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Exploring dependence as a measure of progression in the economic evaluation of dementia interventions through public engagement and systematic review

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Background:

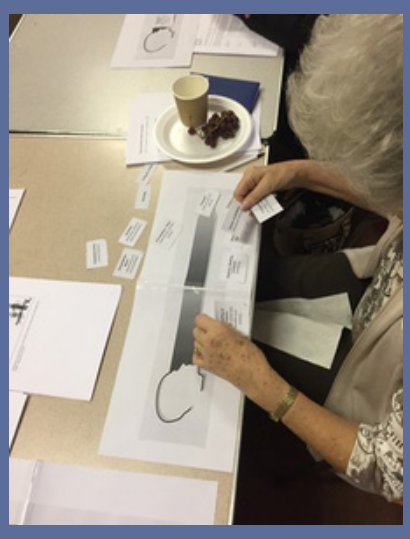
- Although commonly associated with loss of cognitive function, dementia progression affects multiple health domains.
- Decision analytic models in dementia need to incorporate effects on all health domains, rather than focus on cognitive change alone, or risk underestimating the overall impact of dementia progression.
- Dependence (defined by performance in activities of daily living (ADL)) is a broader construct than single-domain clinical measures and may better capture effects of progression.
- Engaging with members of the public when designing decision analytic models can improve their real-world validity.

Objective:

- This review aimed to explore the use of dependence as a measure of dementia progression, focusing on the Bristol Activities of Daily Living Scale (BADLS).
- To invite people with dementia and their caregivers to share their experience of the progression of dependence.

Methods:

- A literature review was conducted to identify primary studies, reviews and policy or clinical guideline documents relevant to dementia progression. The identified literature was then chain searched.
- A public engagement activity was hosted across five sites in Europe to explore dependence progression in dementia (see Figure 1).



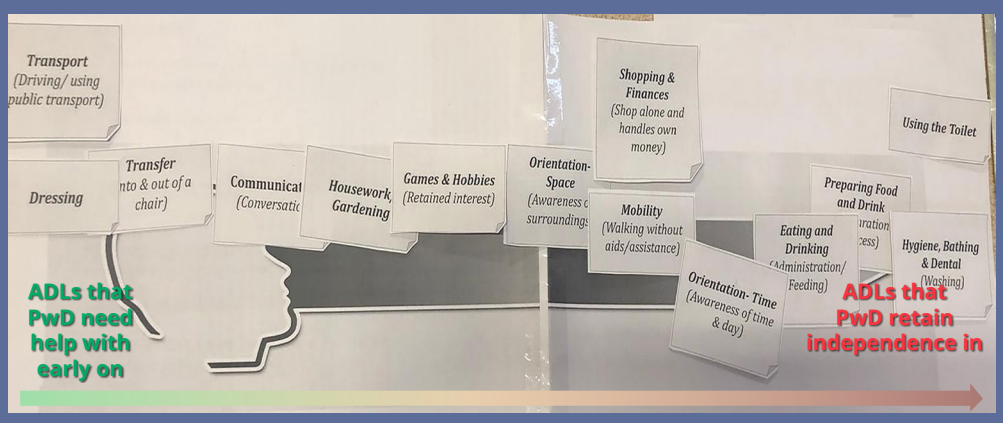


Figure 1; Public engagement activity with people with dementia (PwD) and their caregivers; arranging the BADLS items along a timeline to indicate order of deterioration with time

Results:

- Eleven studies were identified which captured BADLS data in people with various stages of dementia.
- The studies show a large increase in dependence in the mild stage, with BADLS scores peaking at ~14 points, before stabilising and increasing again slowly but steadily through the moderate stage by ~1.5 points over 12 weeks (see Figure 2).

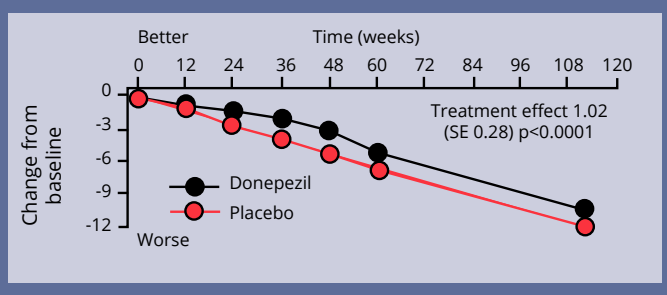


Figure 2; linear change (worsening) of the BADLS score in the placebo arm.[1]

- The public engagement activity demonstrated remarkable similarity in results across the countries, showing earlier impairments with instrumental ADLs, and retained independence in basic ADLs.

Conclusion:

- Dependence is correlated with other measures of disease severity, such as behavioural disturbance and quality of life.
- It provides a simple yet effective measure for use in modelling dementia progression, which better reflects effects on overall health than single-faceted measures.
- It is associated with drivers of cost such as caregiver time and institutionalisation.
- The results of the review and the public engagement activity combined support the validity of using dependence as a measure of dementia progression in economic evaluations.

Reference:

1. *AD2000 Collaborative Group. Long-term donepezil treatment in 565 patients with Alzheimer's disease (AD2000): randomized double-blind trial. Lancet 2004; 363: 2105-15*

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