



Conference Series on  
*Aging in the Americas*



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# Exploring the Economic and Social Effects of Care Dependence in Later Life The 10/66 INDEP study: Mexico, Peru and China

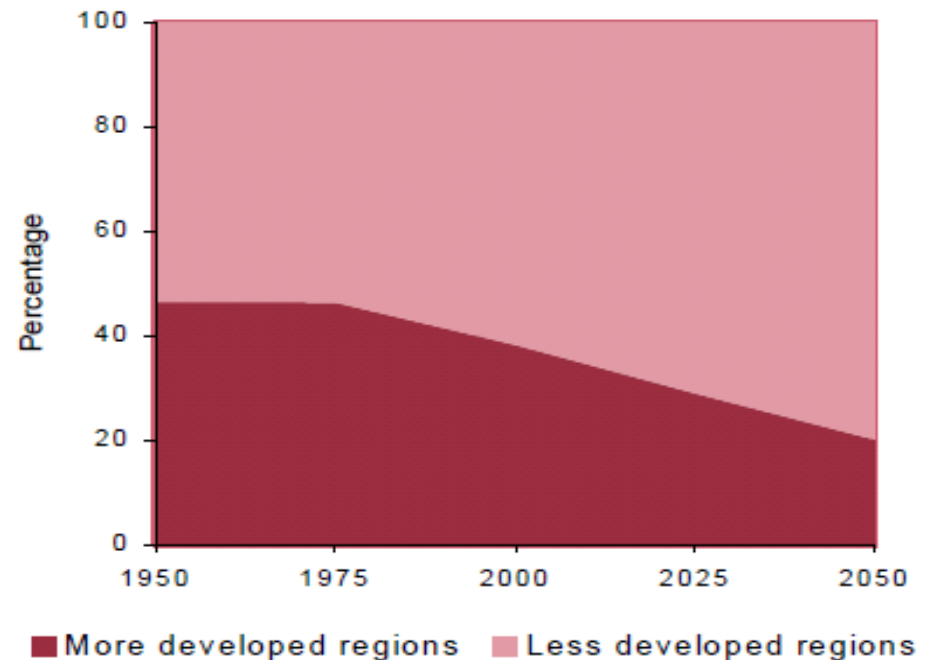
*Dr. Ana Luisa Sosa on behalf of  
10/66 Dementia Research Group  
Laboratory and Dementia Clinic INNNMVS*

September 17-18, 2015  
Mexico City

## Where do older people live?

In 1950, just over half  
of the world's older  
population lived in less  
developed regions

By 2050, will be 80%



## Discourses around global ageing

- Traditional family-based systems of support and care for older people are under threat.
  - fertility rates fall,
  - children migrate away in search of work and economic advancement, and
  - better educated women are less available to take on caring roles



## 10/66 DRG research agenda



## 10/66 research agenda

- Pilot and validation studies (1999-2002)
- Population surveys – baseline phase (2003-2009)
  - Prevalence of dementia and other chronic diseases
  - Impact: disability, dependency, economic cost
  - Access to services
- Incidence phase (2008-2010)
  - Incidence (dementia, stroke, mortality)
  - Risk factors
  - Course and outcome of dementia/ Mild Cognitive Impairment
- **INDEP study (2011-2014)**
  - **Impact of needs for care**
- Third wave (2016-2018)
  - 10 years following study





## 10/66 DRG's Care and dependence data



# Dependence (needs for care)

## BMC Public Health



Research article

Open Access

### Chronic disease prevalence and care among the elderly in urban and rural Beijing, China - a 10/66 Dementia Research Group cross-sectional survey

Zhaorui Liu<sup>1</sup>, Emiliano Albanese<sup>2</sup>, Shuran Li<sup>1</sup>, Yueqin Huang<sup>\*1</sup>, Cleusa P Ferri<sup>2</sup>, Fang Yan<sup>1</sup>, Renata Sousa<sup>2</sup>, Weimin Dang<sup>1</sup> and Martin Prince<sup>2</sup>

