



“A journey without maps”

Balancing the costs of caring for dependent older people

Findings from the 10/66 Dementia Research Group INDEP Study

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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

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
- Caregiver strain is as high as in HIC
- 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)

Carer characteristics by gender (FU survey)

	Female carers N=506	Male carers N=209
Spouse	19%	30%
Son or daughter	48%	57%
Son/ daughter in law	12%	3%
Full or PT employment	41%	60%
Homemaker	38%	5%
Cut back or stopped work	17%	20%
With co-resident children <16 yrs	63%	66%
Psychological morbidity	13%	3%
Carer strain (mean/ SD)	16.8 (14.9)	12.6 (11.4)

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

Baseline

Follow-up

Chronic dependence
households



Incident dependence
households



Control households



Care-exit households



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

Economic indicators

- **Incomes from external sources:**

Any gifts or donations from friends, family (outside the household), charities, NGOs or religious associations...

- **Catastrophic healthcare spending:**

>10% of the total income is spent to cover healthcare costs

- **Economic strain (3 years):**

- Ask for help: friends, relatives, employer, NGOs, religious organisations?
- Borrow from a bank or draw on savings, sell stocks or shares?
- Cut down on food consumption? Run up an account with a shop?
- Try to find extra work?
- Apply for a grant, food parcels/food vouchers?

INDEP Qualitative Methods

- **Case study** methodology (Crowe et al 2011)
- 6 households in each country (n=25)
- Interviews with multiple household members (n=61)
- **“Narrative”** style interviews
- In country analysis → cross-cultural analysis
- **Life history grid** (Eliot 2005)- adapted
- Joint task at beginning of start of interview



ID 722- TIMELINE OF KEY EVENTS

Interviews with IOP, second son (& daughter in law,
fourth son (& daughter in law)

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

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

- Stayed in hospital for 1m
- Second son reports borrowing money to cover his contribution to hospitalisation (600yuan- 3000 yuan in total)
- Followed by 4m of intense care provided by family at home
- IOP feels improved through acupuncture and intravenous infusion
- Medical costs shared between 5 sons

When wife was alive, she decided that care of father (if she died first) should be shared between 5 sons

2003- health insurance, but does not cover Chinese medicine

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

2005
IOP has stroke

180 000 yuan spent on wife’s treatment for cerebral thrombosis- daughter contributed “a lot”

2008
IOP wife dies

IOP moves between households of 5 sons, 3m at each

IOP cites death of wife as the point at which his health worsened (having improved since stroke up until that point)

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- 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”

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
- Consult 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”

A priori theoretical frameworks

Family systems

- **Gender**
- Extended family model (Litwak 1960)
- Deferred reciprocity (Gomez de Conceicao & Montes de Oca 2004)
- “Support bank” (Antonucci 1990)
- Trajectories & turning points

Materialist, simple economic models

- Altruism- maximising efficiency of resource allocation to benefit of all (Becker 1974)
- **Bargaining?** (Agrawal 1997)

