INDEP study – Key Questions

Dependence, impoverishment and vulnerability

• Is the onset of dependence associated with household impoverishment and economic vulnerability?
• What are the pathways?
• What factors make households resilient?
• Does this depend on the external policy environment, including the reach of social protection and health services?
• What factors influence the allocation of care burden inside and outside the household?
INDEP study – Design

• Four countries
  – Peru (Lima urban; Canete rural)
  – Mexico (Mexico City urban; Morelos rural)
  – China (Beijing Xicheng urban; Daxing rural)
  – Nigeria (Nnewi, Anambra rural)

• Mixed methods
  – Nested incidence case control (quantitative)
  – Household case studies (qualitative)
### Four groups of interest

<table>
<thead>
<tr>
<th></th>
<th>Baseline</th>
<th>Follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chronic dependence</td>
<td>![Red Dot]</td>
<td>![Red Dot]</td>
</tr>
<tr>
<td>households</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Incident dependence</td>
<td>![White Dot]</td>
<td>![Red Dot]</td>
</tr>
<tr>
<td>households</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Control households</td>
<td>![White Dot]</td>
<td>![White Dot]</td>
</tr>
<tr>
<td>Care-exit households</td>
<td>![Red Dot]</td>
<td>![White Dot]</td>
</tr>
</tbody>
</table>
INDEPENDENT study – Quantitative methods

• Economic evaluation:
  – Household assets index (goods and amenities)
  – Assets in savings or investments
  – Total monthly equivalent net household income
  – Consumption, including food consumption
  – Out of pocket expenditure (health and home care services)
  – Household debts and loans, & other indicators of financial strain
  – Subjective assessment of financial status

• Household composition and roles:
  – Current composition of the household, and changes since baseline interview
  – Current economic activity of all household members
  – Health status of all household residents, and needs for care
INDEP study – characteristics of selected households and their older residents
Stroke prevalence (baseline and follow-up 10/66 surveys), by household group

Peru          Mexico          China
Dementia prevalence (baseline and follow-up 10/66 surveys), by household group

Peru

Mexico

China

Manuscript in preparation
### Focus of care in INDEP site households by group

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Control households N=668</th>
<th>Incident care households N=490</th>
<th>Chronic care households N=189</th>
</tr>
</thead>
<tbody>
<tr>
<td>No diagnosis</td>
<td>48.8%</td>
<td>18.0%</td>
<td>5.3%</td>
</tr>
<tr>
<td>Dementia only</td>
<td>4.8%</td>
<td>15.3%</td>
<td>18.5%</td>
</tr>
<tr>
<td>Dementia + other disorders</td>
<td>6.0%</td>
<td>27.1%</td>
<td>43.9%</td>
</tr>
<tr>
<td>Other types of comorbidity</td>
<td>7.6%</td>
<td>12.7%</td>
<td>12.2%</td>
</tr>
<tr>
<td>Physical impairments only</td>
<td>29.8%</td>
<td>23.5%</td>
<td>15.3%</td>
</tr>
<tr>
<td>Stroke only</td>
<td>2.4%</td>
<td>2.9%</td>
<td>4.8%</td>
</tr>
<tr>
<td>Depression only</td>
<td>0.6%</td>
<td>0.6%</td>
<td>0.0%</td>
</tr>
</tbody>
</table>
## Carer characteristics by gender (10/66 FU survey)

<table>
<thead>
<tr>
<th></th>
<th>Female carers N=506</th>
<th>Male carers N=209</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spouse</td>
<td>19%</td>
<td>30%</td>
</tr>
<tr>
<td>Son or daughter</td>
<td>48%</td>
<td>57%</td>
</tr>
<tr>
<td>Son/ daughter in law</td>
<td>12%</td>
<td>3%</td>
</tr>
<tr>
<td>Full or PT employment</td>
<td>41%</td>
<td>60%</td>
</tr>
<tr>
<td>Homemaker</td>
<td>38%</td>
<td>5%</td>
</tr>
<tr>
<td>Cut back or stopped work</td>
<td>17%</td>
<td>20%</td>
</tr>
<tr>
<td>With co-resident children &lt;16 yrs</td>
<td>63%</td>
<td>66%</td>
</tr>
<tr>
<td>Psychological morbidity</td>
<td>13%</td>
<td>3%</td>
</tr>
<tr>
<td>Carer strain (mean/ SD)</td>
<td>16.8 (14.9)</td>
<td>12.6 (11.4)</td>
</tr>
</tbody>
</table>
INDEP study – Initial Findings
Prevalence of economic strain indicators – INDEP household survey