CLINICAL INVESTIGATIONS

### The Epidemiology of Dependence in Older People in Nigeria: Prevalence, Determinants, Informal Care, and Health Service Utilization. A 10/66 Dementia Research Group Cross-Sectional Survey

Richard Uwakwe, MBBS,\* Christian C. Ibeh, MBBS,\* Anne Ifeoma Modebe, MBBS,\* Emeka Bo, MBBS,\* Nkiru Ezeama, MBBS,\* Ifeoma Njelita, MBBS,\* Cleusa P. Ferri, PhD,<sup>†</sup> and Martin J. Prince, MD<sup>†</sup>

## BMC Public Health



Research article

Open Access

### The epidemiology of dependency among urban-dwelling older people in the Dominican Republic; a cross-sectional survey

Daisy Acosta<sup>\*1</sup>, Ruth Rottbeck<sup>2</sup>, Guillermina Rodríguez<sup>3</sup>, Cleusa P Ferri<sup>4</sup> and Martin J Prince<sup>4</sup>

- Neglected public health topic
- Prevalence 3-16%
- Associated with
  - comorbidity
  - socioeconomic disadvantage
  - high health costs
- 4 x increase among older people in LMIC forecast to 2050

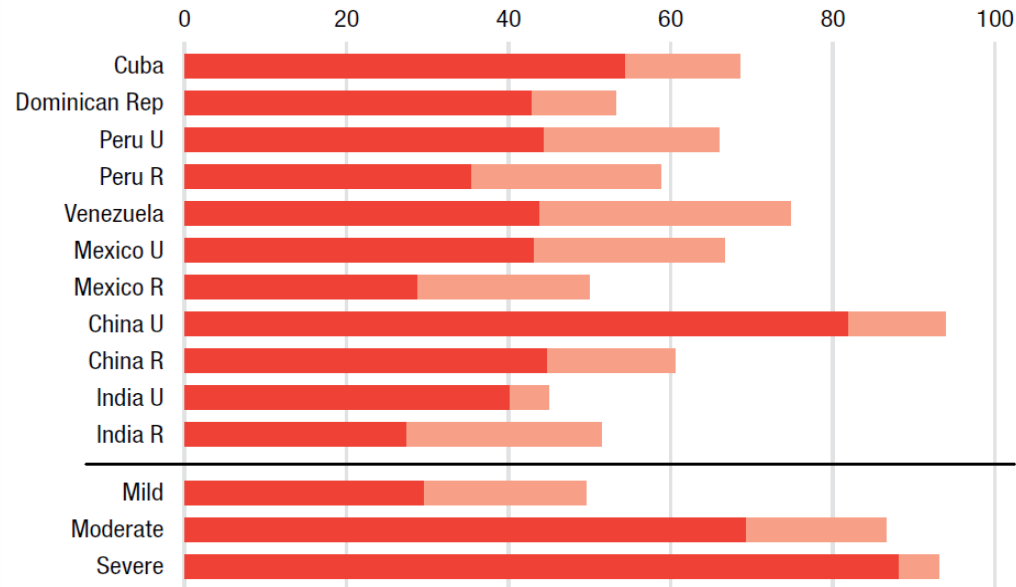
## Disorders of the brain and mind are leading contributors to disability and dependence

Health condition/ impairment	Mean population attributable fraction (Dependence)	Mean population attributable fraction (Disability)
1. Dementia	36.0%	25.1%
2. Limb paralysis/ weakness	11.9%	10.5%
3. Stroke	8.7%	11.4%
4. Depression	6.5%	8.3%
5. Visual impairment	5.4%	6.8%
6. Arthritis	2.6%	9.9%

Sousa et al, Lancet, 2009; BMC Geriatrics 2010



## Needs of care for people with dementia 10/66 DRG study



Some care – more care

## Care arrangements for people with dementia



- Unusual to live alone or with spouse only
- Living with children or children-in-law is the norm
- Children under 16 in 1/3 to 1/2 of households
- Main carer
  - Spouse 8%-43%
  - Child 36%-80%

