with dementia included age differences of less than 15 years even though
189 people with dementia were parents (not in-laws).

190 *2.5. Statistical analysis*

191 Only descriptive statistics were used to quantify the economic burden of dementia care
192 in Japan. We stratified the data by residence type; informal care time was stratified by
193 care-needs level, caregiver's employment status, and caregiver's cohabitation status.

194 We compared informal care times between this study and previous studies focusing on
195 people with dementia in a community setting to validate our measurement of informal
196 care time. We selected previous studies from both Japan and other countries. For non-
197 Japanese studies, we only selected single-country studies that used the RUD. Due to the
198 lack of Japanese studies that used the RUD, we selected studies that reported the
199 caregivers' economic burden and informal care times. We showed 95% confidence
200 intervals for each study by calculating from their mean and standard deviations.

201 To compare dementia care costs among residence types, we need to standardize the
202 dataset by adjusting for the characteristics of people with dementia. We calculated the
203 ratio between the observed and expected values (OE ratio) for the costs of dementia care
204 for each residence type. The mean costs per care-needs level, sex, and age category ($Q[i]$)
205 and the number of people with dementia ($N[i]$) were calculated and multiplied to produce

the expected value as standardized value. The expected total costs for each residence type was calculated using the following formula:

$$the\ expected\ total\ costs = \sum_{i=1}^{n} \{Q(i) \times N(i)\}$$

The observed values were divided by the expected value to produce the OE ratio. An OE ratio that was greater than one indicated that the observed value exceeded the expected value even after adjusting for patient sex, age and care-needs levels.

Comparison of mean total out-of-pocket payments and total costs including informal care costs among residence types was done using the analysis of variance (ANOVA) with the post-hoc Games Howell test. A p-value of <0.05 was considered statistically significant.

In all analyses, we excluded missing values in out-of-pocket payments for healthcare and LTC services if the respondents answered “unknown” for these items. All costs were converted from Japanese yen to US dollars using the purchasing power parity rate in 2016 (¥102 = $1) provided by the Organization for Economic Cooperation and Development. All data were analyzed using IBM SPSS Statistics 23.0 for Windows (SPSS Japan Inc., Tokyo, Japan).

3. Results

3.1. Characteristics of people with dementia and their caregivers

A total of 3916 caregivers answered the questionnaire, but the following were excluded from the analysis: caregivers aged over 100 years (n=7), caregivers with dementia (n=2), caregivers with contradictory information regarding their relationship with people with dementia (n=24), and caregivers who reported an informal care time for ADL or IADL that exceeded 24 hours per day (n=42). After these exclusions, the final sample comprised 3841 respondents.

Table 2 shows the characteristics of people with dementia and their caregivers. More than half of people with dementia were female (68.7%), and the mean age was 82.5 years. The distribution of care-needs levels was similar across the residence types, but the mean ADL and IADL scores were lower in institutionalized people with dementia. In contrast, more than half of the caregivers were male (57.8%), and the mean age was 51.9 years. Almost 80% of the caregivers were providing care to their parents or parents-in-law. Approximately half of the caregivers were employed, and their contribution level was therefore low. Figure 1 shows the result of the comparison of the mean informal care times between the present study and previous studies with 95% confidence intervals.

241 *3.2. Informal care time*

242 Table 3 summarizes the mean daily informal care times according to ADL and IADL
243 scores. The results indicated that informal care was provided in all institutions. Even after
244 adjusting informal care time by the caregivers' contribution levels, there were no major
245 changes in the patterns of informal care time across the residence types. Figure 1 shows
246 the result of comparison of the mean daily informal care time between previous studies
247 and the present study.

248 The mean informal care time for people with dementia in a community setting became
249 longer as their care-needs levels increased (Care-Needs Level 1 through 5: 7.7, 9.7, 10.1,
250 10.4, 10.8 hours respectively). In contrast, institutionalized people with dementia required
251 less informal care time even when their care-needs levels were high. Furthermore,
252 caregivers who had taken nursing care leave from work provided more informal care time
253 (11.9 hours) than those who were employed (7.6 hours). Caregivers who did not cohabit
254 with people with dementia provided almost the same amount of informal care time (9.1
255 hours) as those who cohabited with people with dementia (9.3 hours) in a community
256 setting. We also assessed supervision time, showing about 2.6 hours per day.

