Lumanity

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Economic Burden of Progressive Supranuclear Palsy: A Targeted Literature Review

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INTRODUCTION

- Progressive supranuclear palsy (PSP) is a rare, progressive, and ultimately fatal neurodegenerative disease associated with increasing disability, balance impairment, falls, visual disturbances, cognitive dysfunction, and growing long-term care needs[1,2]
- The economic evidence base is heterogeneous across countries, data sources, and outcome definitions, with inconsistent reporting of direct medical costs, informal caregiving, productivity losses, equipment, home adaptations, and multidisciplinary care. A targeted literature review (TLR) is therefore needed to characterize the economic burden, identify evidence gaps, and inform future research priorities

OBJECTIVES

- This TLR aimed to systematically identify and synthesize the published economic evidence in PSP, encompassing healthcare costs, healthcare resource utilization (HCRU), caregiver burden, productivity losses, and cost-effectiveness, to characterize the existing evidence base, identify key evidence gaps, and inform future economic research

METHODS

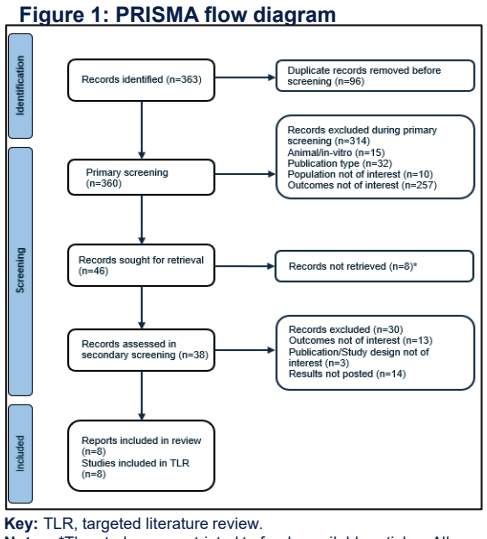
- A TLR was conducted in Embase® from database inception to June 2026 focused on economic evaluation and healthcare cost and resource utilization evidence
- Title and abstracts were screened by a single reviewer against predefined criteria, followed by full-text review to confirm eligibility. A randomized 20% QC was conducted by a senior reviewer after each screening stage. Data were extracted using a standardized grid capturing study characteristics, population details, and outcomes of interest, with a randomized 20% QC by a senior reviewer. Table 1 presents the inclusion criteria

Table 1: PICOS for the economic burden TLR

Category	Inclusion criteria
Population	Patients with progressive supranuclear palsy
Intervention/ Exposure	No intervention limits
Outcomes	Healthcare costs, HCRU, caregiver burden, productivity loses, cost-effectiveness outcomes (e.g., ICER, QALYs), utilities
Study design	Cost-of-illness analyses; observational studies; retrospective database studies; HCRU studies; economic evaluations
Country	No geographic limits
Language	English
Timeline	Database inception to June 2026*

Key: HCRU, health cost resource utilization; ICER, incremental cost-effectiveness ratio, QALYs, quality-adjusted life years; TLR, targeted literature review.
Notes: *Only freely available full-text articles were selected for inclusion, while articles requiring payment or subscription for access were excluded.

Figure 1: PRISMA flow diagram



Key: TLR, targeted literature review.
Notes: *The study was restricted to freely available articles. All non-retrieved publications are paid/subscription based.

