Valuing informal care – an overview

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Valuing informal care: Today's objectives

- 1. Give an overview of methods that have been proposed/used to value costs and/or effects of providing informal care
- 2. To combine the valuation methods with various types of economic evaluations
- 3. To discuss how to link the methods with different decision contexts, e.g. Japan, Netherlands, UK or within UK health versus social care



What is informal care?

Often defined as <u>unpaid care</u> provided by <u>non-professionals</u>

Informal care = a composite commodity consisting of heterogeneous parts produced (<u>unpaid or paid</u>) by one or more members of the social environment of the care recipient



Informal care in economic evaluations

- Adopting a societal perspective implies that costs & effects of informal care should be included
- Excluding informal care involves the danger of shifting costs & effects towards the social network of care recipients
- Please note: the societal perspective is not universally accepted
- Various types of economic evaluations (CEA, CUA, CBA) involve different methods to value informal care

Notice:

- Care recipient main aim intervention
- Informal care main aim intervention



Part 1:

Overview & comparison of monetary valuation methods



Economic evaluations

Focus: care recipient main aim intervention

Approach: monetary valuation methods in order to include informal care on cost side of CEA or CUA



- Proxy good method
- Opportunity cost method
- Contingent valuation method
- Well-being valuation method
- Conjoint analysis/discrete choice experiment



Proxy good method

Value informal care = price of (quasi) market substitute

<u>Required information:</u> How much time would you spend on providing informal care?

- Diary versus recall method
- Hours per week/minutes per day?
- List of pre-specified care tasks?

Assumes informal & formal care perfect substitutes

Opportunity cost method: value = paid work

But:

- 1) What is value for caregivers not participating on labour market?
- 2) Informal care causes lower wages
- 3) Informal care often at cost of leisure
- 4) Informal care involves morbidity & mortality risks
- 5) Measurement problems



- How much time did you give up in order to provide informal care?
 - a) hours paid work per week
 - b) hours unpaid work per week
 - c) hours leisure per week

• How would you allocate your time without the provision of informal care?



Contingent valuation method:

Theoretical basis in welfare economic theory

Advantage:

• Preference based *total valuation* of informal care

But:

Money low at the informal caregivers' agenda (Smith & Wright, 1994)



Suppose the care recipient needs an extra hour of care per week and the government would be willing to compensate you to provide this hour

What is the minimum amount of money you would like to receive from the government to provide this additional hour of care per week?

Please note:

- Who's values count?
- WTA versus WTP



Monetary valuation methods Wellbeing valuation method

Advantages:

- Total valuation of informal care
- No cognitive burden for respondents

Theoretical basis:

Experienced utility as opposed to decision utility (*Kahneman et al.*, 1997)



Measuring wellbeing

Question: In general, how happy are you?

Answer category 1 Fairly happy Fairly happy Not happy



Survey questions:

- Happiness/life satisfaction/wellbeing
- Informal care time
- Income
- Control variables



Results: Monetary valuation methods

- 8-12 Euro per hour
- Proxy good and wellbeing valuation methods best response (least cognitive burden)
- Monetary values could be included at cost side of CEA & CUA



Discussion: Monetary valuation methods

Could monetary valuation methods be of any use within the NICE decision context?

- Proxy good method
- Opportunity cost method
- Contingent valuation method
- Wellbeing valuation method
- Conjoint analysis/discrete choice experiment



Part 2:

Overview & comparison non-monetary valuation methods



- Caregiver burden
- Process utility
- Caregiver quality of life
- Health-related quality of life



Non-monetary valuation methods: Burden

Caregiver burden (Drummond et al., 1991):

Assumption: providing informal care involves burden

"Ideally, the primary outcome variable for a trial such as this [caregiver support program] should be a direct measure of the burden on caregivers" (*Drummond et al., 1991*)

Instruments:

- Zarit Caregiver Burden Scale (ZCBS)
- Caregiver Strain Index (CSI)
- Caregiver Reaction Assessment (CRA)



The Caregiver Strain Index: I am going to read a list of things that other people have found to be difficult. Would you tell me if any of these apply to you? (Give examples)

