Starting in the 1980s there has been an increasing apprehension that traditional clinical end-points such as morbidity and mortality alone do not sufficiently reflect the complexity of outcomes of medical interventions (1). Additional concepts, called patient-reported outcomes (PRO), have been introduced to allow insight into patients' experiences in different areas of function. A large variety of areas, which may be differently affected, have been identified such as mobility, life satisfaction, sexuality, cognition, mood and the ability to fulfil occupational, social, and family roles in daily life. Among PROs, the concept of Quality of life (QoL) has emerged as a broad term to describe those domains of evaluation. This approach is a paradigm shift since it changes the focus of attention from physicians’ (objective) evaluation of symptoms to functioning and establishes the patients’ (subjective) perspective. A large number of QoL life scales and health status measurements are available, generic scales but also disease-specific scales, which can be used over a range of diseases or can individually evaluate the major domains affected by a certain disease, respectively. The Movement Disorder Society has recently evaluated the available health status measurements and scales for patients with Parkinson’s disease (2, 3).

For patients with progressive supranuclear palsy only a few studies have been performed to evaluate health-related quality of life (4-9). Nevertheless, Schrag and coworkers have developed a disease-specific scale for its use in patients with PSP. Unfortunately, not many clinical trials have included this scale, yet(10).

The following scales have been used in patients with PSP to evaluate health status of those patients: the EQ-5D including the EQ-VAS, the QOLAS (a generic, patient-driven approach to QoL assessment), the Medical Outcomes Study Short Form Health Survey (SF-36), the disease-specific QoL instrument for patients with Parkinson’s disease (PD; PDQ-39), the Parkinson’s Disease Questionnaire (PDQ)-8. Independently of the scales used, all studies showed a decreased quality of life in patients with PSP. Quality of life was also more affected compared to idiopathic Parkinson’s disease and age-adjusted normal population, but similar to other atypical Parkinsonian syndromes. The most impaired domains were mobility, activities of daily living and anxiety; determinants of HrQoL were disease severity, depression, dementia.

No data of large longitudinal studies on health-related quality of life in patients with PSP are currently available. Thus, our understanding of domains affected from a patients’ perspective
is limited. In addition, further aspects of quality of life beyond the disease-related domains such as social functioning, religion, etc. have not been evaluated in this group of patients.

References: