

Experiences of research participation for persons living with dementia with Lewy bodies

P-6451

Dr Anni South¹, Dr Joanne Tropea^{2,1}, Dr Jenny Yu^{3,1}, Dr Paula Loveland^{3,1}, Dr Kai Sin Chin^{3,1}, A/Prof. Nawaf Yassi^{3,1}, Prof. Rosie Watson^{3,1}

(1) Department of Aged Care, Royal Melbourne Hospital, Parkville, Australia
(2) Department of Medicine, University of Melbourne, Parkville, Australia
(3) Departments of Medicine and Neurology, Melbourne Brain Centre @ The Royal Melbourne Hospital, Department of Medicine, University of Melbourne, Parkville, Australia.



We undertook an interview-based, qualitative sub-study with participants of an Australian longitudinal observational cohort study of DLB. Although challenging, participation in research supported the proactive stance that participants sought towards their DLB diagnosis. Key enablers of research participation included the rapport and active partnership developed with the research team, and the provision of responsive, practical supports

INTRODUCTION

Dementia with Lewy bodies (DLB) is a common form of dementia that poses complex challenges for both persons diagnosed and caregivers.

The lived experiences and priorities of persons with DLB remain under-explored compared to other forms of dementia [1].

Recruitment into DLB research is challenging due to the complexity of symptoms and associated frailty.

In this qualitative sub-study within an Australian longitudinal, observational cohort study of DLB ("The Lewy Body Study" [2]) we aimed to:

- Describe the lived experiences of a group of research participants in The Lewy Body Study,
- Explore participants’ experiences of DLB and of participation in research,
- Identify potential barriers and enablers of research participation.

RESULTS

We conducted eight in-depth interviews with Lewy Body Study participants, including persons diagnosed with DLB (n=4) and their study partners (n=4) (Table 1) . We generated five themes (Figure 1).

- DLB had significant impacts on participants’ daily activities and life roles.
- These challenges were under-appreciated by others due to the specific and variable nature of DLB symptoms.
- Participants sought ways to remain proactive in the face of their diagnosis.
- Research participation was both practically and emotionally demanding.
- Accounts of research participation were nonetheless positive. Participants recognised themselves as valued and active partners in research.

	Age (years)	Sex	Rurality	Duration of participation (months)	Education (total years)	Study visit assessments (closest to interview)
PD-A	72	Male	Inner regional	16	19	MMSE 26, MoCA 20, CFS 6, CDR-SB 6
SP-A	64	Female				
PD-B	69	Male	Outer metropolitan	12	10	MMSE 29, MoCA 25, CFS 5, CDR-SB 2.5
SP-B	71	Female				
PD-C	78	Male	Inner metropolitan	10	13	MMSE 25, MoCA 18, CFS 5, CDR-SB 2
SP-C	78	Female				
PD-D	79	Male	Outer metropolitan	43	18	MMSE 28, MoCA 26, CFS 5, CDR-SB 3
SP-D	78	Female				

Table 1: Summary of EXPRESS sub-study participant characteristics. PD: Person living with DLB. SP: study partner
MMSE: Mini-Mental State Examination, MoCA: Montreal Cognitive Assessment; CFS: Clinical Frailty Scale; CDR-SB: Clinical Dementia Rating –Sum of Boxes

METHODS

We invited participants enrolled in The Lewy Body Study to take part in semi-structured, individual interviews. Interviews were audio-recorded and transcribed verbatim[#] .

We undertook a six-phase Reflexive Thematic Analysis of the dataset, using an inductive, critical-realist analytic stance [3].

[#]An initial transcription was generated using A-train software [4], with subsequent detailed manual review and editing.

CONCLUSIONS

Although challenging, participants largely perceived taking part in research as beneficial, citing:

- Improved understanding of DLB
- Greater sense of agency
- Making a meaningful contribution to knowledge or to others diagnosed in future.

These benefits arose despite the observational nature of the Lewy Body Study. *"How"* research was conducted mattered as much as *"what"* research was conducted.

Important enablers of research participation included:

- Rapport and partnership developed with the research team
- Practical, responsive supports (e.g. transportation support, meal provision)

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CONTACT

Anni South: anni.south@mh.org.au

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