257

258

3.3. Cost estimation

Figure 2 presents the mean monthly dementia care costs stratified by residence type. Out-of-pocket payments were lower in community-dwelling people with dementia (US$619) than in institutionalized patients (US$1449). In particular, the out-of-pocket payments were higher in LTC facilities and intensive care homes for LTC services not covered by insurance. However, when including informal care costs, the total costs were higher in community-dwelling people with dementia (US$2309) than in institutionalized patients (US$2102). This is because informal care costs were 2.5 to 5 times higher in community-dwelling people with dementia (US$1559) than in those residing in the various institutions. The results of the internal group comparison among residence types for total out-of-pocket payments and total costs including informal care costs, are shown in Supplementary Table 1.

3.4. OE ratios

Table 4 shows the OE ratios for dementia care costs stratified by residence type. The results showed that the out-of-pocket payments for LTC services covered by insurance tended to be higher for people in LTC facilities and intensive care homes. When considering the costs excluding informal care, caregiving for community-dwelling people

with dementia had the lowest OE ratio; however, this residence type was associated with a higher OE ratio after the inclusion of informal care.

4. Discussion

In this study, we comparatively examined the personal cost of dementia care as informal care costs and out-of-pocket payments among different residence types in Japan. The mean informal care time per day was 9.2 hours for community-dwelling people with dementia. The results also indicated that institutionalized people with dementia still received informal care from voluntary caregivers. The out-of-pocket payments for LTC services were higher than for healthcare costs among the different residence types except for patients in sanatoriums and hospitals. With the inclusion of informal care costs, the total costs were higher in community-dwelling people with dementia than those living in institutions.

We compared the mean informal care times among the present study and previous studies that focused on primary caregivers in a community setting [5,7,13,14,26,28–40], and the mean informal care time in a community setting in this study was generally higher than that of previous studies. However, even after adjusting informal care time by the caregivers' contribution levels, the results of informal care times in this study were within

294 the ranges reported by previous studies. The results for informal care time in this study
295 are consistent with those reported in previous studies conducted in Japan (3.4-9.5 hours)
296 [7,28,30–32,36]. Furthermore, these results generally supported our expectations that people
297 with high care-needs levels require longer informal care times in a community setting,
298 and that caregivers provide longer informal care times when they live together with the
299 person with dementia or take a leave of absence from work in order to provide nursing
300 care. Although the RUD questionnaire has predominantly been used in an interview
301 setting [10], these results support the utility of our self-administered questionnaire; however,
302 further analysis is still needed to examine its validity in this application.

303 The importance of this study lies in the use of the RUD questionnaire, which enables
304 international comparisons. However, different informal care times can cause variations in
305 cost estimates [41]. The mean informal care time per day in our sample was longer than
306 those reported in the majority of previous studies (1.45–9.50 hours) [5,7,14,26,28–37,39,40]. This
307 may be influenced by the emphasis on family care in the Confucian values prevalent in
308 East Asian countries [5], which is corroborated by the similarly longer informal care times
309 reported in other Japanese studies [28,31–33,36].

310 Many previous studies that analyzed dementia care costs have omitted informal care in
311 institutionalized people with dementia as it was assumed that only professional care was

312 provided at the institutions [2,3]. However, this study shows that informal care is still
313 provided to institutionalized people with dementia in Japan. The systematic review by
314 Schaller et al. reported that few studies have considered the provision of informal care at
315 institutions [2,42–44]. Other studies have reported that family caregivers provide informal
316 care (such as eating and toileting assistance) when they visit institutionalized people with
317 dementia [2, 38-41]. Some caregivers visit every day and stay for as long as 16 hours [40].
318 It may therefore be advantageous for future studies to conduct more specific surveys
319 focused on informal care provided in institutions.

