



## Medullary Thyroid Carcinoma: Why are One in Four Patients Treated Out of Concordance from the ATA Guidelines?

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The 2009 ATA guidelines for medullary thyroid carcinoma (MTC) represent a landmark document in the management of a rare disease.<sup>1</sup> Despite it being one of the rarest forms of thyroid cancer, the clinical implications of a diagnosis of MTC and its associated morbidity and mortality make its treatment essential to address in this thorough manner.

The authors of the 2009 ATA guidelines specifically state that its goals were to assist in the clinical care of patients and share “current, rational, and optimal medical practice” without an intent to replace individual decision making or clinical judgement, and its intent is similar to other often-referenced guidelines, such as those provided by the National Comprehensive Cancer Network. In this current manuscript, McMullin et al.<sup>2</sup> demonstrated that care concordant to the ATA guidelines is associated with improved overall survival, a reassuring and not surprising observation given the evidence-based nature of the recommendations. Also encouraging were the authors’ findings that since publication of MTC management recommendations by the ATA, the percentage of discordant treatment has decreased from 33 to 26%; however, this discordance may be associated with factors, such as older age, being female, and being treated at a nonacademic center.<sup>3</sup> This article sets up all the necessary supporting data to ask the bigger question of “Why don’t physicians follow guidelines?” We challenge the authors to tackle this query next. This is not a question unique to physicians who

treat MTC; an abundance of articles in the literature describe failure of clinicians to follow guidelines.<sup>4</sup> We do not understand what healthcare providers consider meaningful evidence or how they use such guidelines in their practice, including barriers to doing so. These topics are particularly important to study in rare diseases where treatment information is sparse and familiarity with the disease often is less given its infrequent encounter.

With regards to nonconcordance of treatment specifically in the MTC population, it must be remembered that despite being one diagnosis, this malignancy presents with a wide spectrum of clinical variability due to its biologic nature, innumerable mutations, and association with familial syndromes, which play an important role on the treatment and surveillance of this particular neoplasia. For example, the guidelines state that not all patients with the diagnosis of medullary thyroid carcinoma require treatment with a total thyroidectomy, especially if the diagnosis is made after the initial surgery. A lobectomy can be an acceptable treatment for unifocal disease in patients who do not harbor any causative germline mutations. Such clinical granularity is sometimes missed in data retrieval in large database studies, possibly overestimating the number of discordant treatments. Another example of data that are unable to be extracted is the extent of lymphadenectomy performed, which is important not only because lymph nodes can be resected with thyroid without a formal lymphadenectomy but also one of the most complex decisions to be made in the treatment of medullary thyroid cancer is the extent of lymphadenectomy (if any). Geographic location also has been identified as a factor by McMullin et al. Higher rate of discordance was identified in patients living less than 50 miles from the centers. Interestingly, academic facilities were identified to have higher adherence rates. This discrepancy could be secondary to the

patient investment, because it would seem plausible that patients travelling further are potentially more invested in receiving expertise treatment.

The authors also suggest that similar to transitioning care to specialized, designated, cancer centers for treatment of complex abdominal cancers, consideration of doing the same with MTC may improve adherence to guideline recommendations. This raises another very important question: who should be treating MTC and in which setting? A strong multidisciplinary group, familiar with this complex neoplasia is needed for patients who carry this diagnosis. Literature has shown that high volume is associated with improving surgical outcomes, decreasing hospital stay, complications, and improving overall outcomes.<sup>5–8</sup> This concept has been well applied to endocrine surgery and may be one of the reasons why both McMullin and Chang found that treatment in community centers were less likely to be concordant with ATA guidelines. For this reason, we believe that once the diagnosis is made, patients with MTC should be seen by high-volume experts in the disease, often found in specialized centers where care can be discussed and performed in a multidisciplinary fashion. It is important to reiterate that guidelines are suggestions, and ultimately it comes to the multidisciplinary team to assess what is best for each individual patient, making 100% adherence almost an impossible task.

In conclusion, McMullin et al. highlight an important feature of implementation of society recommendations for specific diseases, such as MTC. The improvement in percentage of adequate procedures performed shows that guidelines have a positive impact on global care. However, due to its rarity and clinical complexity, patients diagnosed preoperatively with MTC as well as patients incidentally found to have MTC after a thyroid procedure should be seen in a specialized, high-volume center.

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