

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

(認知症ケアに関する個人の経済的負担：
日本における居住形態別の比較)

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

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19 Keywords: Informal care; RUD; Dementia; Cost; Japan

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21 Key points

22 ● The personal cost of dementia care across different residence types was quantified.

23 ● Institutionalized patients still received informal care from voluntary caregivers.

24 ● Total costs were higher in community-dwelling patients than those in institutions.

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27

28 **Abstract**

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

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

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

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

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43

44 **Introduction**

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

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

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

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

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

80 Furthermore, people with dementia live both in the community and in specialized
81 institutions. However, few studies have compared the costs of dementia between the
82 community and institutional settings². Moreover, to the best of our knowledge, no studies
83 have clarified the differences in the costs of dementia among the types of institution, such
84 as group homes and LTC facilities. In order to design and implement an integrated
85 community care system, it is important to ascertain the relative costs between home care
86 and care provided in various institutional types.

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

89

90 **2. Methods**

91 *2.1. Web-based survey for data collection on people with dementia and their caregivers*

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

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

107

108 *2.2. Questionnaire*

109 The survey was conducted using the Resource Utilization in Dementia (RUD) 3.0
110 version ⁹ questionnaire that had been revised to accommodate the Japanese healthcare
111 and LTC system. The RUD is currently one of the most useful tools for collecting data on
112 resource utilization in dementia ^{9–11}, and its use allows for international comparisons ².
113 Table 1 shows the components of the revised questionnaire, which included items from
114 the Japanese translation of the RUD that were concerned with informal care duration,
115 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

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

141 2.3. Cost estimation

142 Total costs were estimated based on four components: out-of-pocket payments
143 (copayments) for healthcare services, out-of-pocket payments (copayments) for LTC
144 services covered by insurance, out-of-pocket payments for LTC services not covered by
145 insurance, and informal care costs. Under Japan's universal health system, all residents
146 must be enrolled in healthcare and LTC (≥ 40 years old) insurance. Depending on age and
147 income, enrollees must pay a copayment of 10% to 30% when receiving healthcare and
148 LTC services. Out-of-pocket payments for healthcare services and LTC services were
149 determined through a questionnaire covering the various categories. These costs were
150 substituted by a median of each category, and we calculated the weighted average with

151 the following formula:
$$\frac{\sum_{i=0}^k (\text{median of category}_i) * n_i}{\sum n}$$

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

163 Caregivers were asked to state their contribution to the total informal care received by
164 the patient as one of the following five options: 1–20%, 21–40%, 41–60%, 61–80%, or
165 81–100%. Per RUD instructions, we adjusted the informal care times by these
166 contribution levels to treat all caregivers as primary caregivers and estimate the costs
167 associated with all informal care provided to a patient. Total informal care time was
168 adjusted by dividing by the median of each contribution rate category.

169 The cost of informal care can be estimated using the “opportunity cost” or “replacement

170 cost” approaches ²⁻⁴. The opportunity cost approach estimates the costs due to loss of
171 productivity, whereas the replacement cost approach assumes the informal care services
172 can be similarly valued as home care services provided by professional caregivers.
173 Similar to previous studies that used the RUD ^{1,5,18}, we selected the opportunity cost
174 approach in order to assess informal care time as forgone wages for caregivers. Costs
175 were valued by the caregivers’ monthly mean wage stratified by sex and age¹⁹. We
176 assessed informal care costs for caregivers who were not working or were over 65 years
177 of age at 30% of the mean wage of employed caregivers ²⁰⁻²³. Time spent on supervision
178 was assumed to be zero cost for the same reasons why we assess it separately ^{5,17,18,24}. A
179 maximum daily informal care time of 16 hours was assumed in order to allow for other
180 activities and sleeping time ²⁵⁻²⁷.

181 *2.4 Inclusion and exclusion criteria*

182 We included all caregivers and people with dementia who responded to the web-based
183 survey. However, we excluded the following respondents; (1) caregivers over 100 years
184 old or with dementia from a decline of cognitive function, (2) those who provided
185 contradictory information regarding the caregiver’s relationship with people with
186 dementia, and, (3) those who reported an informal care time for ADL or IADL that
187 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

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

208
$$\text{the expected total costs} = \sum_{i=1}^n \{Q(i) \times N(i)\}$$

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

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

216 In all analyses, we excluded missing values in out-of-pocket payments for healthcare
217 and LTC services if the respondents answered “unknown” for these items. All costs were
218 converted from Japanese yen to US dollars using the purchasing power parity rate in 2016
219 (¥102 = \$1) provided by the Organization for Economic Cooperation and Development.
220 All data were analyzed using IBM SPSS Statistics 23.0 for Windows (SPSS Japan Inc.,
221 Tokyo, Japan).