320 This study also showed that informal care accounts for more than half of the dementia
321 care costs for community-dwelling people with dementia, which is consistent with the
322 findings of previous studies [2–4]. Increasing the number of community-dwelling people
323 with dementia may reduce the costs of formal care by transferring the burden onto
324 caregivers. If adopting a societal or insurance payer's perspective, these results may
325 support the decrease in institutionalization in order to reduce government spending [2].
326 However, the informal caregivers are unlikely to be able to provide adequate care if
327 formal care was substantially reduced. Our results indicate that there is a need for an
328 integrated care system that incorporates and supports community-based care in addition
329 to formal care.

OE ratios were used as an indicator of costs adjusted by patient age, sex, and care-needs levels in each of the residence types. Out-of-pocket-payments for LTC services that are not covered by insurance were found to be particularly high in fee-based homes for older persons or group homes. Several free-form comments from the survey noted that the entrance fees and living expenses are particularly high in these institutions. On the other hand, the caregivers for community-dwelling people with dementia paid substantial amounts for housekeepers and consumables (such as diapers) as out-of-pocket payments not covered by insurance. People with dementia who are institutionalized in LTC health facilities and intensive care homes for older persons generally pay much more for LTC services covered by insurance. This is because these individuals tend to have higher care-needs levels and consume a larger quantity of these services. Cost estimates that only consider payments covered by insurance would underestimate the personal economic burden of patients and caregivers. In this study, we were able to quantify the actual personal economic burden for dementia care that included informal care costs and out-of-pocket payments not covered by insurance. These results support considering the balance between the government's fiscal burden and caregivers' economic burdens to construct a sustainable dementia care system.

There are several limitations to this study. First, we conducted a web-based

questionnaire survey to caregivers of people with dementia. The respondents tended to be male and relatively young, which reflects the general characteristics of web-based research [45,46]. The sample may therefore not be representative of all caregivers, and sampling errors may arise because the sample is limited to individuals who can access the Internet and are registered with an Internet research company. Second, our dataset did not include clinical severity data measured by the Mini Mental State Examination or Neuropsychiatric Inventory questionnaire. However, care-needs levels are determined using an evidence-based computer algorithm and an expert panel to indicate the amount of care required by each person while taking into consideration their symptoms and functional capability. Clinical severity may not be indicative of the burden of care, and the use of care-needs levels therefore allows greater accuracy in determining individual requirements for care.

Conclusion

This study revealed the costs of dementia care in different residence types in Japan. The inclusion of informal care costs reduced the overall cost differences among the residence types. In a community setting, informal care costs were much higher than in institutions, and the total costs that included these informal care costs were also higher

despite the lower out-of-pocket payments. These findings may contribute to the development of dementia care systems in Japan that consider both personal and societal economic burdens.

Abbreviations

ADL: Activities of Daily Life

IADL: Instrumental Activities of Daily Life

LTC: Long-Term Care

OE ratio: the ratio between the observed and expected values

RUD: Resource Utilization in Dementia

SV: Supervision

Declarations

Acknowledgements

None.

Conflicts of interests

The authors declare that they have no competing interests.

Ethics statement

This study was approved by the Ethics Committee of Kyoto University Graduate School of Medicine (R0487). Finishing to answer the questionnaire implied consent.

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545 Table 1. Components of the revised Resource Utilization in Dementia (RUD) questionnaire used for the web-based survey

Caregiver	Person with Dementia
(1) Caregiver's characteristics Age, sex, marital status, number of children, household income, personal income, and number/relationship of people living with the caregiver	**(2) PwD's characteristics** Age, sex, relationship with the caregiver, and number of people living with the PwD [Additional Questions] ADL and IADL function, copayment rate for healthcare services, care-needs level, type of dementia, causes of care needs, and residence type
(3) Caregiver's working status and informal care Contribution level, cohabiting with PwD, informal care time (ADL, IADL, and SV), employment status, paid working hours, reason for unemployment, and working hours [Additional Questions] Visiting duration and type of transportation taken to visit the PwD	**(4) Healthcare and LTC services for dementia care** Utilization of LTC services and healthcare services [Additional Questions] Out-of-pocket payments for healthcare services, LTC services covered by insurance, and LTC services not covered by insurance

