Disability, formal and informal support and quality of life outcomes for older people

Ruth Hancock

Care Policy and Evaluation Centre, LSE

Steve Pudney

ScHARR, University of Sheffield

22 Mar 2021





Objectives

- First phase of EEPRU project
- Focus on disability among older people
- Research issues:
 - Sensitivity of NICE-oriented quality of life measures to disability?
 - Impact of disability on other wellbeing measures: e.g. mental health, loneliness/isolation, life satisfaction
 - Spillovers within couples?
 - How is receipt of formal and informal support related to severity of disability?
 - Gender equality in receipt of support?
 - How is burden of disability shared betwen the disabled person and society at large?
- Cross-section analysis of household data from waves 7 & 9 of UKHLS (Understanding Society)

Understanding Society data

Understanding Society panel survey (UKHLS):

- large sample (c. 40,000 households)
- annual interviews with all adult hh members (c. 100,000)
- samples from nations of the UK (NB different policies on care in Scotland, etc.)
- content covers:
 - hh income & individual income components
 - disability (I)ADLs
 - care receipt
 - hh & personal health & welfare indicators: QoL (SF-6D), mental health (GHQ; WEMWBS), loneliness/isolation, satisfaction
- BUT some difficulties:
 - rotating modules cause problems (e.g. full disability measures in waves 7, 9, etc
 - need for "data cleaning" (esp. receipt of disability benefit and care subsidies)

Data cleaning/imputations

- Missing values for key sources of (pensioner) incomes:
 - State and private pensions
 - Disability benefits
- Disability benefits (DBs):
 - correcting impossible recorded values for non means-tested DBs, payable at one of max 10 rates per year.
 - isolating disability-related amount of any means-tested benefits (MTBs) triggered by receipt of DB (depends on which rate/component is received).
- Jointly received income
 - Standard USoc processes ignore the fact that means-tested benefits are inherently 'joint' (assessed for a 'benefit unit'), so call for a different approach.
- Estimating value of care subsidy for formal (paid-for) care

Data cleaning: methods

- State and private pensions:
 - Missing values replaced by (inflation-adjusted) non-missing values from preceding/succeeding waves (rather than 'similar' individuals in same wave which is essentially the UKHLS method)
- DBs (non means-tested)
 - Use preceding/succeeding waves to replace missing/impossible amounts with closest match to reported non-missing value
 - Allow for source of 'error' to be in the recorded amount, its period code (weekly, monthly etc.) or financial year.
 - If closest match is from a previous/subsequent wave, use corresponding amount for date of interview in current wave.
- Disability-related component of MTBs
 - Use corrected amount of DB to isolate any disability-related component
- Joint income from MTBs (both partners report an amount)
 - Inspect responses and take the sum (each reports 'their' share) or average (each reports the total amount)
 - Latter is most common UKHLS method would overestimate

Estimating formal care subsidy

- UKHLS records:
 - hours of different types of formal care received
 - whether care arranged via Local Authority
 - how much respondent paid towards the care
- For each type of care, gross cost estimated using:
 - reported hours of care
 - typical hourly costs (PSSRU unit cost estimates)
- Care subsidy constructed as difference between estimated total gross cost of services received and respondents' payments
- Where respondents reported paying something but not how much, it
 was imputed as the mean ratio of (non-missing) respondent
 payment to gross cost for the type of service in question
- UKHLS records hours of care in bands; the band mid-point was used in estimating gross cost

Disability categories

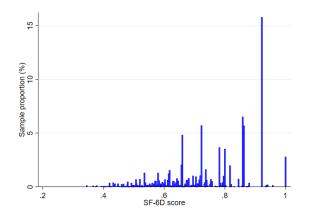
- Additive (I) ADL index, rescaled for s.d. = $1 \Rightarrow 4$ ordinal categories of disability, 0...3
- Personal characteristics vary across disability classes
- E.g. people living alone:

	Sample				Permanent	Home-
	%	Female	Age	Degree	income	owner
0: $D = 0$	21	.63	72	.36	375	.80
1: $D \in (0,0.1]$	39	.66	75	.29	314	.78
2: $D \in (0.1, 0.25]$	26	.70	78	.20	259	.66
3: <i>D</i> > 0.25	15	.73	80	.16	223	.49

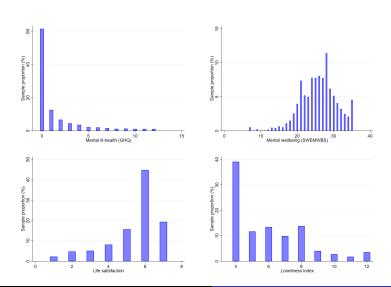
- Comparisons of wellbeing and support outcomes across disability groups distorted by demographic & SES differences
- Inverse probability weighting (IPW) multi-level treatment effect methods
- ⇒ essentially compares mean outcomes for disabled individuals with matched composite non-disabled "controls"

Health-related quality of life: SF-6D

- SF-6D constructed from SF12
- Utility score measure of HRQoL accepted by NICE for cost-effectiveness analysis when EQ-5D isn't available



Mental health (GHQ12 caseness), Mental wellbeing (WEMWB scale), Life satisfaction, Loneliness index