RESULTS

Overview of evidence

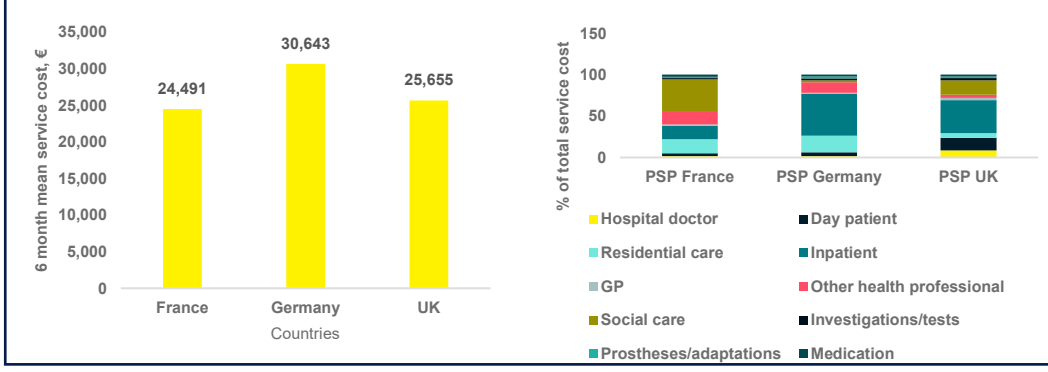
- Of 363 studies screened, 8 studies published between 2015 and 2025 were included (Figure 1)
- Study designs comprised retrospective observational studies (n=7) and one economic model, conducted across multiple countries (n=4), the UK, Italy, Canada, and Israel (n=1 each)
- Most studies assessed HCRU (n=6), including medical costs and caregiving burden; one evaluated cost burden and one assessed treatment cost-effectiveness

Cost and resource utilization

Direct cost:

- A European cost-of-illness study reported 6-month per-patient costs of €24,491-€30,643, with informal caregiving accounting for 68%-76% of total costs. Costs increased with disease severity, and formal care costs were inversely associated with unpaid care costs (Figure 2)[3]
- Inpatient care was the main cost driver in Germany (50.7%) and the UK (40.2%), while social care dominated in France (38.1%). Residential care costs were highest in Germany (20.2%), and hospital-based services were prominent in the UK. Other health professional costs were highest in France (16.5%). GP visits, investigations, prostheses, and medications contributed minimally (≤2.8%) across countries (Figure 2)[3]
- An Israeli claims-based study reported that annual direct medical costs increased from US$8,910 before diagnosis to US$36,693 by Year 10 post-diagnosis, primarily driven by higher hospitalization and outpatient clinic costs (Figure 4)[6]

Figure 2: Mean service cost and distribution of service costs (%) across Europe[3]

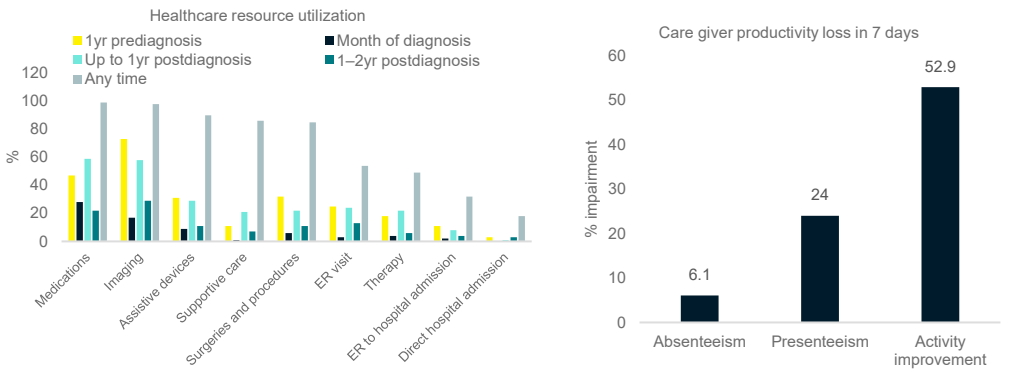


Key: GP, general practitioner; PSP, Progressive supranuclear palsy.

Resource utilization:

- Healthcare resource utilization: A US–Canada study reported high use of medications (100%), imaging (99%), assistive devices (90%), supportive care (86%), and procedures (85%); hospital admissions were least frequent (18.1%) (Figure 3)[9]
- Productivity impairment: Patients with rare diseases reported absenteeism (5.2%), presenteeism (28.0%), and activity impairment (43.1%). PSP caregivers reported absenteeism (6.1%), presenteeism (24.0%), and activity impairment (52.9%) (Figure 3)[10]
- Multidisciplinary care: In Italy, GPs (99.0%) and neurologists (98.4%) were most frequently consulted, followed by physiotherapists (62.7%) and rehabilitation specialists (51.2%) (Fig. 5)[8]
- Caregiving needs: Across Europe, 62%–100% of patients with PSP had a caregiver. Assistance was most commonly required for walking (81%), while 41%–81% needed help with essential daily activities[4]

Figure 3: US and EU healthcare resource utilization and caregiver productivity losses in 7 days[9,10]



Key: ER, emergency room; GP, general practitioner.