546 Abbreviations: ADL, Activities of Daily Living; IADL, Instrumental Activities of Daily Living; LTC, long-term care; PwD, person with dementia; SV, Supervision

Table 2. Characteristics of people with dementia and their caregivers

	Total (n=3841)	Community residence (n=2290)	Elderly housing with care services (n=81)	Fee-based homes for older persons (n=413)	Group homes (n=177)	Long-term care facilities (n=183)	Intensive care homes for older persons (n=396)	Sanatoriums/ Hospitals (n=301)
People with Dementia								
Age, mean±SD, y	82.5±10.77	81.5±10.5	80.1±13.3	84.4±11.1	85.9±8.13	82.4±12.4	85.5±10.8	83.1±10.32
Sex, n (%)								
Female	2640 (68.7)	1514 (66.1)	46 (56.8)	292 (70.7)	144 (81.4)	137 (74.9)	308 (77.8)	199 (66.1)
Male	1201 (31.3)	776 (33.9)	35 (43.2)	121 (29.3)	33 (18.6)	46 (25.1)	88 (22.2)	102 (33.9)
Care-needs level, n (%)								
Support-Needs Level 1-2	422 (11.0)	333 (14.5)	11 (13.6)	44 (10.7)	8 (4.5)	7 (3.8)	5 (1.3)	14 (4.7)
Care-Needs Level 1	551 (14.3)	409 (17.9)	16 (19.8)	47 (11.4)	26 (14.7)	22 (12.0)	14 (3.5)	17 (5.6)
Care-Needs Level 2	685 (17.8)	466 (20.3)	18 (22.2)	83 (20.1)	41 (23.2)	24 (13.1)	30 (7.6)	23 (7.6)
Care-Needs Level 3	695 (18.1)	375 (16.4)	16 (19.8)	75 (18.2)	38 (21.5)	37 (20.2)	103 (26.0)	51 (16.9)
Care-Needs Level 4	494 (12.9)	184 (8.0)	12 (14.8)	54 (13.1)	37 (20.9)	41 (22.4)	112 (28.3)	54 (17.9)
Care-Needs Level 5	501 (13.0)	160 (7.0)	3 (3.7)	59 (14.3)	21 (11.9)	47 (25.7)	111 (28.0)	100 (33.2)
Non-approved/Unknown	493 (12.8)	363 (15.9)	5 (6.2)	51 (12.3)	6 (3.4)	5 (2.7)	21 (5.3)	42 (14.0)
ADL/IADL functional capabilities								
ADL score (0-6), mean	2.7	3.3	3.2	2.2	2.5	1.7	1.2	1
IADL score (0-7), mean	1.0	1.4	1.3	0.8	0.4	0.4	0.3	0.3
Caregivers								
Age, mean±SD, y	51.9±13.20	50.9±13.1	52.4±14.0	51.0±14.1	55.1±12.08	54.7±12.7	54.7±12.9	53.4±12.9
Sex, n (%)								
Female	1622 (42.2)	989 (43.2)	30 (37.0)	157 (38.0)	80 (45.2)	74 (40.4)	155 (39.1)	137 (45.5)
Male	2219 (57.8)	1301 (56.8)	51 (63.0)	256 (62.0)	97 (54.8)	109 (59.6)	241 (60.9)	164 (54.5)
Relationship, n (%)								