	Yes=1	No=0
Sleep is disturbed (e.g., becauseis in and out of bed or wanders around at night)		
It is inconvenient (e.g., because helping takes so much time or it's a long drive over to help)		
It is a physical strain (e.g., because of lifting in and out of a chair; effort or concentration is required)		
It is confining (e.g., helping restricts free time or cannot go visiting)		
There have been family adjustments (e.g., because helping has disrupted routine; there has been no privacy)		
There have been changes in personal plans (e.g., had to turn down a job; could not go on vacation)		
There have been other demands on my time (e.g., from other family members)		
There have been emotional adjustments (e.g., because of severe arguments)		
Some behavior is upsetting (e.g., because of incontinence; has trouble remembering things; oraccuses people of taking things)		
It is upsetting to findhas changed so much from his/her former self (e.g., he/she is a different person than he/she used to be)		
There have been work adjustments (e.g., because of having to take time off)		
It is a financial strain		
Feeling completely overwhelmed (e.g., because of worry about ; concerns about how you will manage)		



Non-monetary valuation methods: Burden

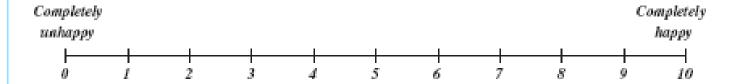
But:

- Sum scores implicitly assume similar weighting for all items
- Partial (valuation) method as opposed to total valuation method
- What about positive aspects of providing informal care?
- Double counting

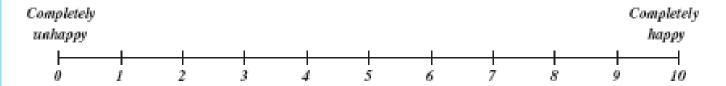


Process utility (Brouwer et al., 2006):

In general, how happy are you?



Suppose a person of you and your care recipient's choice would take over the informal care you are providing. How happy would you be?



How to include in economic evaluations?



Caregiver quality of life (Mohide et al., 1988):

<u>Concept</u>: "In the absence of a quality of life instrument which is applicable to the caregivers of elderly relatives and amenable to a cost-utility analyses, the Caregiver Quality of Life Instrument (CQLI) was developed using Torrance's time trade-off technique" (Mohide et al., 1988)

• Implicit assumption: Caregivers preferences count



Dimensions CQLI:

- Feel physically well and energetic
- Feel happy and free from worry or frustration
- Have sufficient time to socialize with family and friends
- Get an adequate amount of undisturbed sleep
- Get along well with the person being cared for
- Are the calculated utilities using time equivalence scales comparable with QALYs and/or health maximisation?
- Time is the valuation currency in *Mohide et al (1988)* but not in de modern approaches
- What about interdependent utilities?

QALY (Williams, 1989)

"So it is with long-term care. If the alternative is a rapid deterioration of the patient's condition, on both disability and distress dimensions, and, in addition, the imposition of extra disability and distress on informal carers if the alternative is struggling on at home, then I can well imagine that the cost-per-QALY for long-term care may be very favourable even compared with apparently quite dramatic (but very expensive) acute interventions" (Williams, 1989)

Informal care involves even increased mortality risks (Schultz & Beach, 1999)

Issues around QALY and informal care

- Causality heath and providing care
 - Could be solved by means of randomised clinical trials

Value of forgone paid work via QALYs?

• Implicitly assuming general population values count

- Interdependent utility functions/preferences
 - ➤ Value of spillover effects via QALYs?
 - Caregivers might prefer the QALY loss



In sum: non-monetary valuation methods

• Should positive caregiving effects be excluded?

- Methods developed for CUA
 - ➤ Include care-related dimensions neglecting health
 - Focus on health neglecting other dimensions
 - ➤ Solution: combining both? Also for NICE?
 - ➤ What about Japan or the Netherlands



Discussion: Non-monetary valuation methods

Could non-monetary valuation methods be of any use within the NICE decision context?

- Caregiver burden
- Process utility
- Caregiver quality of life
- Health-related quality of life



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Questions & discussion

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