

CAREGIVER BURDEN

MEASUREMENT CHALLENGES & ISSUES

Andrew Lloyd



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MEASUREMENT ISSUES

1. What is the nature of caregiver burden?
2. Implications for HTA
3. Does caregiver burden increase in line with disease severity?
4. Challenges for parents
5. Approaches to measurement

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CAREGIVER BURDEN

Being a caregiver can have a substantial impact on health

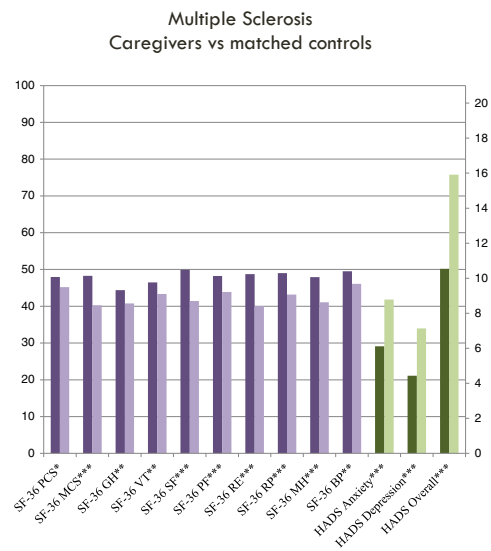
- Undoubtedly affects people's health & wellbeing

What is mechanism of this?

- Physical strain, pain
- Psychological burden
- MS example suggests across all dimensions
- Anxiety, depression prominent

These data show that impact can be quite broad

- Psychological impact; social functioning



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IMPLICATIONS

Suggests that it may not just be the primary caregiver who experiences the burden

Psychological and social impact experienced by wider family

- Should they all be included in an assessment of cost effectiveness?

NICE have reviewed submissions where more than 1 caregiver has been included

Ultimately for HTA bodies to decide

- Has potential to really change priorities of HTA bodies

Grandfather paradox

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GRANDFATHER PARADOX

Grandad is very sad and worried because his granddaughter is ill

- (Grandad is not involved in caring for the child)

An expensive effective treatment has been considered *cost-effective*

- It cures the child of their health problem
- Grandad's psychological health improves
- Therefore there is a QALY gain for both people

However the expensive treatment uses up NHS resources

Displaces existing treatments for other people

- Hip surgery is delayed
- Mental health services are under-funded

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DOES CAREGIVER BURDEN INCREASE WITH DISEASE SEVERITY?

Might be reasonable to assume correlation

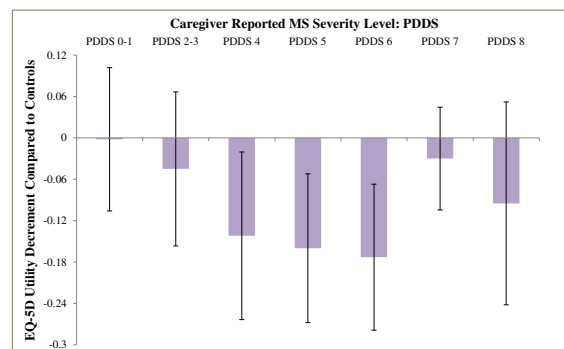
- As disease severity gets worse patient becomes more dependent

However some evidence that this may not be true

- MS study – cross sectional data
- Estimated disutilities by patient disease severity

Shows the importance of empirical data

- Longitudinal data is preferable
- Interventional randomized studies



Acaster et al.: BMC Health Services Research 2013 13:346.

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CHALLENGES OF PARENTING

Much recent HTA focus on burden for parents of children with severe (often rare) disease

- Duchenne muscular dystrophy; seizure disorders; metabolic disorders

Several measurement challenges

It's a privilege to care for my child

How can I complain that I feel tired when my child has

Parents may underreport problems

Many parents describe the overwhelming positive aspects of caring and sense of fulfillment and glow

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STANDARDISED MEASURES

Measures for cost-effectiveness research

CarerQoL

- Includes positive and negative effects of caring
- Includes a scoring function (but not anchored against Dead so less suited for QALYs)
- Widely used and researched

EQ-HWB (e-QALY)

- Initiative led by John Brazier et al, supported by UK MRC; NICE and EuroQoL Research Foundation
- Still under development not yet available
- Designed for health and social care settings

EQ-5D-5L

- Not designed for measuring caregiver burden, but does assess health

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OTHER APPROACHES

Vignette research

Vignettes often used to estimate utilities

Same logic could be applied to assess caregivers

Very reliant on the accuracy of vignette content

Difficult to confirm content validity

May not reflect carer's ability to cope and adjust

Qualitative research

Caregiver burden can be accurately described in detail with qualitative methods

Such data supports

- Quantitative utility estimates
- Deliberative process

Should be included in submissions where caregiver burden influences C/E

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CONCLUSIONS

The burden of caring can be very substantial

Considering this in decision making raises measurement issues and wider concerns

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