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Psychometric validation of new measures of hypothyroid-dependent quality of life (QoL) and symptoms

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Objective: To evaluate the psychometric properties of two new condition-specific questionnaires: (1) the 18-item ThyDQoL, an individualised patient-centred measure of perceived impact of hypothyroidism on QoL, and (2) the 15-item ThySC symptom checklist in which patients provide “bother” ratings for common hypothyroid symptoms.

Method: A cross-sectional survey was conducted with 110 adults with clinical or subclinical hypothyroidism [mean age: 55.1 plus/minus 14.3 (s.d.), range 23–84 years], 103 treated with thyroxine. Respondents rated personally applicable ThyDQoL life domains for importance and impact of their hypothyroidism, and rated ThySC symptoms for bother. Ethical committee approval was obtained.

Results: High completion rates (>98%) indicated the measures’ acceptability to respondents. All 18 ThyDQoL domains were, on average, rated negatively impacted by hypothyroidism and important for QoL. Psychometric analyses indicated that applicable ThyDQoL domains could be summed into an overall Average Weighted Impact score (AWI), for which the sample mean (-3.1 plus/minus 2.2) indicated considerable negative impact of hypothyroidism on QoL (maximum possible range -9 to +3). The most frequently reported ThySC symptoms were tiredness (90% of sample), depression (73%), skin problems (60%), and weight gain (59%). Highest bother ratings were: hair problems (2.3 plus/minus 0.9), weight gain (2.2 plus/minus 0.9), and depression (2.1 plus/minus 0.8), (maximum possible range: 0 to 3, from “not at all” to “very much bothered”). Correlations between ThySC bother ratings and equivalent or near equivalent ThyDQoL domains (energy, weight, bodily discomfort and depression) ranged from -0.4 to -0.43, ($p < 0.05$). The strongest correlation between any individual symptom bother rating and ThyDQoL AWI was for tiredness, -0.61, $p < 0.001$.

Conclusion: Although measures of hypothyroid symptoms are often and erroneously described as QoL measures, symptoms and QoL are distinct and separate patient-reported outcomes. The new ThyDQoL and ThySC questionnaires will be valuable in routine clinical monitoring and clinical trials of treatments for hypothyroidism.