- Economic Strain - past 3 years
- Catastrophic Healthcare Spending
- Resident not working because of caregiving for older person
What is the economic impact of living with a care dependent older person?

<table>
<thead>
<tr>
<th></th>
<th>Incident care households N=</th>
<th>Chronic care households N=</th>
<th>Care exit households N=</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total income</td>
<td>0.97 (0.86-1.08)</td>
<td>0.88 (0.73-1.03)</td>
<td>0.95 (0.82-1.08)</td>
</tr>
<tr>
<td>Income (external sources)</td>
<td>1.07 (0.70-1.43)</td>
<td>0.72 (0.40-1.04)</td>
<td>0.56 (0.29-0.82)</td>
</tr>
<tr>
<td>Expenditure</td>
<td>0.94 (0.86-1.02)</td>
<td>0.88 (0.78-0.98)</td>
<td>1.02 (0.92-1.11)</td>
</tr>
<tr>
<td>Food consumption</td>
<td>1.00 (0.99-1.09)</td>
<td>0.86 (0.74-0.97)</td>
<td>1.06 (0.95-1.18)</td>
</tr>
<tr>
<td>Economic strain</td>
<td>1.22 (0.88-1.57)</td>
<td>1.25 (0.71-1.79)</td>
<td>1.27 (0.81-1.72)</td>
</tr>
<tr>
<td>Healthcare spending</td>
<td>0.96 (0.70-1.22)</td>
<td>0.92 (0.56-1.28)</td>
<td>0.09 (0.03-0.15)</td>
</tr>
<tr>
<td>Catastrophic healthcare spending</td>
<td>1.62 (0.96-2.27)</td>
<td>1.13 (0.33-1.93)</td>
<td>0.37 (0.01-0.72)</td>
</tr>
</tbody>
</table>
Summary of findings

• Some evidence of economic impact of caring for older persons
  – Reduced expenditure and food consumption in chronic care households
  – Trend towards increased economic strain in all care household groups (statistically significant when merged)

• However, regardless of needs for care…
  – Households with older residents often benefit from income from external sources
  – Healthcare spending is also high
  – Both income from external sources, and healthcare spending are much lower in care exit households (after the death of the older residents)

• Catastrophic healthcare spending may be more common in incident care households
What is special about dementia care?

- Care needs begin early and evolve rapidly from IADL to PADL
- Short intervals of care, often requiring constant monitoring and coordination
- People with dementia need more personal care, more hours of care, and more supervision than care dependent people with other conditions
- Dementia carers experience higher carer strain, and are more likely to give up or cut back on work to care

## Economic impact – is dementia care special?

<table>
<thead>
<tr>
<th></th>
<th>Control households N=418</th>
<th>Care households (dementia) N=258</th>
<th>Care households (other reasons) N=201</th>
</tr>
</thead>
<tbody>
<tr>
<td>Expenditure</td>
<td>1 (ref)</td>
<td><strong>0.90 (0.81-1.00)</strong></td>
<td>0.94 (0.85-1.02)</td>
</tr>
<tr>
<td>Food consumption</td>
<td>1 (ref)</td>
<td>0.99 (0.88-1.09)</td>
<td>0.96 (0.86-1.05)</td>
</tr>
<tr>
<td>Economic strain</td>
<td>1 (ref)</td>
<td><strong>1.57 (1.08-2.06)</strong></td>
<td>1.37 (0.92-1.81)</td>
</tr>
<tr>
<td>Healthcare spending (urban sites)</td>
<td>1 (ref)</td>
<td>0.83 (0.50-1.17)</td>
<td><strong>1.73 (1.22-2.23)</strong></td>
</tr>
<tr>
<td>Healthcare spending (rural sites)</td>
<td>1 (ref)</td>
<td><strong>0.12 (0.00-0.23)</strong></td>
<td><strong>0.40 (0.16-0.64)</strong></td>
</tr>
<tr>
<td>Catastrophic healthcare spending</td>
<td>1 (ref)</td>
<td>1.18 (0.28-2.08)</td>
<td>1.65 (0.96-1.34)</td>
</tr>
</tbody>
</table>
Summary of findings