Mother	1513 (39.4)	885 (38.6)	24 (29.6)	137 (33.2)	92 (52.0)	85 (46.4)	184 (35.2)	106 (19.9)
Mother-in-law	511 (13.3)	273 (11.9)	15 (18.5)	70 (16.9)	22 (12.4)	27 (14.8)	57 (14.4)	47 (15.6)
Father	678 (17.7)	463 (20.2)	14 (17.3)	50 (12.1)	17 (9.6)	27 (14.8)	51 (12.9)	56 (18.6)
Father-in-law	244 (6.4)	153 (6.7)	10 (12.3)	32 (7.7)	6 (3.4)	8 (4.4)	17 (4.3)	18 (6.0)
Spouse	197 (5.1)	148 (6.5)	7 (8.6)	7 (1.7)	6 (3.4)	7 (3.8)	7 (1.8)	15 (5.0)
Sibling	58 (1.5)	23 (1.0)	2 (2.5)	12 (2.9)	2 (1.1)	7 (3.8)	7 (1.8)	5 (1.7)
Child	28 (0.7)	14 (0.6)	0 (0.0)	4 (1.0)	1 (0.6)	4 (2.2)	1 (0.3)	4 (1.3)
Friend	28 (0.7)	15 (0.7)	0 (0.0)	5 (1.2)	2 (1.1)	0 (0.0)	3 (0.8)	3 (1.0)
Other (including grandparents)	584 (15.2)	316 (13.8)	9 (11.1)	96 (23.2)	29 (16.4)	18 (9.8)	69 (17.4)	47 (15.6)
Contribution level for caregiving, n (%)								
1-20%	1939 (50.5)	848 (37.0)	36 (44.4)	283 (68.5)	140 (79.1)	127 (69.4)	308 (77.8)	197 (65.4)
21-40%	787 (20.5)	544 (23.8)	25 (30.9)	87 (21.1)	18 (10.2)	25 (13.7)	46 (11.6)	42 (14.0)
41-60%	434 (11.3)	344 (15.0)	13 (16.0)	26 (6.3)	3 (1.7)	10 (5.5)	15 (3.8)	23 (7.6)
61-80%	261 (6.8)	218 (9.5)	5 (6.2)	7 (1.7)	4 (2.3)	9 (4.9)	4 (1.0)	14 (4.7)
81-100%	420 (10.9)	336 (14.7)	2 (2.5)	10 (2.4)	12 (6.8)	12 (6.6)	23 (5.8)	25 (8.3)
Currently employed, n (%)	2083 (54.2)	1284 (56.1)	41 (50.6)	206 (50.0)	95 (53.7)	87 (47.5)	218 (55.1)	152 (50.5)

ADL: Activities of Daily Living, IADL: Instrumental Activities of Daily Living, SD: Standard Deviation

Table 3. Mean informal care time per day according to residence type

	Mean±SD	Total	Community residence (n=2290)	Elderly housing with care services (n=81)	Fee-based homes for older persons (n=413)	Group homes (n=177)	Long-term care facilities (n=183)	Intensive care homes for older persons (n=396)	Sanatoriums/ Hospitals (n=301)
Adjusted[a]	ADL	4.5±3.9	4.9±3.6	4.2±3.4	4.4±4.3	3.6±4.8	3.4±4.3	3.6±4.4	3.3±4.0
	IADL	3.7±3.4	4.3±3.2	3.9±3.6	3.2±3.4	2.2±3.5	2.4±3.4	2.5±3.3	2.9±3.7
	ADL+IADL	8.1±6.0	9.2±5.5	8.0±6.0	7.6±6.4	5.7±6.4	5.8±6.2	6.1±6.4	6.2±6.2
Non-Adjusted	ADL	2.4±3.0	2.9±3.2	2.2±3.1	1.8±2.5	1.4±2.8	1.5±2.6	1.6±2.8	1.5±2.6
	IADL	2.0±2.8	2.6±3.0	2.0±2.8	1.5±2.3	1.0±2.0	1.3±2.9	1.1±2.1	1.4±2.3
	ADL+IADL	4.4±5.3	5.4±5.6	4.2±5.2	3.3±4.2	2.4±4.0	2.8±4.8	2.6±4.4	2.9±4.4

Abbreviations: ADL, Activities of Daily Living; IADL, Instrumental Activities of Daily Living; SD, Standard Deviation.

[a] Adjusted using the caregivers' contribution levels.

