

PE1463/FFFF

Letter from Professor Rudolf Hoermann of 20 September 2016

Subject: Comments on submission of document PE1463DDDD, Scottish Government Letter of UK.

I am in receipt of a copy of the above communication and wish to briefly reply to its comments. While many of the responses would deserve a detailed analysis and broader discussion based on their merits, to save time and focus concentration it may suffice to address the main question that encompasses many of the other aspects.

I am writing in my capacity as both an endocrinologist with more than 30 years of clinical experience in treating thyroid patients and a scientist/researcher who analysed more than 10,000 patient records and authored a multitude of peer-reviewed articles in the field. My view is personal and independent, although I am a member of the German, European and American Thyroid Association, and Thyroid UK has asked my opinion on this.

The following statement cited literally from the response letter lies in the heart of the current discussion "The BTA, the Association of Clinical Biochemistry (ACB), British Thyroid Foundation (BTF), The Royal College of Physicians (RCP) and the Society for Endocrinology (SFE) agreed the following statements in relation to treating people who do not respond well to L-T4:

- Synthetic L-T4 remains the treatment of choice in hypothyroidism with the aim of therapy being to restore physical and psychological well-being while maintaining normal laboratory reference range serum TSH levels (1/++0). "

We may ask a simple question. Does this aim as defined above achieve the desired outcome for the majority of patients with hypothyroidism when treated with the currently recommended evidence-based mode of therapy?

Study after study has shown that this is objectively not the case, with the latest addition to this collection being added in 2016 (1). The conclusion of this well conducted large Danish study reads "Many aspects of HRQL improved during the first six months of LT4 therapy, but full recovery was not obtained. Our results may help clinicians inform patients about expected clinical treatment effects."(1)

That means, in the year 2016, any and every patient suffering from hypothyroidism - let alone less frequent cases with more specific needs - can expect that their symptoms may improve with the recommended treatment modality, but patients should also be told the full truth that they cannot expect with the standard treatment offered to restore their quality of life to a level that is found in a healthy population.

As such, the findings of the survey conducted by Thyroid UK are generally in close accord with more rigorous scientific studies, supplementing the latter with a patient perspective.

These findings are not surprising, nor are they scientifically unexplained (2,3). Yet what is surprising is that all this evidence is missing from the statements of prominent opinion-formers, as you are well aware of. This begs the questions as to whether the evidence based-guidelines are strongly evidence-based. As valuable as guidelines are, when critically examined, most studies have concluded that the evidence some recommendations are based on turns out to be frequently weak when suitable quality standards are applied to the guidelines themselves. This statement by McAlister et al. (4) is typical for many others “As a result, less than one-third of recommendations that advocated specific cardiovascular risk management therapies in these evidence-based guidelines were actually based on high-quality evidence.”(4)

Given the known limitations of evidence-based guidelines aiming at averaged consensus recommendations, should patients and doctors be allowed to choose alternative ways in the treatment of hypothyroidism on an individual basis, if they wish to do so to potentially improve their quality of life where the standard LT4 treatment fails to deliver on this promise, and when the alternatives such as T3 addition have been largely proven to be safe (5).

The final question relates to the role of government institutions. Is their role to be content with assertions that have been repeatedly discredited or should citizens expect them to independently define and supervise a set of rules that assure high quality standards for patient care.

While I would not anticipate that the remaining problems will be readily solvable, I would expect less lecturing from an outdated knowledge base and more awareness for the undeniable existence and magnitude of the issues. At the very least, patients and doctors alike should not be unnecessarily and unreasonably restricted in their treatment options.

Rudolf Hoermann, MD PhD

References

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