Cost of Dementia in India
a jigsaw puzzle

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Disclosure

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Dementia: new estimates for India

millions

2005 2010 2015 2020 2025 2030 2035 2040 2045 2050

3.7 6.4 12.5

Bharath & Rao, India
CoD, ADI 2013
Years Lived with Disability

- Stroke: 10.30%
- Arthritis: 9.66%
- Blindness: 21.93%
- Deafness: 10.82%
- Mental disorders: 9.31%
- Respiratory: 6.40%
- Heart disease: 5.39%
- Genitourinary: 1.86%
- Endocrine: 0.85%
- Digestive: 5.60%
- Diabetes: 2.55%
- Dementia: 11.9%

Years Life Lost

- Heart disease: 32.99%
- Stroke: 17.85%
- Cancer: 22.56%
- Skin: 0.16%
- Respiratory: 12.38%
- Mental disorders: 1.29%
- Dementia: 1.1%
- Diabetes: 3.71%
- Digestive: 4.66%
- Endocrine: 0.61%
- Genitourinary: 2.36%

Bharath & Rao, India
CoD, ADI 2013
COST OF ILLNESS

Economic Burden

Bharath & Rao, India
CoD, ADI 2013
OOPS

- Direct/Formal – Medical
- Direct/Formal – Social - paid care
- Informal – Social Care/Physical care

Societal Cost

- Loss of Productivity
- Provision of Resources – Infrastructure, Human resources, Training
Cost of Dementia

• WHY ASSESS **OOPS** in India?
• No prospective work so far
• Estimated at 9383 to 13700 M USD for 3.16 M PwD by Wimo et al. (188 to 274 USD)
• Of relevance to individual family members
• Initiative to understand the Economic Burden of Dementia which is increasing
• Influences Policy, Program, Resource Allocation by government
<table>
<thead>
<tr>
<th>Components and assumptions for costs</th>
<th>Need and Applicability</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mild</td>
</tr>
<tr>
<td>1. Medical Consultation</td>
<td>++</td>
</tr>
<tr>
<td></td>
<td>100%</td>
</tr>
<tr>
<td>2. Medication</td>
<td>++</td>
</tr>
<tr>
<td></td>
<td>100%</td>
</tr>
<tr>
<td>3. Lost Productivity</td>
<td>++</td>
</tr>
<tr>
<td></td>
<td>100%</td>
</tr>
<tr>
<td>4. Informal Care Giving</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>100%</td>
</tr>
<tr>
<td>5. Paid care / residential care by health aide</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>NE</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Hospitalization</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>10%</td>
</tr>
<tr>
<td>7. Day Care</td>
<td>++</td>
</tr>
<tr>
<td></td>
<td>10%</td>
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<tr>
<td>8. Special Food</td>
<td>-NE</td>
</tr>
<tr>
<td></td>
<td>33%</td>
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<tr>
<td>9. Changes to the House</td>
<td>+</td>
</tr>
<tr>
<td></td>
<td>50%</td>
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<tr>
<td>Particulars</td>
<td>Severity of Dementia</td>
</tr>
<tr>
<td>------------------------------------</td>
<td>----------------------</td>
</tr>
<tr>
<td></td>
<td>Mild</td>
</tr>
<tr>
<td>1) Medication</td>
<td>3,600</td>
</tr>
<tr>
<td>2) Consultation</td>
<td>1,700</td>
</tr>
<tr>
<td>3) Investigation (one time)</td>
<td>3,000</td>
</tr>
<tr>
<td>4) Hospitalisation</td>
<td>0</td>
</tr>
<tr>
<td>5) Transportation</td>
<td>1,200</td>
</tr>
<tr>
<td>6) Paid / Residential care</td>
<td>0</td>
</tr>
<tr>
<td>7) Day care</td>
<td>9,600</td>
</tr>
<tr>
<td>8) Lost Productivity</td>
<td>36,000</td>
</tr>
<tr>
<td>9) Informal Care (Opportunity Lost)</td>
<td>12,000</td>
</tr>
<tr>
<td>10) Special food</td>
<td>0</td>
</tr>
<tr>
<td>11) House modification (one time)</td>
<td>2,500</td>
</tr>
</tbody>
</table>
## TOTAL costs

<table>
<thead>
<tr>
<th>Particulars</th>
<th>Severity of Dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mild</td>
</tr>
<tr>
<td><strong>TOTAL cost per person</strong></td>
<td>69,600</td>
</tr>
<tr>
<td><strong>PwD (in millions)</strong></td>
<td>1.107</td>
</tr>
<tr>
<td><strong>Overall cost (in millions)</strong></td>
<td>77,047</td>
</tr>
</tbody>
</table>

