Preferences in the management of dementia with Lewy bodies: protocol for a best-worst scaling and discrete choice experiment

Paula S Donnelly[1], Marco Boeri[1], AP Passmore[1], Noleen McCorry[1], Joseph PM Kane[1]
[1]Centre for Public Health, Queen's University, Belfast, UK

pdonnelly546@qub.ac.uk

Introduction

Dementia with Lewy Bodies (DLB) management is complex due to a lack of evidence from clinical trials, risks and the unwanted side effects of medications. For example, often the treatment of one symptom in DLB can exacerbate other facets of the disease. Responding to all the symptoms in an individual with DLB is therefore challenging and clinical management requires understanding the treatment priorities of patients and their care partners.

Clinical trials for DLB are prioritised in the Alzheimer's Disease-Related Dementia Summit 2022 recommendations, however randomized clinical trials in DLB remain few relative to other dementia subtypes. Of the few that do exist, a wide range of clinical outcomes have been reported and no single symptom has been favoured as a primary endpoint (1).

To ensure that future DLB trials for disease modifying therapies reflect the preferences of those affected by DLB in the design of their primary and secondary outcomes, research is needed to elicit the treatment priorities and preferences of individuals with DLB and their care partners.

Aim

Accordingly, this study will use an online survey incorporating two health economic approaches namely, best-worst scaling (BWS) and a discrete choice experiment (DCE) to elicit and quantify the preferences of individuals with DLB and their care partners in relation to the treatment of DLB symptoms.

Method

Using global voluntary sector networks, we will recruit 100 individuals who either have a diagnosis of DLB or who are a care partner for an individual with DLB. The BWS and DCE will be applied together in a self-administered online survey.

Best-Worst Scaling

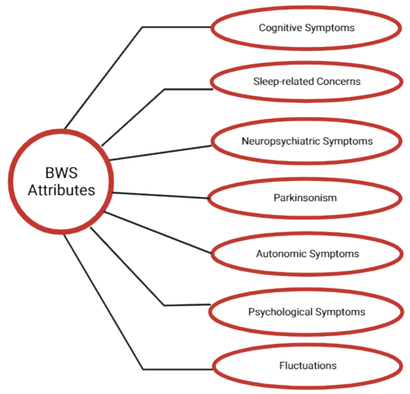
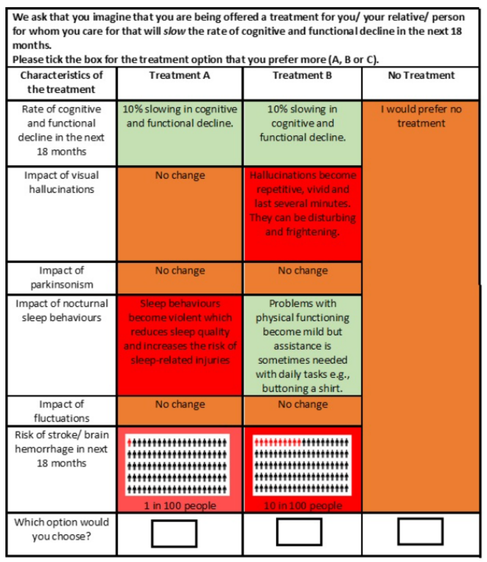


Figure 1: DLB symptom domains for inclusion in the best-worst scaling exercises

BWS is a prioritization method grounded in random utility theory. BWS involves the presentation of choice tasks containing sets of attributes larger than two in which participants are asked to choose their 'best' and 'worst' option. The attributes in this study represent DLB symptom domains (figure 1). A balanced incomplete block design will be used to design the choice sets. The BWS will provide a relative ranking of the included symptom domains according to the preferences of the respondents.

Discrete Choice Experiment



We ask that you imagine that you are being offered a treatment for you/ your relative/ person for whom you care for that will *slow* the rate of cognitive and functional decline in the next 18 months.
Please tick the box for the treatment option that you prefer more (A, B or C).

Characteristics of the treatment	Treatment A	Treatment B	No Treatment
Rate of cognitive and functional decline in the next 18 months	10% slowing in cognitive and functional decline.	10% slowing in cognitive and functional decline.	I would prefer no treatment
Impact of visual hallucinations	No change	Hallucinations become repetitive, vivid and last several minutes. They can be disturbing and frightening.	
Impact of parkinsonism	No change	No change	
Impact of nocturnal sleep behaviours	Sleep behaviours become violent which reduces sleep quality and increases the risk of sleep-related injuries	Problems with physical functioning become mild but assistance is sometimes needed with daily tasks e.g., buttoning a shirt.	
Impact of fluctuations	No change	No change	
Risk of stroke/ brain hemorrhage in next 18 months	1 in 100 people	10 in 100 people	
Which option would you choose?	☐	☐	☐

Figure 2: Example discrete choice question

DCEs enable the identification of both preferences and trade-offs made by individuals in benefit-risk decisions. This allows researchers to determine how individuals value different attributes of a service or treatment. DCEs require respondents to select their preferred choice from a set of hypothetical alternatives. Each alternative is described by several attributes which vary across levels. Because respondents are forced to make trade-offs, this method more closely resembles clinical decision-making whereby individuals must consider benefits, risks and side effects.

Example attributes for the proposed study are shown in figure 2. Example levels are also shown. The levels of variation, although hypothetical, are informed by evidence synthesis and consultation.

Expected Results

We aim to:

- Determine the relative importance of DLB symptoms
- Establish how individuals trade between different symptoms and risks when deciding on treatment
- Better understand preferences for treatment and the impact on choice of potential risks and side effects

Our findings will inform choice of primary and secondary outcomes in DLB trials. They will inform our understanding of the levels of risk and benefit individuals will tolerate which is important as trials of potentially disease modifying agents, such as anti-amyloid therapies, are pursued.

References

(1) Grycuk E, Eichenholtz E, Aarsland D, Betzhold S, Daly G, Folkerts AK, et al. Developing a core outcome set (COS) for Dementia with Lewy bodies (DLB). HRB Open Res. 2022 Aug 18;5:57.

QUEEN'S UNIVERSITY BELFAST

Department for the Economy
www.economy-ni.gov.uk