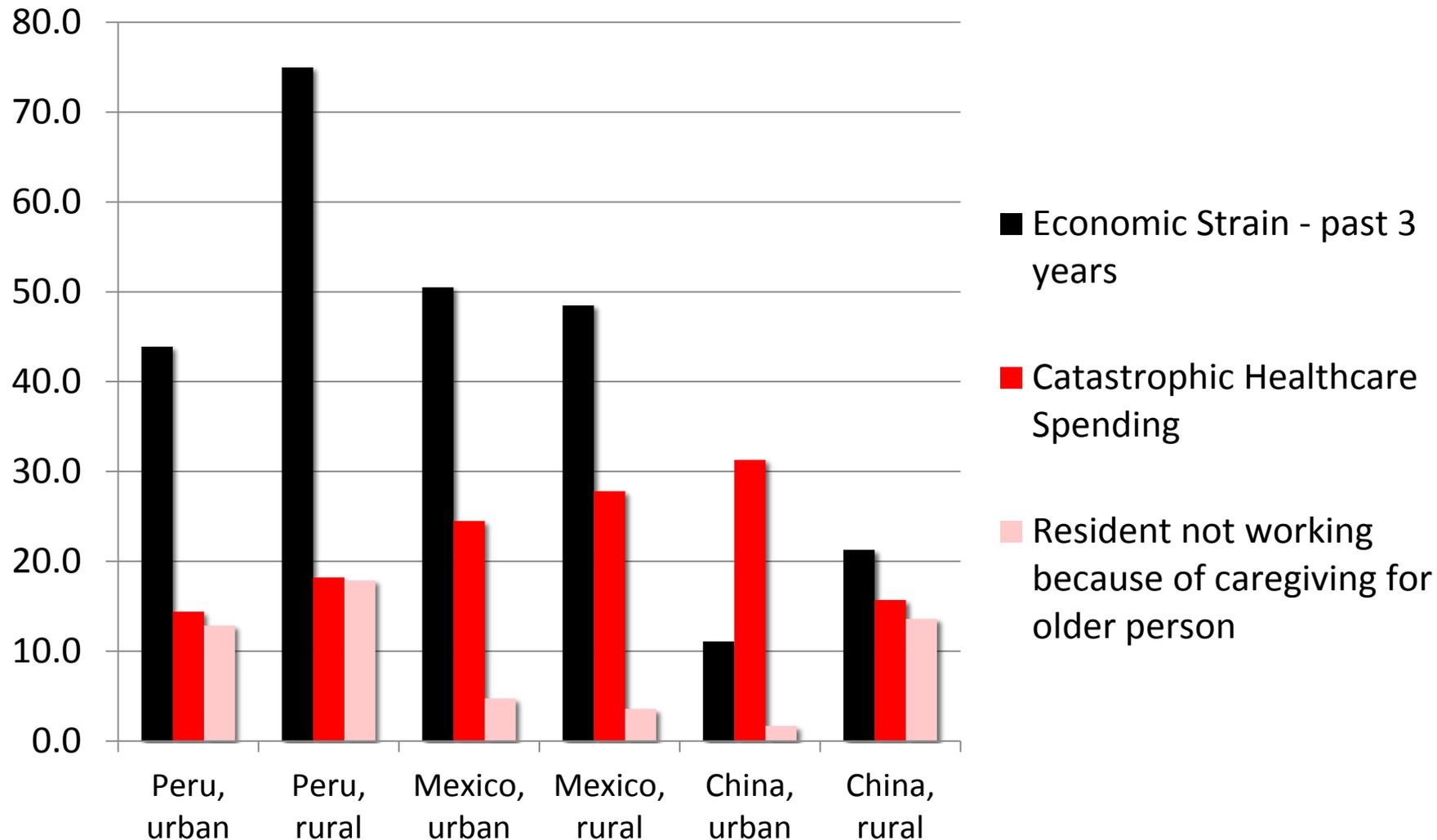
QUANTITATIVE FINDINGS

Household income and expenditure – INDEP household survey

	Total Income*	Income from external sources*	Expenditure *	Food consumption *
	<i>Mean (SD)</i>	<i>Mean (SD)</i>	<i>Mean (SD)</i>	<i>Mean (SD)</i>
Peru, urban	786 (359)	92 (145)	317 (125)	157 (61)
Peru, rural	444 (351)	18 (46)	211 (131)	122 (60)
Mexico, urban	419 (323)	77 (104)	238 (122)	141 (86)
Mexico, rural	163 (143)	4 (17)	155 (90)	103 (62)
China, urban	1653 (3014)	44 (98)	287 (105)	184 (108)
China, rural	3575 (4826)	23 (140)	255 (223)	124 (98)

