

## Quality of life, activities of daily living, symptoms and satisfaction with treatment and care in treated hypothyroid patients vs controls: Preliminary results of a large Dutch study

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**Background:** Hypothyroidism is a common endocrine disorder and the standard treatment is substitution therapy with levo-thyroxine, l-T<sub>4</sub>. Although many patients improve upon treatment with l-T<sub>4</sub>, a proportion appears to experience residual hypothyroid complaints despite treatment, even when plasma TSH and FT<sub>4</sub> are within reference ranges.

**Methods:** Using an on-line survey we investigated 1. the quality of life (ThyPRO), 2. the activities of daily living (SF-36), 3. the symptoms, 4. the satisfaction with treatment and 5. care (ThyTSQ) in diagnosed hypothyroid patients over 18 years using >6 months treatment. Patients were recruited by emails of patient organizations, posters in pharmacies and health centers and twitter/facebook. Control persons (without thyroid disease, >18 yrs) were recruited randomly. All respondents (partially) completed the survey on their own initiative.

**Results:** Preliminary results of analyzing this cohort (1030 patients and 214 controls) in the period Apr2015-May2015, have revealed the following:

1. A significant decrease in quality of life in these hypothyroid patients compared to controls.
2. Respondents appeared to have more difficulties with activities of daily living and 77% of these patients indicated not feeling well when TSH and FT<sub>4</sub> values are within normal range.
3. Patients reported significantly more symptoms related to hypothyroidism than control persons.
4. Patients were only moderately satisfied with generic l-T<sub>4</sub> and with Thyrax.
5. Patients were moderately to fairly satisfied about the health care provided. Less satisfaction was found around diagnosis, on information about thyroid disease/treatment, and on how seriously they were taken by the doctor.

**Conclusions:** A preliminary conclusion is that persisting complaints in treated hypothyroid patients despite 'normal' blood values are present among these

respondents. Reasons are unclear as yet, and might include insufficient biochemical monitoring, intrinsic shortcomings of l-T4 therapy, or having a chronic/auto-immune condition.

In caring for hypothyroid patients more attention should be paid to providing information about hypothyroidism and treatment. Furthermore, we should address the fact that many patients don't feel taken seriously.