## Caring for people with dementia in LMIC

- 3-4 hours of personal ADL care per day
- 8 hours for those with severe dementia
- Economic impact (giving up paid work to care/ paid caregivers)
- Social protection is fragile in most countries
- Limited helpseeking, but caregivers crave more information, advice and support

Shaji et al 2004

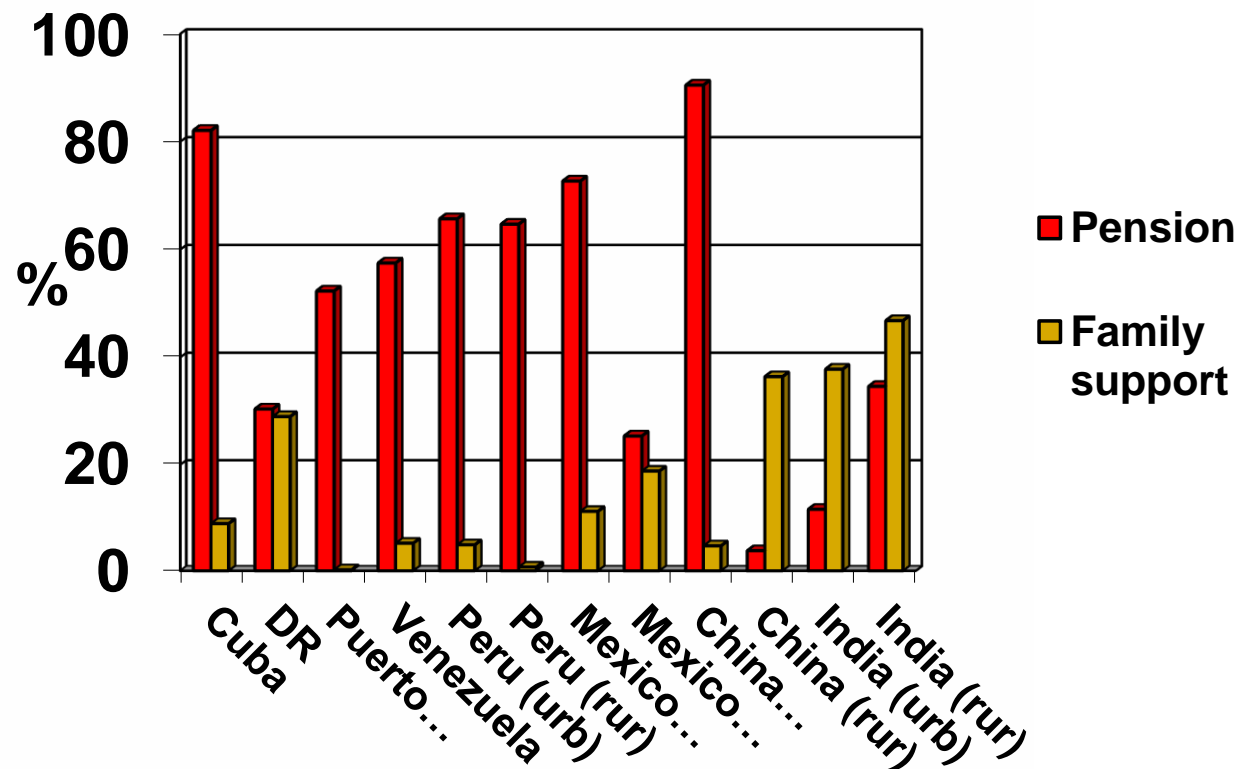
## Informal care – direct or indirect costs?