222

223 **3. Results**

224 *3.1. Characteristics of people with dementia and their caregivers*

225 A total of 3916 caregivers answered the questionnaire, but the following were excluded
226 from the analysis: caregivers aged over 100 years (n=7), caregivers with dementia (n=2),
227 caregivers with contradictory information regarding their relationship with people with
228 dementia (n=24), and caregivers who reported an informal care time for ADL or IADL
229 that exceeded 24 hours per day (n=42). After these exclusions, the final sample comprised
230 3841 respondents.

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

240

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

259 *3.3. Cost estimation*

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

271 *3.4. OE ratios*

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

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

278

279 **4. Discussion**

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

289 We compared the mean informal care times among the present study and previous
290 studies that focused on primary caregivers in a community setting^{5,7,13,14,26,28-40}, and the
291 mean informal care time in a community setting in this study was generally higher than
292 that of previous studies. However, even after adjusting informal care time by the
293 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.

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

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

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

360

361 **Conclusion**

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

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

369

370 **Abbreviations**

371 ADL: Activities of Daily Life

372 IADL: Instrumental Activities of Daily Life

373 LTC: Long-Term Care

374 OE ratio: the ratio between the observed and expected values

375 RUD: Resource Utilization in Dementia

376 SV: Supervision

377

378 **Declarations**

379 **Acknowledgements**

380 None.

381 **Conflicts of interests**

382 The authors declare that they have no competing interests.

383 **Ethics statement**

384 This study was approved by the Ethics Committee of Kyoto University Graduate School
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393

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

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.

1 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

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

3 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.

4 Figure 1. Comparison of mean informal care times among the present study and previous studies ^{5,7,13,14,26,28-40}

5

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

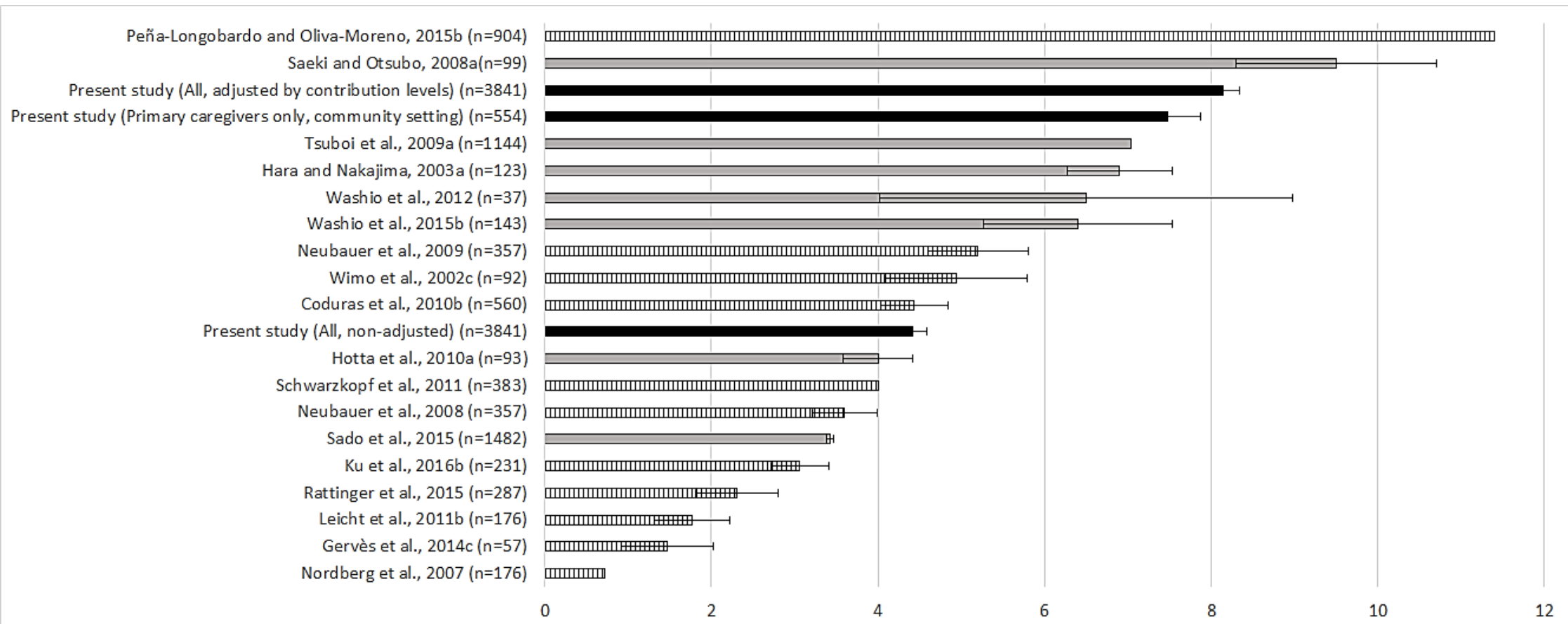
7 Three types of results from the present study are provided: (1) Adjusted costs using the caregivers' contribution levels, (2) non-adjusted costs, and (3) costs for
8 primary caregivers (contribution level >60%) in a community setting. Also, we showed the 95% confidence interval of the mean value excluding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