Figure 4: Direct medical costs before and after PSP diagnosis in Israel[6]

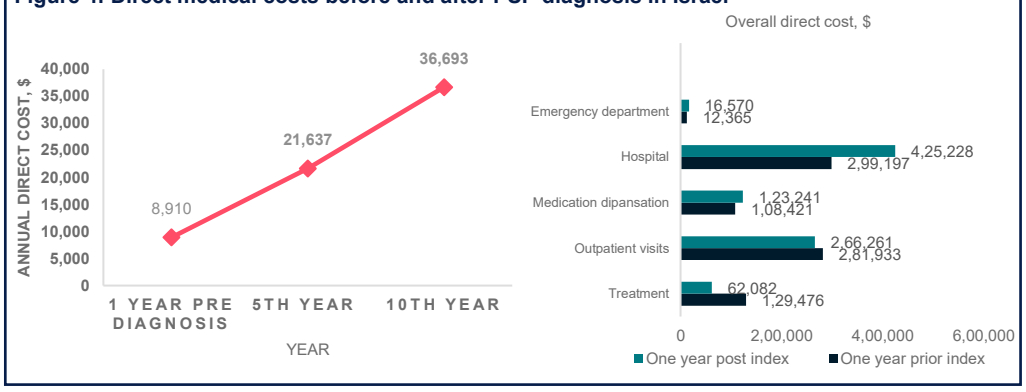
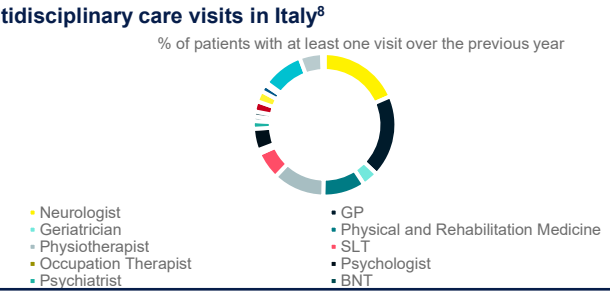


Figure 5: Multidisciplinary care visits in Italy[8]



Key: BNT, botulinum toxin treatment; GP, general practitioner; SLT, speech and language therapist.

Economic evaluation review:

Evidence on cost-effectiveness was limited to one study, which estimated £286,000 in net savings over 3 years with preventive zoledronate therapy by reducing fractures and healthcare costs. No incremental cost-effectiveness ratio (ICER) per quality-adjusted life year (QALY) was reported, as the analysis focused on net cost savings rather than cost-utility[7]

Discussion

- Economic burden: PSP incurs substantial direct and societal costs, with informal caregiving accounting for 68%–76% of total costs in one European study
- Variation in cost drivers: Inpatient and residential care dominated costs in Germany, social care in France, and hospital services in the UK
- Resource utilization and care needs: Frequent healthcare service use, multidisciplinary care, and assistance with daily activities reflect the complex needs of patients with PSP. Broader rare disease evidence also indicates substantial productivity losses among patients and caregivers
- Limited economic evaluations: Only one study estimated net savings of approximately £286,000 over 3 years with preventive zoledronate therapy

Limitations

- Methodological heterogeneity: Differences in costing methods, analytical perspectives, and currencies limited comparisons across studies
- Potential evidence gaps: English-language and freely available full-text restrictions may have excluded relevant studies
- Limited geographical coverage: Sparse evidence across regions limits the generalizability of findings

Conclusion

PSP imposes a substantial economic and societal burden, particularly through informal caregiving. However, evidence on treatment cost-effectiveness remains limited, highlighting the need for robust economic evaluations of existing and emerging therapies and supportive care interventions.

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An electronic version of the poster can be viewed by scanning the QR code.

Poster presented at the 2026 ISPOR Europe; 8-11 November 2026; Vienna, Austria.