

Patient Experiences	
	Yumoto and Suwa [28] Changes in the daily life of people with DLB: Most common symptoms were cognitive decline, visual hallucinations, RBSD, and parkinsonism. Difficulties were due to symptoms Pt was aware and unaware of. Themes: bodily discomfort (trouble moving/doing), daily obstacles (forgetting, communicating), psychological pain, isolation, frustration, depression.
	van de Beek, et al. [42] Parkinsonism was the most frequent core feature in MCI-LB (69%). LB fared worse on neuropsychiatric symptoms, non-memory cognitive domains, and CG burden. LB group declined faster on attention
	ALL SYMPTOMS Larsson, et al. [51] Themes focus on: (1) disease impact, i.e., symptom experience and restricted activities; (2) self-perception and coping strategies; (3) importance of others. Patients reported wide range of symptoms and prioritized physical complaints over cognitive, in contrast to CG perspective in other studies. Diverse symptoms Functional impacts Pt priority physical symptoms
	Donaghy, et al. [43] Symptoms more common in DLB and MCI-LB: fluctuating attention/ concentration, rigidity/stiffness, shuffling, handwriting changes, drooling, frequent falls, posture changes, weak voice, REM sleep behavior disorder, spatial misperception, loss of smell, slowness, visual hallucinations.
	Galvin, et al. [56] Presenting symptom were cognitive (48%), motor (39%), or mixed 13%. Multiple visits (>6) and multiple doctors (3.3 ± 1.5) needed to establish LBD diagnosis; 31% took > 2 years. Initial diagnosis not LBD in 78%: PD, AD, FTD, MDD.
	Matterson, et al. [40] Themes: (1) symptoms of cognitive fluctuations were inconsistent; (2) both Pt and CG had sleep disturbances due to DLB. Poor sleep quality was a trigger for worsening cognitive fluctuations. Excessive daytime sleepiness was common.
	COGNITIVE Harding, et al. [29] Pt had worsening cognitive symptoms (70%), ability to do things (62%), well-being (57%) and changes to medication (26%). Carers had less support (55%) which adversely affected their mental health.
	Bradshaw, et al. [45] DLB CG cited lapse in awareness or attention, lost ability to engage in meaningful cognitive or physical activity with short lived alterations in cognitive and functional abilities vs. AD CG reporting confusion and more persistent alterations
SYMP	Yumoto and Suwa [41] Difficulties from hallucinations included feeling something strange is happening, discomfort, activity restrictions, inability to talk to family about it, and emotional distress. 70% did not use term hallucination.
	PSYCHIATRIC Cagnin, et al. [58] Worsening of behavioral and psychological symptoms - 59.6% had worsening or onset of new BPSD, which was higher for DLB (63.8%). DLB Pt with BPSD had > neuropsychiatric symptoms vs. other groups. Worsening was most frequently reported for: irritability (40.2%), apathy (34.5%), agitation (30.7%), anxiety (29%), depression (25.1%), sleep disorder (24%), delusions and hallucinations (10%). BPSD was similar by CDR severity across diseases. Behavioral and Psychiatric symptoms
	Ballard, et al. [46] 93% DLB experienced at least one type of visual hallucination, and 56% had multiple, which was significantly more common than in the AD group.
	SLEEP Kashihara, et al. [44] Sleep problems, vivid dreams, and nocturnal vocalization were more frequent in patients with PAF, IPD and DLB vs. controls. Difficulty falling asleep was similar to stroke controls. Awakenings higher in iPD group. Daytime sleepiness was higher in iPD and DLB.
	Volkmer, et al. [77] Themes for LBD group related to aphasia: (1) communication difficulties a key problem, (2) feeling of isolation due to speech issues (worse for CG than for Pt), (3) doing anything that helps, (4) low access to speech and language therapy.
THEMATIC	URINARY Coindreau, et al. [71] 100% had over active bladder, stress incontinence (94%), detrusor overactivity (93%), bladder pressure elevation (79%), voiding difficulties (16%), constipation [92%), and fecal incontinence (44%)
PEOPLE WITH LBD/DLB	Yumoto and Suwa [28] Changes in the daily life of people with DLB: Most common symptoms were cognitive decline, visual hallucinations, RBSD, and parkinsonism. Difficulties were due to symptoms Pt was aware and unaware of. Themes: bodily discomfort (trouble moing/doing), daily obstacles (forgetting, communicating), psychological pain, isolation, frustration, depression.
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	Watermeyer, et al. [53] Goals for cognitive rehab were: use technology (email), engage in leisure activities; manage medications; manage self (ADL), orient self to time/place, remember where things are, have social life, manage anxiety. Goals for cognitive rehab
	Armstrong, et al. [26] Themes: Participants valued clinician time, diagnosis, education, symptom management, communication, and caring staff. Needs included education for Pt, CG, non-specialist clinicians and community providers, scheduling difficulties, CG support, financial concerns, advance care planning, local resources, and effective treatments for symptoms
	Armstrong, et al. [47] Themes: Research priorities for Pt and CG were DLB symptoms, therapies to prevent, cure, or delay progression, impact on daily function, quality of life, caregiving, and improving education.

Notes. Reference number shown as [#].