Centre	Cut back on work to care	Additional informal unpaid care	Paid care	
			Day	Night
Cuba	19.2%	27.5%	7.9%	1.9%
Dom. Rep.	14.1%	20.0%	9.9%	7.7%
Puerto Rico	7.7%	26.2%	11.1%	1.7%
Venezuela	14.2%	36.9%	8.4%	2.1%
Peru (urban)	6.2%	27.1%	22.5%	15.6%
Peru (rural)	11.1%	19.4%	2.8%	2.8%
Mexico (urban)	12.8%	33.7%	2.4%	1.2%
Mexico (rural)	11.8%	21.2%	1.2%	0%
China (urban)	6.1%	7.4%	46.9%	45.7%
China (rural)	30.4%	14.3%	0%	0%
India (urban)	14.7%	6.7%	0%	0%
India (rural)	10.3%	19.8%	0%	0%

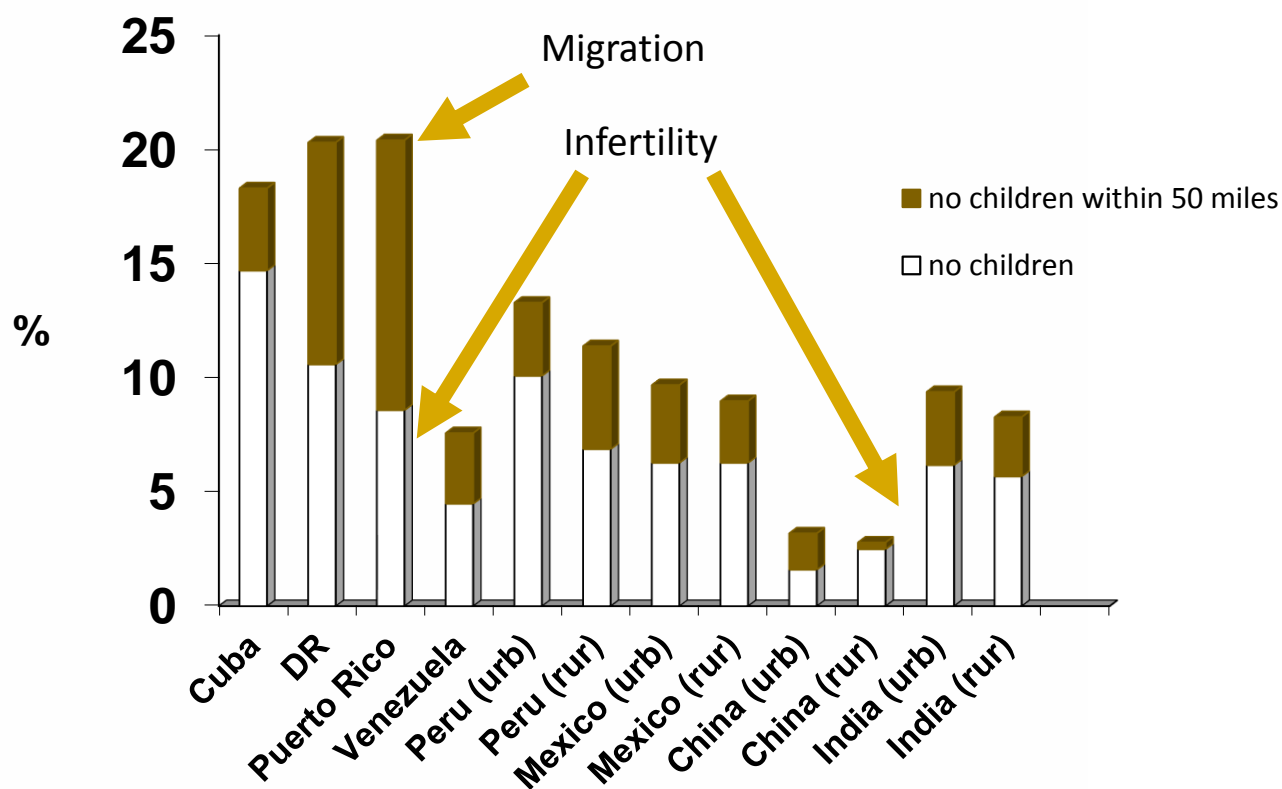


# Income support from family, and government or occupational pension

(% in receipt of income from those sources)



## Social protection (un)availability of children for support



## Dementia and healthcare

- Dementia is a hidden problem (demand)
  - Little awareness
  - Not medicalized
  - People do not seek help
- Health services do not meet the needs of older people (supply)
  - No domiciliary assessment/ care
  - Clinic based service
  - No continuing care
  - 'Out of pocket' expenses