- Economic impact slightly more prominent among households providing care for one or more people with dementia
- Increased healthcare spending confined to
  - households providing care to older people for reasons other than dementia
  - urban rather than rural districts
- Low healthcare spending on people with dementia consistent with
  - low awareness, and limited help-seeking
  - low levels of health service utilisation (10/66 - Albanese et al, BMC Health Services 2011)
Qualitative Study
INDEP study – Qualitative methods

- Why mixed methods?
- Case study methodology
- 6 households in each country
- Interviews with multiple household members
- “Narrative” style interviews
- In country analysis → cross-cultural analysis
INDEP study – Qualitative methods

Box 1 Topics of Interest for Qualitative Interviews

- **Chronic poverty** i.e. households with few economic resources wherein this situation has been long-term rather than short-term
- **Incident poverty** - i.e. short-term reduction in economic wealth, often due to illness, job-loss, household changes
- **Large households** i.e. those with extended families living in the same household
- **Large families** i.e. those households where the older person has many children (not necessarily living in the same household
- **Small households** i.e. where older people live alone or with a spouse only
- **Households with substantial difficulties** i.e. substance abuse, debt, violence
- **Households that seem to be coping well** with the challenges of dependency and/or economic poverty
- **Female-headed households**
- Households where there is **more than one dependent person** i.e. older person + others who need substantial care- young children, others with disability
- **Other households that stand out**/were memorable for some reason

*Criteria were selected after consideration of the INDEP themes and research questions, discussions of emergent findings from pilot interviews and meeting with members of staff from HelpAge International and ADI (carried out 13\textsuperscript{th}-17\textsuperscript{th} June, London).*
RESEARCH QUESTIONS

ECONOMICS

- Is dependence associated with household impoverishment/vulnerability?
- How and why do households providing care for older people experience economic stress?

RESILIENCE

- What factors contribute to household resilience?
- To what extent does this depend on policies - social protection & health services?

CARE

- Who cares?
- What factors influence distribution of care?
- How are care-related decisions made/justified?
- What are the effects on carers and how do they perceive care duties?
- Are some arrangements more effective than others?

INTERVIEW TOPICS

WHO IS IN THE HOUSEHOLD?

WHEN DID DEPENDENCE BEGIN, PROGRESSION, CAUSE?

ECONOMIC CHANGES DUE TO DEPENDENCY

CAUSALITY OF ECONOMIC AND COMPOSITION CHANGES

HOUSEHOLD & FAMILY COPING STRATEGIES

CARE-GIVING & CARE RECEIVING

DECISION-MAKING

OLDER PERSON - decision-making and influence

CARER - time spent caring, previous activities, other care, other activities
Case Studies

• Data collection is complete in Mexico and Peru
  • Peru = 6 households (4 x urban and 2 x rural) as well as interviews with two paid carers (working in the urban catchment)
  • Mexico = 6 households (3 x urban and 3 x rural)
  • China = 3 households (2 x rural and 1 x urban).
• A short-list for households for the final interviews has been drawn-up
• In Nigeria, pilot interviews have been carried out with one household
• For data from Mexico and Peru, preliminary in-country coding, based on the initial scheme developed in London is underway

➤ Examples from China & Peru
Emerging Themes

- How care dependence affects household finances & relationships
- Burden of care is shared by siblings
- Flow of resources: older people → younger generation
Case Study- China
1956-75
- Older person was a "captain"
- Got hepatitis in '75 and was in hospital for 2m
- Couldn't work afterwards
- IOP attributes poor health of second son to time when he was born: '60s not enough food, clothes, later children luckier, better times