10 ^a Including supervision

11 ^b Weekly informal care time converted into daily informal care time (7 days/week)

12 ^c Monthly informal care time converted into daily informal care time (30 days/week)

13

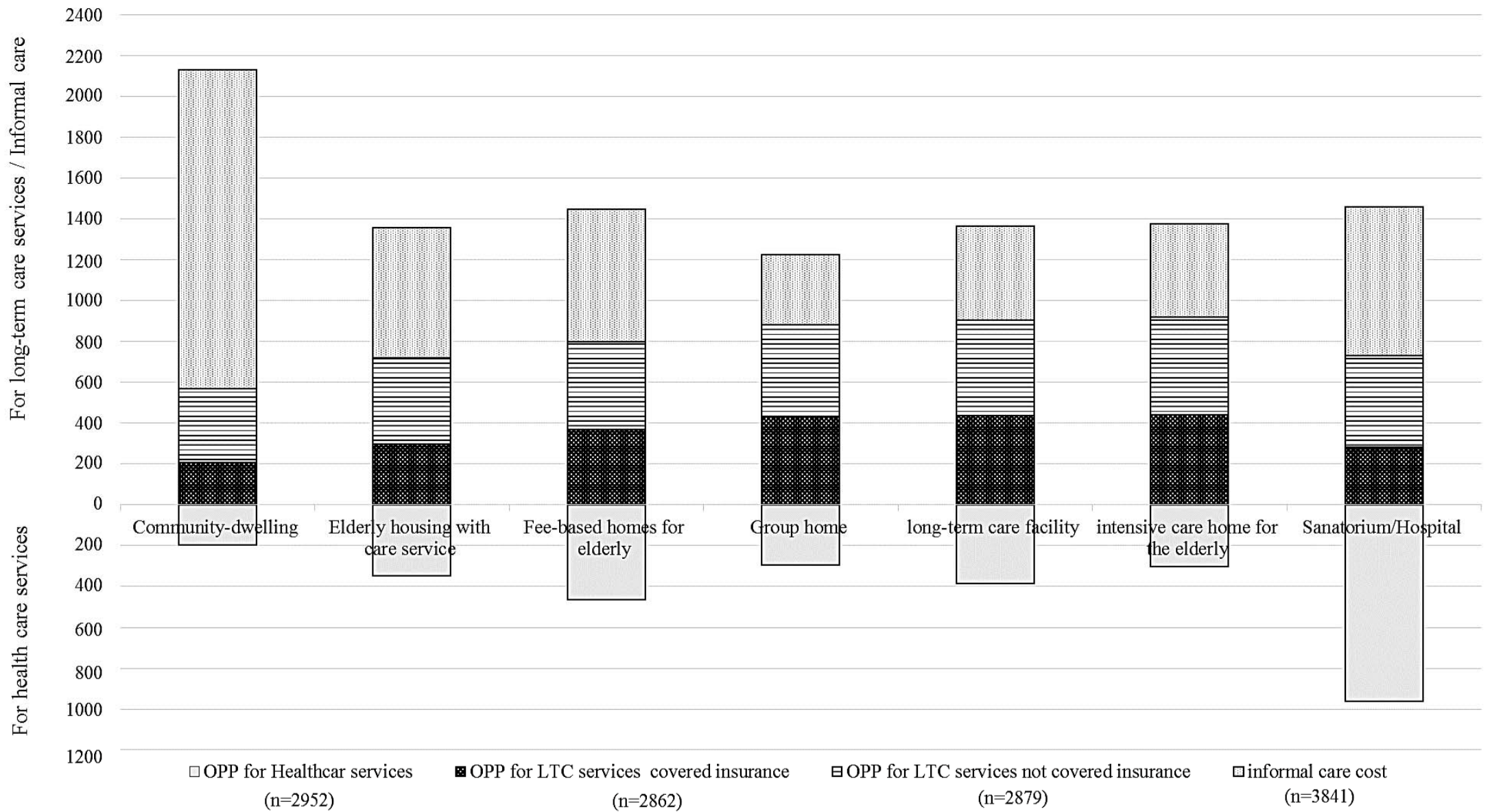


14 Figure 2. Mean monthly costs of dementia care according to residence type

15

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

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



1 **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

2 Abbreviation: SD, Standard Deviation

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

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

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

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

7