**ABSTRACT**

To fulfill the need for a disease-specific tool to measure quality of life in patients with neuroendocrine tumors, the Norfolk QOL-NET was developed in 2004 at the Neuroendocrine Unit at Eastern Virginia Medical School. We aimed to capture the spectrum of symptoms and the impact of physical and psychological functioning related to NETs by eliciting patients’ own perceptions of their illness. The questionnaire was developed using a rigorous design method that included an item pool from patient input and a panel of health-care professionals using the Delphi method to reach consensus on the questions for content validity. After approval by four national thought leaders who ensured that the items embraced all aspects of the disease, the QOL-NET was presented to a focus group of 20 patients and pilot tested for readability and content. All suggestions were discussed until the group reached meaningful and acceptable changes. We then explored the questionnaire’s structure through interpretation of psychometric factor analysis, determined its discriminatory capability, analyzed its reliability and reproducibility, and correlated the scores of the QOL-NET with tumor burden, biochemical markers, and symptom score.

**OBJECTIVES**

- Examine the relationship of quality of life measures in neuroendocrine tumor patients using the Norfolk QOL-NET by correlating the total questionnaire score with each of the Norfolk QOL-NET domains, with tumor burden, biochemical status, and the Norfolk Carcinoid Symptom Score.
- The purpose of this study was to examine the relationship of QOL measures in NET patients using Norfolk QOL-NET and its 7 domains with tumor burden, biochemistry and the Norfolk Carcinoid Symptom Score.

**METHODS**

Norfolk QOL-NET developed at the Neuroendocrine Unit at EVMS in 2004: 72 Questions

**SUBJECTS**

- Patients (n): 29
  - Men: 17 (58.62%)
  - Women: 12 (41.38%)
- Age Mean ± SD: 59 ± 11 years
- Race: 89% White, 11% other

**CONCLUSIONS**

We observed a strong correlation between the total Norfolk QOL-NET score and each of its 7 domains with symptoms, tumor burden, and biochemical markers.

The strongest correlation between the total Norfolk QOL-NET score and its domains, was with Physical Functioning.

All the domains of the Norfolk QOL-NET - except for Depression - correlate positively with the Carcinoid Symptom Score.

Tumor burden correlates with the Physical Functioning, Gastrointestinal and depression domains.

Serotonin was the only biochemical marker that correlated positively with a poor quality of life in patients with neuroendocrine tumors.

Norfolk QOL-NET is sensitive to symptom change, physical functioning, respiratory and gastrointestinal progression or remission.

The relationship between high levels of circulating Serotonin in patients with neuroendocrine tumors and poor quality of life – particularly depression – led to the premise that SSIEP, the precursor of serotonin is deviated into tumor production of serotonin, which does not cross the blood brain barrier leading to a deficiency in brain serotonin.

Norfolk QOL-NET is sensitive to symptom change, physical functioning, respiratory and gastrointestinal progression or remission.

Norfolk QOL-NET may be a useful guide for changes in therapy to alter apparent health status as well as an end point in clinical studies.

**BIOCHEMICAL MARKERS AND TUMOR BURDEN**

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