Table 4. OE ratio for dementia care costs according to residence type

	Community residence (n=2290)	Elderly housing with care services (n=81)	Fee-based homes for older persons (n=413)	Group homes (n=177)	Long-term care facilities (n=183)	Intensive care homes for older persons (n=396)	Sanatoriums /Hospitals (n=301)
A: Informal care costs	1.31	0.53	0.59	0.32	0.43	0.42	0.65
B: OPP for LTC services not covered by insurance	0.58	1.64	2.11	2.09	1.06	1.01	1.46
C: OPP for LTC services covered by insurance	0.84	1.11	1.30	1.40	1.28	1.28	0.93
D: OPP for healthcare services	0.68	1.19	1.45	1.02	1.02	0.88	2.45
OPP for LTC services (B+C)	0.72	1.46	1.76	1.81	1.13	1.14	1.19
Total LTC costs (A+B+C)	1.10	0.87	1.02	0.88	0.71	0.7	0.86
Total OPP (B+C+D)	0.73	1.42	1.70	1.58	1.12	1.08	1.59
Total healthcare and LTC costs (A+B+C+D)	1.06	0.93	1.11	0.87	0.77	0.72	1.10

Abbreviations: LTC, Long-term care; OE, observed/expected; OPP, out-of-pocket payments.

The OE ratios were calculated for each residence type after adjusting for sex, age, and care-needs levels of people with dementia. Missing values were excluded from analysis.

Figure 1. Comparison of mean informal care times among the present study and previous studies [5,7,13,14,26,28–40]

The lined bars indicate non-Japanese studies, the grey bars indicate Japanese studies, and the black bars indicate the present study.

Three types of results from the present study are provided: (1) Adjusted costs using the caregivers' contribution levels, (2) non-adjusted costs, and (3) costs for primary caregivers (contribution level >60%) in a community setting. Also, we showed the 95% confidence interval of the mean value excluding some previous studies that did not include the standard deviation.

[a] Including supervision

[b] Weekly informal care time converted into daily informal care time (7 days/week)

[c] Monthly informal care time converted into daily informal care time (30 days/week)