1982 (post reform and opening-up)
- Parents built homes for all sons
- IOP had "good brain", raised chickens, saved money on food and expenses
- Oil mill- make peanut oil
- Rented unused land in village to plant large area of crops

1997-2004
- Second son ill with AS (form of arthritis)
- Only wife able to work
- Required care
- Borrowed 50 000 yuan for medication- now paid back
- No insurance at that time
- Costs not shared with family

2003- health insurance, but does not cover Chinese medicine

2005-8
- Family members take it in turns to go to IOP house and cook

2008
- IOP wife dies
- 180 000 yuan spent on wife's treatment for cerebral thrombosis- daughter contributed "a lot"

2009
- Second son borrows money to redecorate house (not yet paid back)

2013- IOP
- "I decided everything in the last 10yrs, now I’m tired of it"
- "Can do most things- walk carefully and slowly, need someone to pour hot water, prepare medicine"
- Frail "legs..heavy and very tired..afraid I would fall down and break my legs..but haven't until now"
- "Are you satisfied [with care]? "Uh, what can I do? This is the only way. Before my wife’s death, we lived on our own and didn’t need care"
- Concerned that 2nd son’s wife is sick- hospital for 10d, not sure what’s wrong; 5th son’s wife gallbladder op

2013- Fourth son
- Runs shop, lives in former home of IOP
- All farmland is rented out (to nephew)- kept enough to grow enough for meals for family
- Cooks 6 meals/d when IOP there
- Perceives wealth to be close to village median
- Consults elder about big things, like building a house
- Eldest brother organises things- when facing problems, difficulties related to IOP
- Thinks IOP is "upset" now and is not sure if he is "muddled"

2013- second son
- Work as farmers- only income
- Burden of work seasonal
- Increased pressure re. cooking, spend more when IOP stays with them, work is disrupted
- Earn more now than earlier
- 2 x sons now working and contributing to household economy
- "It’s OK. But we don’t have savings. I think even though we are poor, we can live a very good life if we have health. Health is most important"

ID 722- TIMELINE OF KEY EVENTS

Interviews with IOP, second son (& daughter in law, fourth son (& daughter in law)
Case Study- Peru
Mr. T and Mrs. L are independent healthy individuals.

Mrs. L starts to develop memory problems.

Mr. T has diabetes and HBP, he also has Sx for prostate problem.

Mr. T is carer and informant

Mrs. L gets diagnosed with dementia

Mrs. L dementia is very advance and she needs care all the time.

Mr. T deteriorates and is bedbound and blind.


10/66 Incidence Study

INDEP
Mr. T works as a fisherman and Mrs. L is a housewife.

They own a house and land in Cerro Azul.

Mr. T is retired. He works “part time” at the beach.

Children get married and move out of the house.

Both older adults live on Mr. T pension

Earthquake
Land sharing

Grandchildren move in
Both Mr. T and Mrs. L are independent healthy adults.

Mr. T is main carer for Mrs. L

Laura lives with them and supervises Mrs. L

Vanesa moves in the house

Laura goes abroad to work and Vanesa stays to care

Laura comes back and decides to take care of her parents.
She makes arrangements with her sisters.

Children get married and move out of the house.

Mr. T is retired and they live on his pension, he starts having health problems and has prostate surgery.

Mrs. L starts to develop memory problems.

198

2000

2007

2009

2012

2013

Mr. T is taken to the doctor and is given a diagnosis.

Mr. T has a fall and can't walk anymore.

Mrs. L is taken to the doctor and is given a diagnosis.

Martin moves in with Vanesa.

Laura goes to Arequipa and leaves Vanesa as main carer.

10/66 Visit

Laura supervises Mrs. L and Mr. T still works at the beach.

Both elderly people have deteriorated and develop caring needs most of the time.

Earthquake

Mr. T decides to share his land with his children.

Mr. T works as a fisherman for a coast company and Mrs. L is a housewife. They both live in the same house.

Laura comes back and arranges care schedule with sisters.

INDEP

Laura supervises Mrs. L and Mr. T still works at the beach.