* *Equivalised for household size, International \$, 2011*

Prevalence of economic strain indicators – INDEP household survey



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

	Current care <i>n=292</i>	Incident care n=225	Chronic care n=67	Care exit n=156
Total income	1.00 (0.91-1.10)	1.02 (0.92-1.14)	0.94 (0.81-1.11)	1.02 (0.89-1.16)
Income from paid work	0.88 (0.78-1.00)	0.90 (0.78-1.04)	0.90 (0.71-1.12)	1.02 (0.88-1.19)
Income from private transfers	1.04 (0.89-1.23)	1.07 (0.89-1.28)	0.93 (0.71-1.22)	0.80 (0.61-1.05)
Consumption	0.96 (0.89-1.03)	0.98 (0.90-1.06)	0.88 (0.77-0.99)	1.01 (0.92-1.12)
Food consumption	0.98 (0.91-1.07)	1.02 (0.93-1.11)	0.90 (0.79-1.03)	1.06 (0.95-1.17)
Economic strain	1.37 (0.97-1.92)	1.33 (0.92-1.94)	1.58 (0.90-2.77)	1.15 (0.75-1.77)
Dissatisfaction with economic circumstances	1.28 (0.92-1.77)	1.11 (0.78-1.58)	1.74 (1.02-2.97)	0.70 (0.46-1.06)

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

	Current care <i>n=292</i>	Incident <i>n=225</i>	Chronic <i>n=67</i>	Care exit <i>n=156</i>
Healthcare expenditure	1.55 (1.26-1.90)	1.33 (1.07-1.64)	1.40 (1.04-1.87)	0.46 (0.34-0.62)
Catastrophic healthcare expenditure	1.64 (1.20-2.22)	1.71 (1.24-2.37)	1.67 (0.99-2.81)	0.63 (0.35-1.13)
Another resident is not working*	2.08 (1.37-3.16)	2.22 (1.43-3.43)	2.15 (1.04-4.42)	Omitted

* *main reason cited is to care for older person*

Summary of findings

- **Some evidence of economic impact of caring for older persons**
 - Decreased income from paid work for all care households
 - Reduced expenditure and increased dissatisfaction with economic circumstances in chronic care households
 - Trend towards increased economic strain in all care household groups (statistically significant when merged)
- **However, regardless of needs for care...**
 - 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**

QUALITATIVE FINDINGS

Costs: one-off → on-going

- Often perceived to mark onset of needs
- Hospitalisation
- Care whilst in hospital (China)
- Rehabilitation
- Medication
- Transport (China)
- Special diet (Nigeria)
- Costs not covered by insurance

Example: Ernesto from Mexico (80yrs, kidney disease)