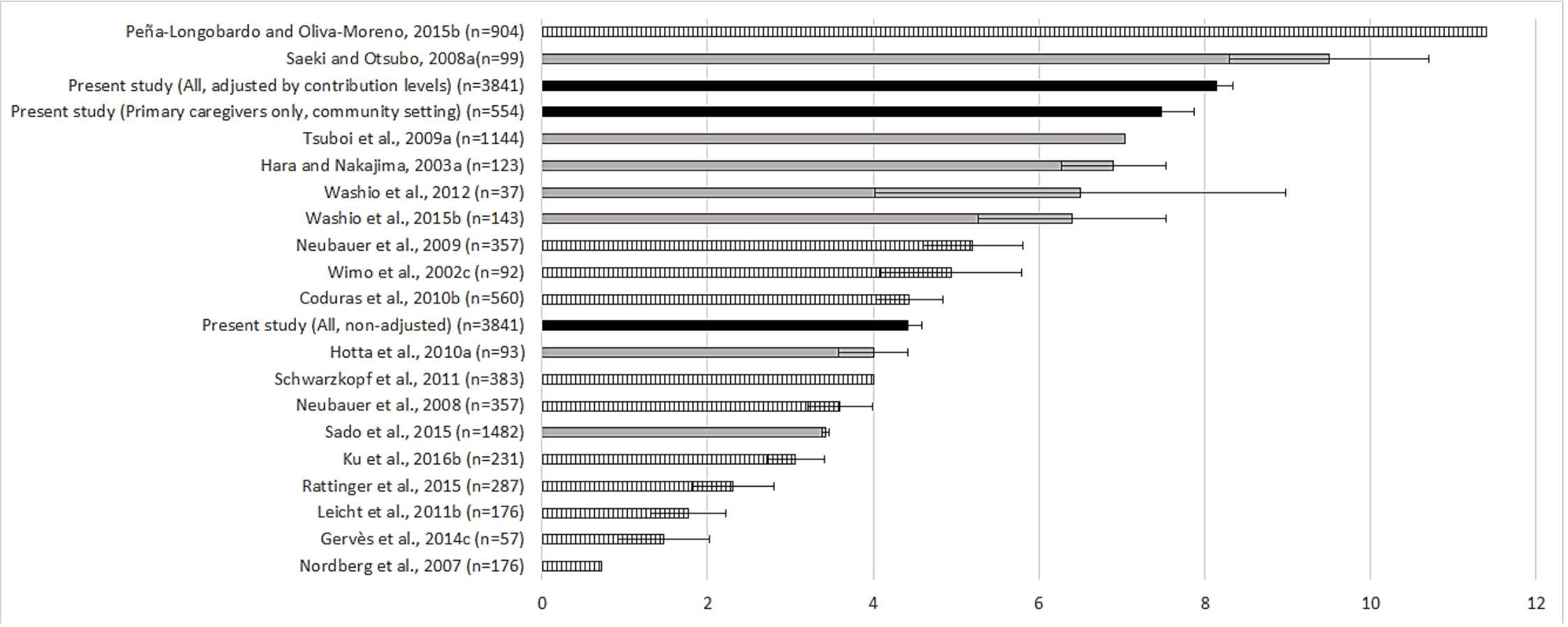
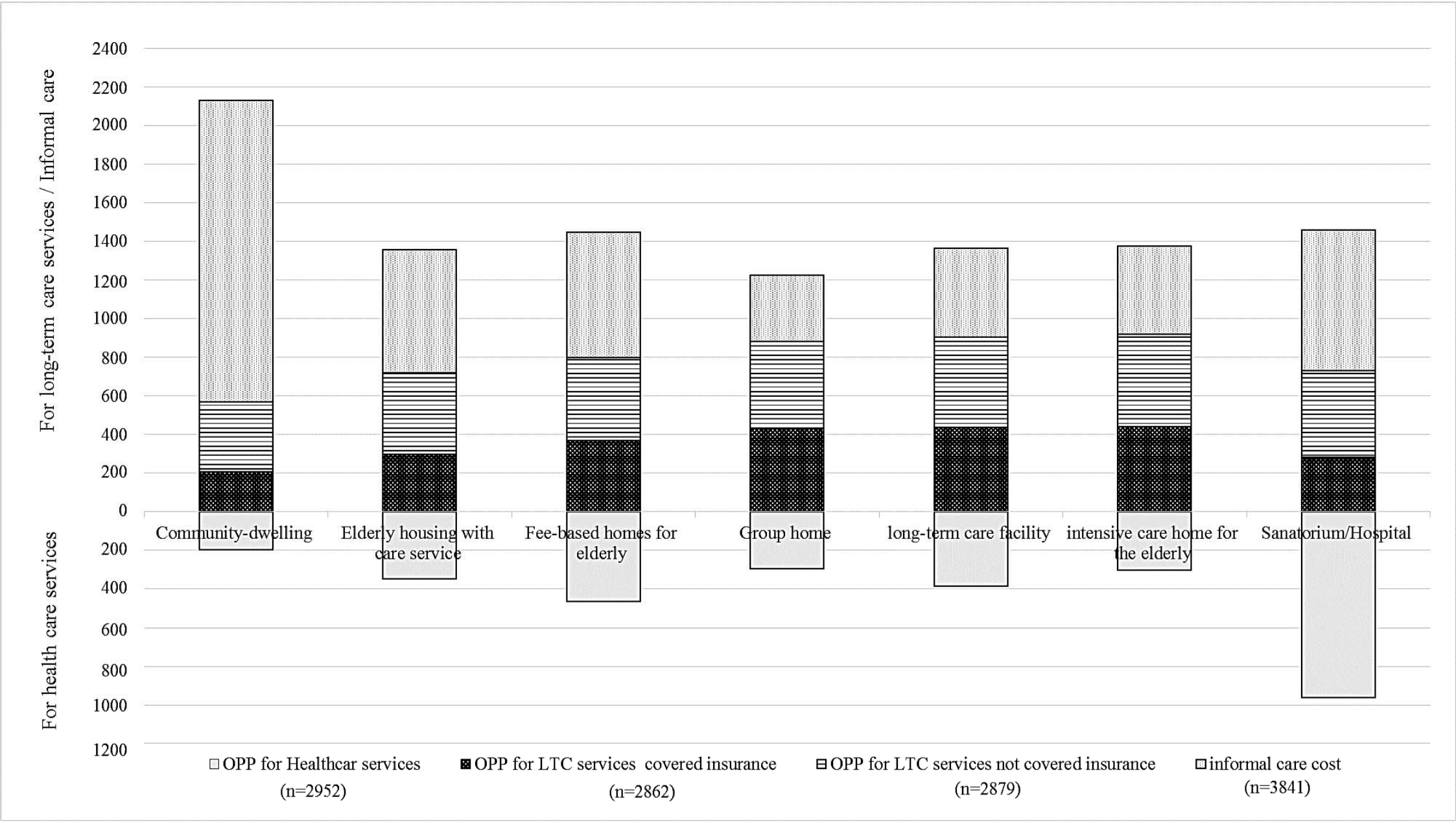