Prince et al, World Psychiatry, 2007

Albanese et al, BMC HSR 2011

## What is special about dementia care?

- Care needs begin early and evolve rapidly from IADL to BADL
- 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





## 10/66 DRG INDEP study



## 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?

## Four groups of interest

- **Chronic dependence households** (households containing one or more care dependent older people at baseline, who remain care dependent in the incidence survey).
- **Incident dependence households** (where all older residents were independent at baseline, but in which one or more have become care dependent by the incidence survey).
- **Control households** (where all older residents are independent at baseline, and remain so at the incidence survey).
- **Care exit households** (where a care dependent older person at baseline had died by the time of the follow-up assessment).

## INDEP 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 – Qualitative methods

## 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



## INDEP study – characteristics of selected areas and macro-economic changes



## Selected areas and macro-economic changes

- Over the ten years since the sites were originally selected (2003-2006) several have undergone significant change and development
  - All three countries have benefited from sustained high levels of economic growth
  - Nevertheless, the fragmented architecture of pension and social assistance programs has resulted in gaps in coverage, inequality and unfairness
  - In Latin America generally, coverage by contributory pension schemes is low because of the ceiling imposed by the dominant informal labour sector; coverage by contributory pensions, around 40%, has been boosted to 60% by the recent rise in non-contributory pension schemes, but these are generally of much lower value



## INDEP study – Initial Findings





## Household characteristics

HOUSEHOLD CHARACTERISTICS	Peru (urban)	Peru (rural)	Mexico (urban)	Mexico (rural)	China (urban)	China (rural)
Number of households (weighted number)	140 (703)	56 (371)	190 (600)	167 (597)	177 (508)	147 (611)
Older adults only	14.2%	28.8%	33.0%	30.8%	39.2%	12.9%
Older adults with younger adults	85.8%	70.7%	64.4%	66.4%	58.6%	79.5%
Younger adults only	0.0%	0.5%	2.6%	2.8%	2.2%	7.6%
With children <16 years (%)	22.9%	24.3%	24.7%	39.7%	3.8%	21.4%
Home ownership (%)	91.6%	96.6%	97.9%	100.0%	52.1%	100.0%
<u>Catastrophic healthcare costs (&gt;10% of household income)</u>	11.4%	14.2%	25.2%	31.1%	29.1%	12.2%