2012 health crisis- kidney disease

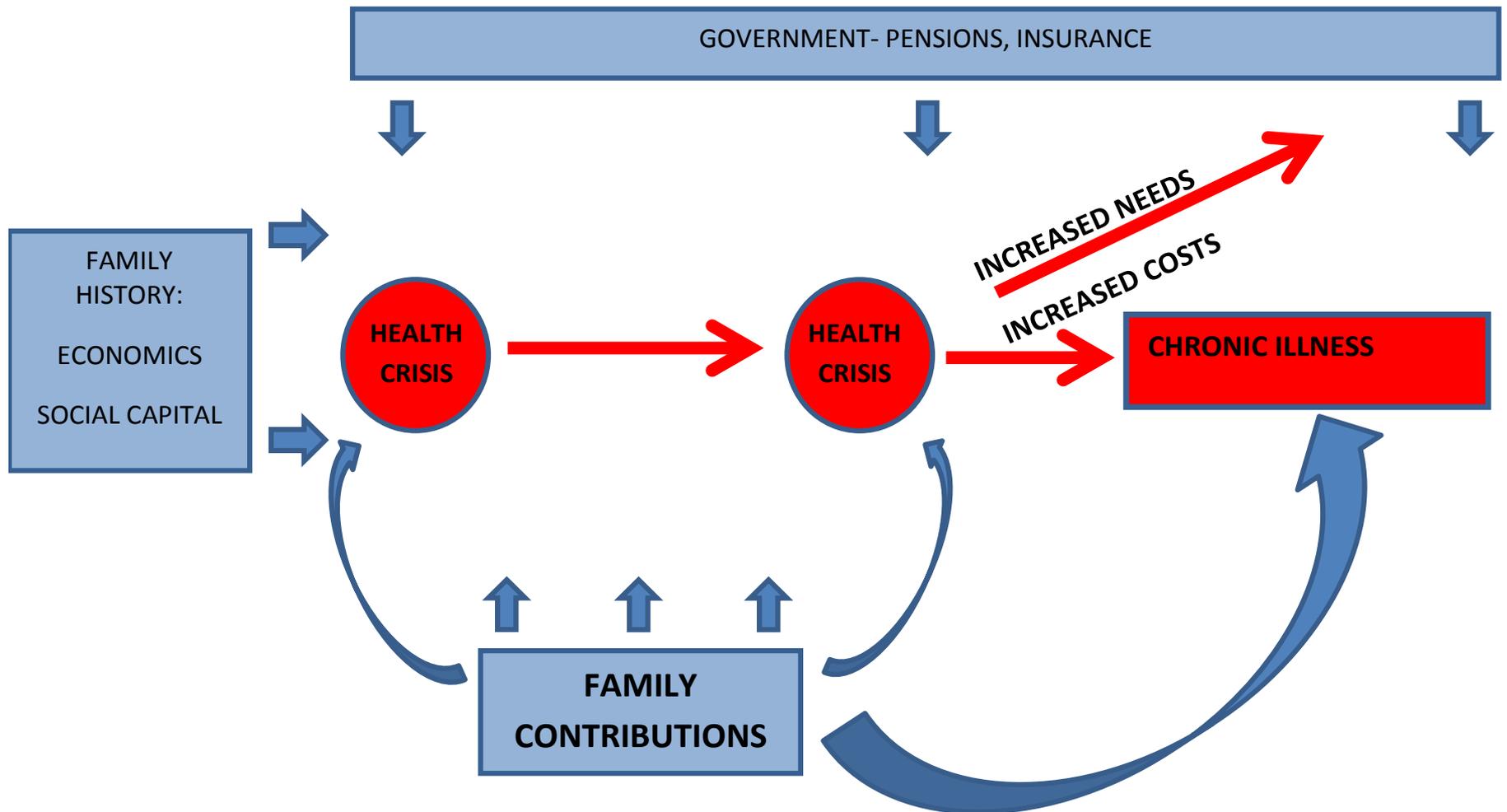
- ER (selected for economic reasons-Y)
- **2d hospitalisation- insertion of catheter 30-40 000 pesos at one hospital but J found a place = 13000**
- J + nephews found money



2013 dialysis sessions 3 times/2 weeks

- **1200 pesos each time**
- HH expenses for Y have increased
- Paid for by Y and Ernesto contributes
- Currently not covered by Seguro- family in dispute
- Y arranging for dialysis via Seguro

Meeting the costs of increased dependence



Who cares and who pays for it?

- Care is women's work
- Men equipped for decision-making, financial contributions
- New dilemmas for women who work outside the house
- Paying for care- who?

I: "Doesn't it [her mother-in-law's dependence] stop your husband from engaging in his own activities even in his business?"

N: "He will tell you that there is division of labour and his work is not taking care of women"

I: "Ok, tell us about the division of labour in this household"

N: "He said he cannot do any of the things I do"

I: "Like what?"

N: "Bathing mama, feeding her, his major work is contributing money and in decision making. If am not around he can only call to ask me where is mama's drug and he can give her the drugs."

