LETTER TO THE EDITORS

How often are patients with progressive supranuclear palsy really falling?

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Dear Sirs,

Progressive supranuclear palsy (PSP) is a neurodegenerative condition marked by supranuclear ophthalmoplegia, pseudobulbar palsy, and gait instability leading to repeated falls. We undertook a systematic review to determine how the rate of falls was measured in PSP studies; a cardinal feature of the condition. We searched Pubmed using following the search terms,: [("progressive supranuclear palsy" OR PSP OR "Steele-Richardson-Olszewski syndrome") AND falls], as well as performing an individual search of the MeSH terms "progressive supranuclear palsy AND accidental falls", up to March 2019. Papers were included if they reported the incidence of falling and were in English. All study designs were included (observational or interventional) as long as they included more than one participant.

Thirty papers were identified with a mean number of participants of 47.6 (range 8–350). Study designs ranged from prospective and retrospective cohorts to small-scale trials.

Only two studies documented an absolute number of falls using a falls diary (the established gold standard) [1], or mean number of falls per patient. A study by Zwergal et al. reported a total of 195 falls occurring in 16 patients [mean 11.8 (range 1–40)] over a 6-month period [2]. Another study reported by Clerici et al. demonstrated a mean of 7 and 8 falls over a 1-month period from 12 patients at baseline prior to allocation to two rehabilitation programmes [3]. A further paper (Srulijes et al.) reported a quantitative falls rate of 46.2 per year for a whole cohort in a comparative study of PSP patients ($n = 12$) compared to other neurodegenerative diseases [4]. A selection of other studies quantified falls

prospectively but did not report quantitative data for falls values at publication. The majority of studies used either medical record review or a semi-quantitative ordinal scale as found in the PSPRS (Progressive Supranuclear Palsy Rating Scale) or UPDRS (Unified Parkinson's Disease Rating Scale) [5, 6]. Patients were usually divided into arbitrary groups such as "frequent" or "infrequent" fallers, with inconsistent cutoffs. Where medical records were reviewed, a binary variable (presence or absence of falls) was usually recorded.

It is surprising that few studies have sought to provide prospective data on fall frequency given that falls are a major feature in PSP. The PSPRS captures falls as an ordinal variable (0 = none in the past year, $1 \leq 1$ per month, 2 = 1–4 per month, 3 = 5–30 per month, 4 > 30 per month or chairbound). This can be used for comparing group differences but does not provide an absolute difference in falls rate and has an unbounded top category. Additionally, the score is retrospective relying on patient/carer recall with a greater degree of measurement error and potential recall bias. However, where retrospective studies are performed and falls data collected, we appreciate that collecting absolute data retrospectively may also be obscured by recall bias making a truly accurate picture hard to obtain. We advocate that future PSP studies should collect falls data using the current gold standard ProFANE (Prevention of Falls Network Europe) methods [1], and that a prospective approach is best. This will provide more useful and reliable data on falls in this high-risk population and enable better-designed intervention studies to be undertaken to tackle this debilitating problem.

Compliance with ethical standards

Conflicts of interest On behalf of all authors, the corresponding author states that there is no conflict of interest.

Ethical standards All studies in this review have been approved by the appropriate ethics committee and have therefore been performed in

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accordance with the ethical standards laid down in the 1964 Declaration of Helsinki and its later amendments.

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