**TOTAL for all PwD in India** INR 500,279 million (house hold cost)

Bharath & Rao, India
CoD, ADI 2013
Prospective Study

- To assess the Household Cost of PwD
- Interview with 40 patients and their carers
- Interviewed on Items of Care for the previous 1-3 months
- Providing Cost for the items – formal/informal
- Focus Group Discussion with Experts
- Development of an Assessment Scale
- Interview of 50 to 100 PwD on treatment for > 1 yr and their carers on OOPS
Description of the Items

• Direct Medical Cost – Consultation
  - Medications
  - Hospitalization

• Indirect Medical Cost – Co-morbidity / Appliances

• Direct Care Cost – Paid services

• Informal Care Cost – Family Care, Loss of wages
Respondents

• 56 PwD and their care givers interviewed
• Age - 40 to 82 yrs [Mean 63.3 ±14.1 yrs]
• M:F::36:20 (19 of the F were housewives)
• Illiterate/sign – 21; Sec Sch -27; Grad – 8
• Nobody except one continued to work
• Family Income Rs.150 – Rs 50,000/pm (Rs.5304/- Median Rs.2833/-)
• 29 months of consultation at NIMHANS – 2.89 visits in the previous 12 months
Carers & Caring

• 22 came with women who were care providers; 12 wives, 7 daughters and 3 d-i-l
• 19 were sons where the wives or d-i-l were the primary carers
• Remaining had other relatives who came with the pt as they knew the system
• 24 had mild; 28 mod and 5 severe disability
• Conversion of care into hours per day like Wimo et al was not effective.
Jigsaw Puzzle –
More pieces missing

- Hospital Based
- 46 (82%) had family contribution for care.
- Only 9 had Old Age or Disability Pension. 1 still worked.
- None had Health Insurance
- Transport charges for the day were reported
- How much spent on food on day of interview was mentioned.
Direct Medical Cost – Puzzles

- Cost of consultation, Medication, Investigations not very distinct and clear to most of them.
- Accurate cost of medication not possible to assess
- Interrupted Medication or Hospital Visit
- Hospitalization – actual cost not known
- Co Morbidity cost difficult to assess
### Last Visit

<table>
<thead>
<tr>
<th>Particulars</th>
<th>Cost - INR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consultation</td>
<td>10 - 90</td>
</tr>
<tr>
<td>Investigation</td>
<td>175 - 280</td>
</tr>
<tr>
<td>Medication</td>
<td>Free to 142</td>
</tr>
<tr>
<td>Travel</td>
<td>212 to 745</td>
</tr>
<tr>
<td>Food for the day</td>
<td>44 to 174</td>
</tr>
<tr>
<td>Money paid to attendant</td>
<td>120 to 1251</td>
</tr>
</tbody>
</table>
Informal Care - Puzzles

• A Concept not understood often with the average care giver
• Out of 56 PwD only 2 had Formal Care Givers in the cities;
• Paid charges Rs. 8000 & Rs.14,000/=pm
• All others were informal care givers – family members / relatives.
• Most care givers were women who had never held any paid jobs .
• None had been compensated for Lost Wages
Informal Care - Puzzles

• While most had borrowed money from the family for the care, most said that they did not take extra help to care for the PwD.

• They excluded family members who lived under the same roof

• The concept of number of hours spent in care was not a familiar concept for all of them.

• Informal care was by women who did not hold jobs outside house.
## Informal Care - Cost

<table>
<thead>
<tr>
<th>Heading</th>
<th>Cost in INR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Loss of pay for PwD</td>
<td>00</td>
</tr>
<tr>
<td>Loss of pay for Care Giver</td>
<td>133 to 174</td>
</tr>
<tr>
<td>Paid carer</td>
<td>***</td>
</tr>
</tbody>
</table>

*Bharath & Rao, India*  
*CoD, ADI 2013*
The Skew

- Willingness to pay for the extra help from an outsider – alien however when discussed most named a cost.
- 7 were willing to pay <Rs.1000/pm, 21 Rs.1001 to Rs.3000, 21 Rs.3001 to Rs.6000/pm and 3 >Rs.6000/= 
- Informal Care – Rs. 12,000 to Rs.72,000/= (pa)
- 50% IF Total care ?? Rs.24,000 to 144,000 (480 to 2880 USD)
Realities

- A comprehensive estimate of OOPS ??
- Several unanswered questions
- Minimum Wages are included for HW
- Cost of medication for government included
- Cost of investigation included at government
- Should we stick to Wimo’s estimate based on GDP, PPP and average wages
In Future

• Report is being submitted to NIMHANS & the funding agency on the comparative cost of SMI and Dementia
• Shared with Government
• Publications
• Community Based Study is necessary with sensitization
• Acknowledgements: Saijan and Vanitha – Research Assistants.
• Dr. Vinutha who did a thesis in this area.
• Prof. M. Varghese, Dr. Sivakumar PT, Dept Psychiatry, NIMHANS, Other Members of the Geriatric Group, Sanofi India – for new initiatives
• Families of PwD and members of ARDSI