INFORMAL CARE COST AND OUT-OF-POCKET PAYMENT TO SUPPORT PEOPLE WITH DEMENTIA: THEIR MICRO-LEVEL DETERMINANTS IN A LARGE SAMPLE SURVEY IN JAPAN

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The number of people with dementia in Japan

The number of people with dementia (million)

+ Costs of Care for people with dementia

- Medical costs covered by healthcare insurance:
  - Copayments (10% or 20% or 30%)

- Care costs covered by LTC insurance:
  - Copayments (10% or 20%)

- Care costs uncovered by LTC insurance:
  - Out-of-pocket payment

Informal care

Copayments

Copayments

Copayments

3
Objectives

To clarify the cost of informal care and out-of-pocket payments for caregiving for people with dementia in Japan

To investigate the relationship between these estimated costs and the characteristics of people with dementia and their caregivers.
Definition of costs

- Economic burden
  - Informal care cost
  - Out-of-pocket payments
    - Medical care
    - Care services covered by LTC insurance
    - Care services uncovered by LTC insurance
Online Survey

- A cross-sectional online survey (March 7 to March 14 in 2016)
- With a self-administered questionnaire
- Study population: panels of online research company (over 30, not the professional caregiver)
- Sample size: 3600 (30’s-60’s: each 850, over 70’s: 200)
Characteristics of online survey

- Collecting the data
  - Speedy
  - Cost-benefit
  - Large quantity
  - Complex questionnaire

- Throughout the online research company = “volunteer panels”
  - Incentive as a monetary point
  - Avoiding low quality answers

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Eysenbach. JMIR Publications. 2004;6(3):e34
Questionnaire

Resource Utilization in Dementia (RUD) 3.0

- A standardized tool
- The most widely used instrument for resource use data collection on dementia care

We revised RUD to suit the Japanese healthcare and long-term care system.

<table>
<thead>
<tr>
<th>About caregiver</th>
<th>About person with dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>(1) Characteristics of caregiver</strong></td>
<td><strong>(2) Characteristics of person with dementia</strong></td>
</tr>
<tr>
<td>age, sex, marriage, number of children, home income, personal income, people living with caregivers</td>
<td>age, sex, relationships with caregiver, people living with PwD, ADL/IADL function (which PwD can do), the ration of copayments for medical services, care-need levels, type of dementia, causes of care-need, residential type</td>
</tr>
<tr>
<td><strong>(3) About caregiver's working status and informal care</strong></td>
<td><strong>(4) About medical and LTC services for dementia care</strong></td>
</tr>
<tr>
<td>contribution rate for care, whether living with PwD, visiting time and types of transportation, informal care time (ADL/IADL/SV), working status, paid working time, the reason of unemployment, working time</td>
<td>Utilization of LTC services, Utilization of healthcare services, Copayments (healthcare services), Copayments(LTC services), Out-of-pocket payments (uncovered by LTC insurance),</td>
</tr>
</tbody>
</table>

Wimo et al. Archives of Gerontorogy and Geriatrics. 2007;44:71-81
Wimo et al. Alzheimer’s and Dementia. 2013;9:429-435 a
How to calculate costs of dementia

Informal care costs

- **Opportunity cost approach** VS Replacement cost approach

  - Adjusting by the ratio of contribution of caregivers

  - Informal care time (up to 16 hours/day) = Activity of Daily Living (ADL) + Instrumental Activity of Daily Living (IADL)

  - **Unit cost**: Average wage in Japan stratified by gender and age
    (Caregivers who unemployed or over 65 years old: 30% of costs)

Out-of-pocket payments

- Categorical question

References:
- Kraft et al. *Swiss Medical Weekly*. 2010; 140:w13093
Statistical analysis:

- Descriptive statistics
- Exhaustive Chi-square Automatic Interaction Detection (CHAID) analysis

Outcome: Informal care cost and out-of-pocket payments

Explanatory variables:

Factors of people with dementia
- Gender, Age, Care-need levels, ADL function, IADL function, Disease caused care-need

Factors of Caregivers
- Gender, Age, Marriage, Children, Cohabitation with PwD, Employment status

Economic factors
- House income of caregivers, the ratio of healthcare costs
Selection Process

Collection (n=3916)

Contradiction answer (n=75)

- Missing data of Care-need levels (n=493)
- Missing data of medical costs (n=686)
- Missing data of care costs (n=437)

