

HYPOPARATHYROIDISM AS A CONSEQUENCE OF CANCER-RELATED SURGERY OF THE THYROID, PARATHYROID, OR NECK: UNDERSTANDING THE BURDEN OF ILLNESS (PARADOX STUDY)

Clarke, Bart¹; Sanders, James²; Lagast, Hjalmar³

¹Mayo Clinic Rochester, Endocrinology Metabolism Diabetes & Nutrition, Rochester, MN, USA; ²Hypoparathyroidism Association, Inc., Idaho Falls, ID, USA; ³NPS Pharmaceuticals, Inc., Bedminster, NJ, USA

Background/Purpose: Hypoparathyroidism is a rare, complex endocrine disorder of absent or low levels of parathyroid hormone, and subsequently hypocalcemia, often as a consequence of thyroid, parathyroid, or neck cancer-related treatment. The PARADOX study assessed the clinical and personal disease impact.

Methods: Patients aged ≥ 18 years and diagnosed with hypoparathyroidism ≥ 6 months ago completed an institutional review board–approved, self-reported questionnaire.

Results: The study population (N=374) included mostly women, 85%; mean age, 49 years; surgery of the thyroid, parathyroid, or neck for cancer, 43%; mean disease duration, 13 years; moderate-severe disease condition, 79%. Patients reported visiting an average of 6 different specialists or physicians before and after diagnosis. More than 10 symptoms were experienced by 72% of patients in the preceding 12 months, despite standard symptomatic management (eg, calcium and active vitamin D). Symptoms were experienced for an average 13 hours/day. Comorbidities were experienced by 69% of patients. Disease-associated hospital stays or emergency department visits were required by 79% of patients. Most patients strongly agreed with feeling unprepared to manage the condition at diagnosis (56%), that controlling their hypoparathyroidism was harder than expected (60%), and were concerned about long-term complications of their current medications (75%). Forty-five percent reported significant interference from hypoparathyroidism in their lives. The experience of patients with thyroid, parathyroid, or neck cancer-related disease etiology will be presented.

Discussion & Conclusion: Patients with hypoparathyroidism have a substantial multidimensional burden of illness, experiencing comorbidities, acute episodes of hypocalcemia, and a nearly continuous presence of symptoms despite standard symptomatic management.