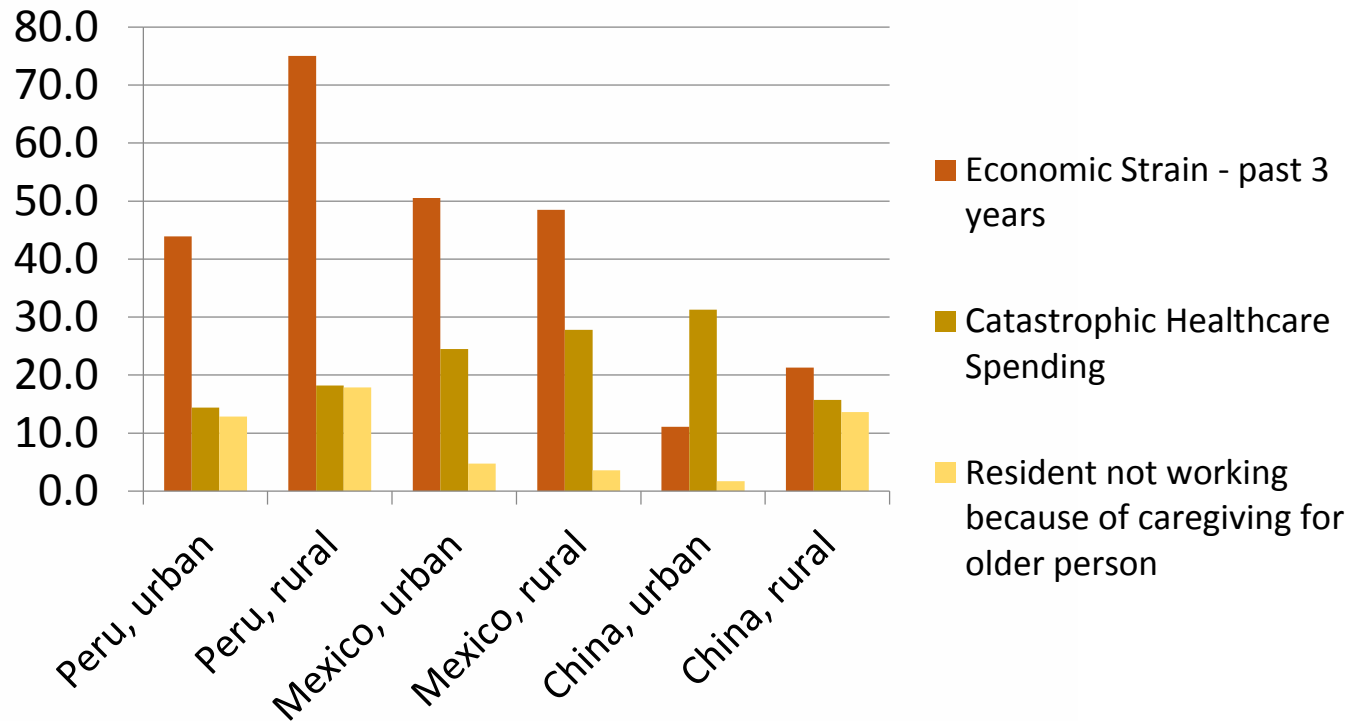
## Individual characteristics

INDIVIDUAL CHARACTERISTICS	Peru (urban)	Peru (rural)	Mexico (urban)	Mexico (rural)	China (urban)	China (rural)
Number of individual residents (weighted)	611	228	685	604	455	594
Female gender (%)	58.0%	50.9%	64.7%	54.4%	59.7%	50.1%
<5 years (%)	5.7%	3.5%	2.6%	2.8%	0.5%	2.8%
65+ (%)	32.8%	39.1%	41.9%	35.9%	54.6%	33.9%
Children and adults, work condition (%)						
5-15, in paid work	0.0%	0.0%	0.0%	0.9%	0.0%	1.2%
16-64						
Limiting long-term illness or disability	0.6%	11.5%	2.2%	3.2%	0.9%	0.0%
65+						
In work	4.6%	15.3%	11.7%	22.8%	0.0%	7.3%
Seeking work	3.3%	0.0%	0.0%	0.0%	0.0%	0.0%
Adults receiving a pension (%), by age						
65+ years	70.0%	59.8%	65.7%	90.5%	94.6%	14.8%
Monthly income from pensions (international \$) - mean (SD)	391 (190)	268 (75)	278 (308)	90 (122)	752 (706)	108 (125)

## Monthly total equivalized household income, expenditure and food consumption (international \$, 2011)

Site		Equivalized household income	Equivalized household expenditure	Equivalized food consumption
Peru, urban	Mean (95% CI)	838 (730-946)	321 (293-349)	163 (148-178)
Peru, rural	Mean (95% CI)	504 (358-651)	238 (161-314)	121 (93-149)
Mexico, urban	Mean (95% CI)	427 (368-486)	233 (209-256)	138 (122-154)
<b>Mexico, rural</b>	<b>Mean (95% CI)</b>	<b>149 (125-173)</b>	165 (131-200)	101 (84-117)
China, urban	Mean (95% CI)	1456 (1135-1795)	284 (263-304)	182 (166-197)
China, rural	Mean (95% CI)	3128 (1828-4427)	237 (189-285)	122 (86-157)

## Prevalence of economic strain indicators – INDEP household survey



# What is the economic impact of living with a care dependent older person?

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



## 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
  - 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

## Care dependence and impoverishment

Changes in care dependent households	Possible effects
Giving up or cutting back on work to care	Total Income ↓ External income support ↑
Increased costs of health and social care	Other expenditure ↓ Food consumption ↓
Increased costs/ reduced income	Economic strain ↑



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