Analysis (n=2225)
### Characteristics of people with dementia

**People with Dementia** (n=2225)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean (SD), y</td>
<td>82.6(10.9)</td>
</tr>
<tr>
<td>Sex, n(%)</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>1535(69.0)</td>
</tr>
<tr>
<td>Male</td>
<td>690(31.0)</td>
</tr>
<tr>
<td>Care/Support-needs level, n(%)</td>
<td></td>
</tr>
<tr>
<td>Support-need level 1 · 2</td>
<td>285(12.8)</td>
</tr>
<tr>
<td>Care-need level 1</td>
<td>402(18.1)</td>
</tr>
<tr>
<td>Care-need level 2</td>
<td>457(20.5)</td>
</tr>
<tr>
<td>Care-need level 3</td>
<td>438(19.7)</td>
</tr>
<tr>
<td>Care-need level 4</td>
<td>315(14.2)</td>
</tr>
<tr>
<td>Care-need level 5</td>
<td>328(14.7)</td>
</tr>
</tbody>
</table>
## Characteristics of Caregivers

### Caregivers (n=2225)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean (SD), y</td>
<td>53.4(13.2)</td>
</tr>
<tr>
<td>Sex, n(%)</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>802(36.0)</td>
</tr>
<tr>
<td>Male</td>
<td>1423(64.0)</td>
</tr>
<tr>
<td>Caregivers working for pay, n(%)</td>
<td>1218(54.7)</td>
</tr>
<tr>
<td>Relationship, n(%)</td>
<td></td>
</tr>
<tr>
<td>Parents</td>
<td>1786(80.3)</td>
</tr>
<tr>
<td>Spouse</td>
<td>139(6.2)</td>
</tr>
<tr>
<td>Sibling</td>
<td>34(1.5)</td>
</tr>
<tr>
<td>Child(ren)</td>
<td>23(1.0)</td>
</tr>
<tr>
<td>Friend</td>
<td>11(0.5)</td>
</tr>
<tr>
<td>Other</td>
<td>232(10.4)</td>
</tr>
<tr>
<td>Contribution rate for caregiving, n(%)</td>
<td></td>
</tr>
<tr>
<td>1-20%</td>
<td>941(42.3)</td>
</tr>
<tr>
<td>21-40%</td>
<td>504(22.7)</td>
</tr>
<tr>
<td>41-60%</td>
<td>302(13.6)</td>
</tr>
<tr>
<td>61-80%</td>
<td>195(8.8)</td>
</tr>
<tr>
<td>81-100%</td>
<td>283(12.7)</td>
</tr>
</tbody>
</table>
Informal care time per day

<table>
<thead>
<tr>
<th>Study</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Adjusted by contribution rate</strong></td>
<td></td>
</tr>
<tr>
<td>ADL</td>
<td>4.59 (3.81)</td>
</tr>
<tr>
<td>IADL</td>
<td>3.88 (3.34)</td>
</tr>
<tr>
<td><strong>Non-adjusted by contribution rate</strong></td>
<td></td>
</tr>
<tr>
<td>ADL</td>
<td>2.44 (2.54)</td>
</tr>
<tr>
<td>IADL</td>
<td>2.13 (2.41)</td>
</tr>
</tbody>
</table>

Informal care time = care time for ADL and IADL
## Costs for dementia care

<table>
<thead>
<tr>
<th></th>
<th>Informal care costs(¥)</th>
<th>Out-of-pocket payments(¥)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean (SD)</td>
<td>134,329 (186,662)</td>
<td>99,844 (121,136)</td>
</tr>
<tr>
<td>Median (Q₁ - Q₃)</td>
<td>67,217 (13,393-177,745)</td>
<td>72,500 (27,500 – 130,000)</td>
</tr>
</tbody>
</table>
CHAID (informal care costs)

- Characteristics of PwD
- Characteristics of caregivers
- Economic characteristics

Informal care cost ¥134,239

Living with caregivers or not

- Living with ¥210,295
  - Employment status
    - Employed ¥279,141
    - Nursing care leave ¥386,518
    - Unemployed ¥105,745
  - Caregivers' age
    - 30-39 ¥251,168
    - 40-57 ¥337,971
    - 58-65 ¥233,699
    - 66- ¥94,742
  - Care-need levels
    - Support-need level
      - Care-need level 1 ¥83,608
    - Care-need level 2-3 ¥102,780
    - Care-need level 4-5 ¥151,128