Peña-Longobardo and Oliva-Moreno, 2015b (n=904)
Saeki and Otsubo, 2008a(n=99)
Present study (All, adjusted by contribution levels) (n=3841)
Present study (Primary caregivers only, community setting) (n=554)
Tsuboi et al., 2009a (n=1144)
Hara and Nakajima, 2003a (n=123)
Washio et al., 2012 (n=37)
Washio et al., 2015b (n=143)
Neubauer et al., 2009 (n=357)
Wimo et al., 2002c (n=92)
Coduras et al., 2010b (n=560)
Present study (All, non-adjusted) (n=3841)
Hotta et al., 2010a (n=93)
Schwarzkopf et al., 2011 (n=383)
Neubauer et al., 2008 (n=357)
Sado et al., 2015 (n=1482)
Ku et al., 2016b (n=231)
Rattinger et al., 2015 (n=287)
Leicht et al., 2011b (n=176)
Gervès et al., 2014c (n=57)
Nordberg et al., 2007 (n=176)
0
2
4
6
8
10
12

Figure 2. Mean monthly costs of dementia care according to residence type

Abbreviations: LTC, Long-term care; OPP, out-of-pocket payments.

All costs are expressed as US dollars using the purchasing power parity rate in 2016 (¥102=$1). Missing values were excluded from analysis.


For long-term care services / Informal care
For health care services
2400
2200
2000
1800
1600
1400
1200
1000
800
600
400
200
0
200
400
600
800
1000
1200
Community-dwelling
Elderly housing with care service
Fee-based homes for elderly
Group home
long-term care facility
intensive care home for the elderly
Sanatorium/Hospital
OPP for Healthcar services (n=2952)
OPP for LTC services covered insurance (n=2862)
OPP for LTC services not covered insurance (n=2879)
informal care cost (n=3841)

Supplementary Table 1. Total out-of-pocket payments and total costs comparing among residence types

Mean±SD	A: Community residence (n=1558)	B: Elderly housing with care services (n=59)	C: Fee-based homes for older persons (n=238)	D: Group homes (n=100)	E: Long-term care facilities (n=109)	F: Intensive care homes for older persons (n=248)	G: Sanatoriums/ Hospitals (n=170)
Total out-of-pocket payments †	619±976	1324±1493	1620±1550	1505±831	1252±955	1182±1207	1734±1641
Total healthcare and LTC costs‡ (including informal care costs)	2309±2314	2089±1879	2453±2095	1861±1132	1785±1366	1657±1739	2610±2387

Abbreviation: SD, Standard Deviation

Multiple comparison among residence types used analysis of variance (ANOVA) with Post-Hoc Games Howell test ($p<0.05$)

† Singificant difference between following pairs: A vs. B, C, D, E, F, G; C vs. F; E vs. G; F vs. G

‡ Singificant difference between following pairs: A vs. D, E, F; C vs. D, E, F; D vs. G; E vs. G; F vs. G

All costs are expressed as US dollars using the purchasing power parity rate in 2016 (¥102=$1).