Economic and social impacts of providing long-term care to dependent older people

Alzheimer’s Disease International 29th International Conference
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Research jointly supported by the ESRC and DFID
The INDEP (10/66) Study Team

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Peru (Instituto de la Memoria, Depresión y Enfermedades de Riesgo): Mariella Guerra, Sara Gallardo.

Mexico (National Autonomous University of Mexico): Ana Luisa Sosa, Veronica Montes de Oca, Isaac Acosta.

China (Peking University): Zhaorui Liu, Hong Wang.

Nigeria (Nnamdi Azikiwe University): Richard Uwakwe, Peter Ezeah

....and others!

Speaker: Peter Lloyd-Sherlock, University of East Anglia (UK).
Long-term care

A new challenge for international development?
The Millennium Development Goals

1. Reduce poverty and social exclusion
2. Achieve universal primary education
3. Promote gender equality and empower women
4. Reduce child mortality
5. Improve maternal health
6. Combat HIV/AIDS and tuberculosis
7. Ensure environmental sustainability
8. Partnership for development
The Millennium Development Goals

1. Eradicate extreme poverty and hunger

3. Promote gender equality and empower women
Links between illness, dependency and poverty

Poverty and deprivation

Capacity to cope (social protection)

Vulnerability to illness & its consequences

Susceptibility to illness

Illness and dependency

Vulnerability to illness & its consequences

Susceptibility to illness

Poverty and deprivation

Capacity to cope (social protection)
Gender equality and empowering women
INDEP Research questions (1)

To what extent is the onset of dependence associated with household impoverishment and economic vulnerability?

What are the pathways between care dependence and changes to household economic status?

What factors influence household resilience in the face of increased dependence?

To what extent does this depend on the external policy environment, including the reach of social protection and health services?
INDEP Research questions (2)

How is the care burden distributed across household members and wider kinship networks?

What factors influence the distribution of the care inside and outside the household?

How are decisions about care made and justified?

What are the effects on carers and how do they perceive care duties?

Are some care arrangements more effective than others in limiting the economic effects of dependence?
INDEP Study Design

4 country study (China, Mexico, Nigeria and Peru)

2003-8: Prevalence and incidence surveys of dementia and dependency

Quantitative tool:
- Chronic dependence
- Incident dependence
- Care exit
- Controls

(Approx 750 households, rural and urban catchments)
INDEP Study Design (2)

Qualitative tool:

at least 6 case studies in each country

multiple interviews

(Benefits of a mixed methods design)
Economic effects of care dependence

Household composition:

Edelmira (index older person, 90 advanced dementia)

Hermelinda (daughter, main carer, works full-time)

Grandson and grandson’s wife (both work)

Marisol (paid carer) (£420 per month)
Economic effects of care dependence

Progression of care dependence:

2001: 1st develops symptoms of AD
2003: diagnosed
2007: falls and breaks hip

2007: intersection of dependency and family crises
  H’s divorce and depression
  Addiction problems of wider family
  Finding a suitable carer
Economic effects of care dependence

Responding to the crisis:

H comes to terms with divorce
Finding a satisfactory carer
Remittances from other children

But:

“You can call my family a dysfunctional one”
Paid care costs over 70% of H’s work income
Associations between dependence and economic strain for Lima (age-adjusted odds ratios, 95% CI)

<table>
<thead>
<tr>
<th></th>
<th>Control</th>
<th>Incident care</th>
<th>Chronic care</th>
<th>Care exit</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health care costs</td>
<td>1</td>
<td>2.32 (1.63-3.30)</td>
<td>2.29 (1.52-3.45)</td>
<td>0.71 (0.43-1.16)</td>
</tr>
<tr>
<td>Catastrophic health care spending</td>
<td>1</td>
<td>4.47 (1.49-14.00)</td>
<td>5.35 (1.61-17.8)</td>
<td>Omitted</td>
</tr>
<tr>
<td>Currently experiencing economic strain</td>
<td>1</td>
<td>1.89 (1.05-3.42)</td>
<td>1.75 (0.83-3.66)</td>
<td>4.72 (2.38-9.39)</td>
</tr>
</tbody>
</table>
## Care dependence and gender relations.

<table>
<thead>
<tr>
<th>Country</th>
<th>Urban</th>
<th>Rural</th>
</tr>
</thead>
<tbody>
<tr>
<td>Peru</td>
<td>N=135</td>
<td>N=26</td>
</tr>
<tr>
<td>Mexico</td>
<td>Urban</td>
<td>N=114</td>
</tr>
<tr>
<td></td>
<td>Rural</td>
<td>N=82</td>
</tr>
<tr>
<td>China</td>
<td>Urban</td>
<td>N=183</td>
</tr>
<tr>
<td></td>
<td>Rural</td>
<td>N=54</td>
</tr>
<tr>
<td>Nigeria</td>
<td>N=228</td>
<td></td>
</tr>
</tbody>
</table>

### Carer characteristics

<table>
<thead>
<tr>
<th>Type</th>
<th>Peru Urban</th>
<th>Peru Rural</th>
<th>Mexico Urban</th>
<th>Mexico Rural</th>
<th>China Urban</th>
<th>China Rural</th>
<th>Nigeria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spouse</td>
<td>19%</td>
<td>27%</td>
<td>17%</td>
<td>16%</td>
<td>39%</td>
<td>39%</td>
<td>13.7%</td>
</tr>
<tr>
<td>Child or child-in-law</td>
<td>40%</td>
<td>50%</td>
<td>74%</td>
<td>66%</td>
<td>43%</td>
<td>59%</td>
<td>68.0%</td>
</tr>
<tr>
<td>Non-relative</td>
<td>25%</td>
<td>4%</td>
<td>4%</td>
<td>0%</td>
<td>16%</td>
<td>2%</td>
<td>1.4%</td>
</tr>
<tr>
<td>Female carer</td>
<td>86%</td>
<td>89%</td>
<td>83%</td>
<td>82%</td>
<td>67%</td>
<td>50%</td>
<td>63.2%</td>
</tr>
</tbody>
</table>

### Care arrangements

<table>
<thead>
<tr>
<th>Type</th>
<th>Peru Urban</th>
<th>Peru Rural</th>
<th>Mexico Urban</th>
<th>Mexico Rural</th>
<th>China Urban</th>
<th>China Rural</th>
<th>Nigeria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer has cut back on work to care</td>
<td>16%</td>
<td>23%</td>
<td>25%</td>
<td>37%</td>
<td>4%</td>
<td>48%</td>
<td>39.2%</td>
</tr>
<tr>
<td>Additional informal carer or carers</td>
<td>46%</td>
<td>58%</td>
<td>55%</td>
<td>59%</td>
<td>7%</td>
<td>22%</td>
<td>66.5%</td>
</tr>
<tr>
<td>Paid carer</td>
<td>33.3%</td>
<td>7.7%</td>
<td>3.5%</td>
<td>1.2%</td>
<td>45.4%</td>
<td>1.9%</td>
<td>2.1%</td>
</tr>
</tbody>
</table>

Care dependence and gender relations.

Juan and Yolanda
Care dependence and gender relations.

Don Pio, Rosa and Piedad
Preliminary findings

Economic effects of dependence are:

- Multi-dimensional
- Dynamic
- Influenced by wider family and environmental effects
Preliminary findings

Effects of dependence on gender relations:

- Disproportionate burden on women
- Disruption of working lives

But: variable perceptions and experiences
INDEP Workshop

Saturday 2-3.30pm
San Juan 6-7