- Not living with ¥100,622
  - Employment status
    - Employed ¥112,527
    - Nursing care leave ¥298,178
    - Unemployed ¥49,452
    - ADL (walking)
      - Can ¥94,756
      - Cannot ¥131,380
    - Disease
      - Have ¥56,123
      - Not have ¥31,474
  - Institutionalized/Inhospitalized ¥47,892
  - Unemployed ¥31,285
Comparing sub categories stratified by CHAID analysis

- **Caregivers living with PwD**
  - Nursing care leave: 386,518

- **Caregivers NOT living with PwD**
  - Low: 83,608
  - Mid: 102,780
  - High: 151,128

Differences between Care-need levels
CHAID (Out-of-pocket payments)

□ Characteristics of PwD
■ Characteristics of caregivers
■ Economic characteristics

Out-of-pocket payment ¥99,844
Residential type
- At home ¥67,307
- Public Institution ¥122,873
- Private Institution Hospitals/Sanatorium ¥175,428
- Private Institution Group home ¥146,091

Paid work situation
- Employed ¥73,503
- Nursing care leave ¥150,109
- Unemployed ¥50,667

Caregivers’ house income
- 0-4 Million ¥48,519
- 4-10 Million ¥69,495
- 10-12 Million ¥92,917
- Over 12 Million ¥138,767

ADL (Toilet)
- Can ¥39,583
- Cannot ¥69,973

All IADL function
- Can ¥124,630
- Cannot ¥192,573

Caregivers’ gender
- Female ¥158,227
- Male ¥211,753
### Comparing sub categories stratified by CHAID analysis

<table>
<thead>
<tr>
<th>Home income level</th>
<th>At home</th>
<th>At private Institute</th>
<th>Nursing care leave</th>
</tr>
</thead>
<tbody>
<tr>
<td>High</td>
<td>138,767</td>
<td>150,109</td>
<td>211,753</td>
</tr>
<tr>
<td>Low</td>
<td>48,519</td>
<td>39,583</td>
<td></td>
</tr>
</tbody>
</table>

- **At home**
  - Home income level: High, Low
  - Nursing care leave: 211,753
  - Total: 150,109

- **At private Institute**
  - Home income level: High, Low
  - Nursing care leave: 138,767
  - Total: 211,753

- **Non-employed/can toilet**
  - Home income level: High, Low
  - Nursing care leave: 39,583
  - Total: 48,519

<table>
<thead>
<tr>
<th>($)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
</tr>
<tr>
<td>50,000</td>
</tr>
<tr>
<td>100,000</td>
</tr>
<tr>
<td>150,000</td>
</tr>
<tr>
<td>200,000</td>
</tr>
<tr>
<td>250,000</td>
</tr>
</tbody>
</table>
Validity of collecting data of informal care time

Differences in informal care time are one of the major causes of variations in informal care cost estimates.

- Larger than studies in other countries but almost as same as studies in Japan
- Effect of adjusting by contribution rate
- Role of Pilot test

We need the observational time study for validation of revised RUD as self-administrated online questionnaire
Factors related with informal care costs

Care-need levels partly related to informal care costs.

- Known factors related to informal care costs
  — dementia severity, ADL • IADL function

  Bergvall et al. *International Psychogeriatrics*. 2011; 23(1):73-85
  Li-Jung Ku et al. *PLOS*. 2016;11(2):e0148779
  Rattinger et al. *Alzheimer’s & Dementia*. 2015;11:946-954

This study mainly clarified caregivers’ cohabitation and employment status related to informal care costs

- A few studies considered about caregivers’ characteristics as a cost driver.

Factors related with out-of-pocket payments

Residential types primarily related to out-of-pocket payments

- Differences of payments for entering institution between types
  - Private VS Public

If the caregivers are employed, then their house income related to out-of-pocket payments

- How much they use the LTC services up to the limiting costs are free.
- Some care services need to pay all costs. — institutionalization
Limitation

- Online survey
  - Bias towards men or young people
  - Because of the survey through the internet company, there must be more anonymous data.

- Self-administrated questionnaire
  - RUD has been used with interviewers. (sometimes in cohort study)
  - We need more validation of RUD for use as an online questionnaire.
Conclusion

- This study quantified informal care costs and out-of-pocket payments for people with dementia (PWD) in Japan.
- Informal care costs were influenced by the status of caregivers such as living together with PWD and their employment status.
- Out-of-pocket payments were mainly influenced by the residential type, ADL levels, and care-need levels of PWD.
- This study is useful for designing regional systems for dementia care in Japan, considering both societal economic burden and access for care services.
Thank you for your attention!!