Couples: "Impact" of wife's disability in couples

	Base level		Effect of Wife					
Outcome	None	Mild	Medium	Severe	P-value			
Direct effects on wife								
SF-6D	0.850	-0.055***	-0.170***	-0.281***	0.0000			
Mental ill-health	0.528	0.416**	1.235***	4.844***	0.0000			
Mental wellbeing	28.01	-1.274***	-2.720 ***	-7.031***	0.0000			
Life satisfaction	5.989	-0.155**	-0.527***	-1.626***	0.0000			
Loneliness	4.684	0.177	0.576***	1.206 ***	0.0000			
Spillover effects on husband								
SF-6D	0.788	0.000	-0.012	-0.103	0.2332			
Mental ill-health	0.705	0.141	0.179	0.737*	0.1483			
Mental wellbeing	27.18	-0.232	-0.535	-1.161*	0.2975			
Life satisfaction	5.797	-0.145**	-0.166*	-0.484***	0.0121			
Loneliness	4.884	-0.161	-0.289	0.345	0.1572			
Joint significance test for spillovers (men & women): $\chi^2(30) = 40.13$ ($P = 0.1023$)								

- Strong effect across all wellbeing measures
- Weak evidence for spillovers:
 - only significant impact on life satisfaction of husbands
 - insignificant overall test
 - ⇒ spurious multiple testing effect ?

"Impact" of disability on receipt of public support (£pw)

Receipt	Receipt Base level			Effect of disability				
$(\pounds$ per week $)$	None	Mild	Medium	Severe				
Men living alone								
Disability benefit	1.24	4.62***	16.94***	41.30***				
LA care subsidy	0	3.01***	23.54***	203.27***				
Women living alone								
Disability benefit	0.15	1.65***	18.59***	52.41***				
LA care subsidy	0	3.05***	34.25***	120.92***				
Couples: male partner's disability								
Disability benefit	6.15***	3.00*	10.56***	49.04				
LA care subsidy	0	1.68***	14.94***	88.43***				
Couples: female partner's disability								
Disability benefit	7.26***	2.11	6.82***	48.77***				
LA care subsidy	0	3.29***	10.01***	75.65***				

- Steep disability gradients especially for social care subsidy
- Evidence of gender differences in access to public support ?

Male-female mean differences in levels of public support (£pw)

Type of	Gende	Overall χ^2						
support	None	one Mild Medium Severe		$ extcolor{P}$ -value				
Living alone								
Disability benefit	1.10*	4.06***	-0.55	-10.02	0.0058			
LA care subsidy	0	-0.04	-10.71	82.35	0.4664			
Living in couples								
Disability benefit	-1.10	-0.22	2.64	-0.83	0.8506			
LA care subsidy	0	-1.61**	4.94	12.78	0.0594			

- Modest gender differences in public support at low levels of disability:
 - advantage in DB for lone men with mild disability?
 - advantage in care subsidy for wives with mild disability ?

"Impact" of disability on hours of care received

	Male disability			Female disability			Gender equality	
	Mild	Medium	Severe	Mild	Medium	Severe	<i>P</i> -value	
Living alone								
Formal	0.06***	0.47***	6.71**	0.04***	1.00***	3.95***	0.2117	
Informal	0.09**	0.88***	3.81***	0.07***	1.12***	7.45***	0.0195	
	Living in couples							
Formal	0.03***	0.19**	2.98**	0.04***	0.20***	2.46**	0.9534	
Spouse	0.13***	3.26***	35.1***	0.22***	4.03***	28.0***	0.3896	
Other	0.01	0.14***	1.21***	0.05*	0.22***	2.92***	0.1151	

- Some gender-specific advantage in informal care for severely disabled women living alone?
- In couples, the spouse is the dominant source of care (and no significant gender difference)

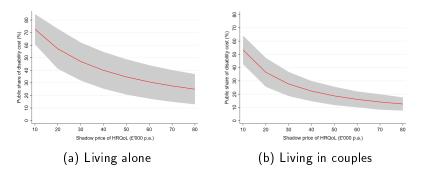
Public/private sharing of disability costs

- Notation:
 - Population proportions with disability levels $0...3 = p_0...p_3$
 - Mean levels of public support: $0, b_1...b_3$
 - Aggregate cost of support: $B = p_1b_1 + ... + p_3b_3$
 - Mean disability-specific HRQoL: $w_0, w_1(b_1)...w_3(b_3)$
 - Social unit value of HRQoL = V
 - Optimum social welfare: $\tilde{S} = V \left[w_0 + \sum_{j=1}^{3} p_j (w_j(\tilde{b}_j) w_0) \right] \tilde{B}$
- Marginal impact of increase in extreme disability $(dp_3, dp_0 = -dp_3)$:

$$d\tilde{S} = V\left[\left(w_3(\tilde{b}_j) - w_0\right)\right] - \tilde{b}_3$$

Total cost of additional disability =
 social value of private HRQoL impact
 + cost of additional public support

Public/private cost sharing (SF-6D)



- For valuation V = £70,000 (Green Book), public share of burden is 28% (singles), 14% (couples)
- (Assumes no spillover on HRQoL of spouse)
- Underlines the importance of partner-carers for disability policy

Main points for future research

- Dynamics:
 - improve precision by adding wave 11
 - robust picture of disability impacts for onset and change in disability over time?
- Measurement error:
 - evidence of 'churning' in reported disability status?
 - possible impact of measurement error?
- Spillovers:
 - weak cross-section evidence for spillovers across multiple wellbeing outcomes
 - surprising to some (but possibly reassuring for NICE)
 - is the finding robust?