O-2

Development and Validation of the Disease-Specific QOL-CD Quality of Life Questionnaire for Patients with Cushing's Disease

M. Cusimano[1], T. Huang[1], A. Marchie[1], H. Smyth[1], K. Kovacs[2]; [1]Division of Neurosurgery, St. Michael's Hospital, Toronto, ON/Canada, [2]Division of Pathology, St. Michael's Hospital, Toronto, ON/Canada

BACKGROUND: Cushing's disease (CD) patients experience a range of debilitating symptoms that significantly impair quality of life (QOL) as assessed using generic measures. These generic measures are inadequate to capture disease-specific nuances, emphasizing the need for a CD-specific questionnaire.

METHODS: 96 CD patients (86 females and 10 males; mean age 45.2 ± 14.2 years) participated. 177 items were generated by 9 CD patients, 2 caregivers, 7 healthcare providers, and a MEDLINE search. This list was reduced to the final 56-item version of the QOL-CD through content analysis, dual scaling, and patients' rating. Evidence for test-retest reliability was sought through administering the QOL-CD 1 week apart and Cronbach's α of each subscale. Construct validity was assessed through extreme group analysis and comparison with the normal Canadian population. Concurrent validity was evaluated through comparison with the SF-36, Functional Assessment of Cancer Therapy–Brain, and Karnofsky Performance Status.

RESULTS: The QOL-CD was feasible (mean completion time 15 minutes, with 70% believing accurate capture of QOL), reliable (CD 1 week apart: r = 0.86; control 1 week apart: r = 0.83; Cronbach's α: general health = 0.73, emotional health = 0.85, physical health = 0.78, mental status = 0.82, social well-being = 0.63, medical treatment = 0.54), and valid (extreme group testing $p < 0.001$; SF-36 and QOL-CD general health: r = 0.56, social well-being: r = 0.21, emotional health: r = 0.61, total score: r = 0.58; FACT-Br and QOL-CD physical health: r = 0.47, social well-being: r = 0.21, emotional health: r = 0.34, total score: r = 0.68; KPS and QOL-CD general health: r = 0.32, total score: r = 0.14).

CONCLUSION: The QOL-CD questionnaire has been developed for CD patients and has demonstrated evidence for validity and reliability.

ABSTRACT ID: 108