

Research Priorities of Caregivers and Individuals with Dementia with Lewy Bodies: An Interview Study

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For which topic were research priorities identified?

dementia with Lewy bodies

In which location was the research priority setting conducted?

North America - USA

Why was it conducted at all?

Funding bodies are placing increased emphasis on patient and public involvement in research, but the research priorities of individuals and caregivers living with dementia with Lewy bodies (DLB) are unknown.

What was the objective?

to identify the research priorities of individuals with dementia with Lewy bodies and of their caregivers to guide research

What was the outcome?

a list of 9 research topics

How long did the research prioritization take?

January 2018 - May 2019

Which methods were used to identify research priorities?

interview

How were the priorities for research identified exactly?

Step 1: interviews: to investigate the research priorities of individuals living with DLB and caregivers of individuals living with DLB, semi-structured interview guide designed, questions asked about priorities for DLB research in general and then specifically about priorities regarding research on DLB symptoms, daily challenges, caregiving/family life, and diagnosis, participants also asked to indicate how they would divide \$1000 to spend on DLB research and to prioritize what research was most important to them. Step 2: data processing: thematic content analysis

Which stakeholders took part?

Individuals living with DLB and caregivers. 20 individuals with DLB and 25 caregivers participated.

How were stakeholders recruited?

Individuals with DLB and caregivers of individuals with DLB were recruited from the UF Health Norman Fixel Institute for Neurological Diseases, a Lewy Body Dementia Association Research Center of Excellence. Inclusion criteria were: (1) patient or caregiver of a patient followed at the Fixel Institute, (2) personal diagnosis of DLB [9] or caregiver for an individual diagnosed with DLB, (3) if a person with DLB, clinician-judged mild-moderate severity such that the individual could understand the study and provide personal opinions, and (4) willingness to participate in a telephone interview.

Were stakeholders actively involved or did they just participate?

Stakeholders were mere participants of the research prioritization process; they were not actively involved in the process.