HH529, Nigeria, daughter-in-law of older lady with dementia

Intergenerational ties

- Children of older people have strong commitment to providing care
- In response to the care they received in early life
- However, bi-directional relationship
- Households fluid, responsive to needs

“My dad raised us up when we were children, so now we must look after him”

HH722, urban China, son of frail older man with stroke

“The death of her husband has compounded my problems, I take care of them and her six children. They are mostly girls and some of them are serving as housemaids and house-helps for people in various towns in Nigeria”

HH208, Nigeria, older man with stroke

Meeting the needs of multiple generations

Older caregivers

- Children of older person (case) are often older themselves
- Chronic health problems of their own
- Costs

Grand-children, great grand-children

- Who is primary caregiver?
- Costs of education etc.

Mei: I'll tell you the truth - I'm a cancer patient.
I: Oh, your third younger sister told us that.

Mei: She is my mother, so I have to do my duty as her daughter. In fact, I'm also elderly in age, what is more, I'm suffering from a serious disease. Is it right?

Lan's daughter, Mei, China

Paying for dependence: government contributions

- Non-existent in Nigeria
- Not all costs covered by insurance
- Choosing private healthcare: waiting times, supply (Mexico)
- Pension is a constant (small) contributor to healthcare, household costs- not responsive to changing needs

“Nearly two years, the insurance covered 50% of the costs. It is very helpful to us, and our pressure has been reduced a lot. Without this insurance, the expenses will be too much”

Lan’s son, urban China
Lan has stroke, diabetes

Coping strategies

Cutting costs

- Stopping or cutting back on healthcare
- Shopping around for cheaper treatment
- Tightening up living expenses

Drawing on other sources of money

- Borrowing
- Drawing upon existing resources (property)

“In fact, whenever we are going to hospital, we collect rent from tenants in the houses because at this time our elder brother has not found a job”

Cynthia’s daughter, Nigeria

“Every session is stressful because my dad says “No, let’s not go [for dialysis] twice a week, let’s just go once a week and we can go on Saturday, I don’t feel so bad”

Ernesto’s daughter, Mexico

Impact

- Dynamic process of addressing changing costs/circumstances → family conflict
 - Economic strain
 - Curtailed careers
 - Reduced income generation opportunities
- **Impoverishment**

“The little money we realise goes to their upkeep and care. Even this sister staying here couldn’t look for a job anywhere again because our parents need somebody that will always be close to them all the time”

Godwin and Linda’s daughter, Nigeria. Linda has stroke, Godwin has mobility problems

Discussion- qualitative findings

- Consistent with quantitative- dependence has severe consequences for some
- **Gender** norms permeate care arrangements
- Set limits for bargaining
- **Challenged by women who work**
- Care of older people seen as a **reciprocal** investment
- Mid generation is stretched- meeting needs of young and old (Fingerman et al 2011)

Implications of qual & quant findings

- Family system is under strain
- Public systems to bolster families
- Reactive/responsive to needs
- Regulation of paid care
- Community-based care/training for older people & their families → reduced carer strain (eg. Helping Carers to Care- Guerra et al 2011, Garilova et al 2009)
- Continued scale-up of social protection

INDEP publications & materials

- INDEP film from Peru
<https://www.youtube.com/watch?v=qNr5Vta17PQ>
- Prince MJ, Lloyd-Sherlock P, Guerra M, Huang Y, Sosa AL, Uwakwe R, Acosta I, Liu Z, Gallardo S, Guerchet M, Mayston R, de Oca VM, Wang H, Ezeah P. (2016) [The economic status of older people's households in urban and rural settings in Peru, Mexico and China: a 10/66 INDEP study cross-sectional survey.](#) Springerplus. Mar 2;5:258.
- Mayston R, Guerra M, Huang Y, Sosa AL, Uwakwe R, Acosta I, Ezeah P, Gallardo S, de Oca VM, Wang H, Guerchet M, Liu Z, Sanchez M, Lloyd-Sherlock P, Prince MJ. (2014) [Exploring the economic and social effects of care dependence in later life: protocol for the 10/66 research group INDEP study.](#) Springerplus. Jul 28;3:379.

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