

Development of a Goal Area Inventory for Dementia with Lewy Bodies for use in Goal Attainment Scaling



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► Background

Assessing treatment response and identifying meaningful change in dementia with Lewy bodies (DLB) is challenging due to heterogeneity in symptom presentation and disease progression. Goal Attainment Scaling (GAS), an individualized outcome measure, addresses this heterogeneity by quantifying treatment effects based on patient-specific goals and challenges. To support standardized GAS implementation while maintaining individualization, condition-specific goal inventories, i.e., structured item banks of patient-relevant treatment goals, are increasingly used. Here, we aimed to develop a DLB-specific goal inventory that captured key symptoms and functional challenges, informed by expert clinicians, and patient/caregiver perspectives. This was to be utilized in facilitating GAS.

► Methods

A dementia inventory containing 67 goal areas developed based on symptoms and challenges identified by over 4,000 clinicians, patients, and caregivers¹, was reviewed and adapted to DLB by expert clinicians through a workshop with two clinicians. The resulting draft inventory was further refined through semi-structured interviews (n=7) with patients diagnosed with DLB and/or their caregivers (n=10). Revisions were made based on patient/caregiver priorities as well as the relevance of the goals to DLB and also to improve their clarity.

► Methods

Goal Title	
Much more than expected	+2
Somewhat more than expected	+1
The expected level of outcome	0
Somewhat less than expected	-1
Much less than expected	-2

Clinician & Care Partner Rating	
+2	+2
+1	+1
0	0
-1	-1
-2	-2

Set & Scale Goals

Rank

Rate Attainment

1 2 3

Goal inventories support rigor by:

- Standardizing interviewer training, goal scale development, and data capture;
- Aligning participant goals with the intervention’s mechanism of action;
- Providing a common language for patients and clinicians.

► Results

Subsequent patient and caregiver feedback informed iterative refinement. One domain title was modified; 18 goal areas were revised (including the merger of one area), and 17 new goal areas were added. The **DLB goal inventory**, encompassing cognition, behavior, daily function, executive function, and physical manifestations, with 47 items, was developed.

► Results

The initial adaptation of Dementia Goal Inventory following a non-systematic literature review and workshop with two expert clinicians yielded 29 goal areas.

► Discussion and Conclusion

Incorporating patient and caregiver input substantially expanded and refined the inventory. This highlights the central role of stakeholder perspectives in developing clinically meaningful outcome measures for DLB. The DLB Goal Inventory provides a standardized yet flexible framework for applying GAS in DLB, supporting patient-centered assessment of meaningful within-patient change across research and care settings.

► References

¹ Rockwood K. An individualized approach to tracking and treating Alzheimer’s disease. Clin Pharmacol Ther. 2010;88(4):446–449. doi:10.1038/clpt.2010.68.