

## **SUN-432: Utilizing Patient Online Forums to Capture Experiences and Perceptions Associated with the Use of Desiccated Thyroid Extract**

Freddy Toloza. *University of Arkansas and Mayo Clinic*

Freddy J K Toloza Bonilla, MD<sup>1</sup>, Nataly R. Espinoza, MD<sup>2</sup>, Omar El Kawkgi, MD<sup>3</sup>, Elizabeth H. Golembiewski, MPH<sup>2</sup>, Oscar J. Ponce, MD<sup>2</sup>, Lixia Yao, PhD<sup>4</sup>, Spyridoula Maraka, MD, MS<sup>5</sup>, Naykky M. Singh Ospina, MD, MS<sup>6</sup>, Juan Pablo Brito, MD, MS<sup>2</sup>.

<sup>1</sup>University of Arkansas for Medical Sciences & Knowledge and Evaluation Research Unit, Mayo Clinic, Little Rock, AR, <sup>2</sup>Knowledge and Evaluation Research Unit, Division of Endocrinology, Diabetes, Metabolism and Nutrition, Mayo Clinic, Rochester, MN, <sup>3</sup>Division of Endocrinology, Diabetes, Metabolism and Nutrition, Mayo Clinic, Rochester, MN, <sup>4</sup>Division of Biomedical Statistics and Informatics, Department of Health Sciences Research, Mayo Clinic, Rochester, MN, <sup>5</sup>University of Arkansas for Medical Sciences - Central Arkansas Veterans Healthcare System & Knowledge and Evaluation Research Unit, Mayo Clinic, Little Rock, AR, <sup>6</sup>University of Florida & Knowledge and Evaluation Research Unit, Mayo Clinic, Gainesville, FL.

**Background:** It is estimated that 10-25% of patients with hypothyroidism use desiccated thyroid extract (DTE) as their primary thyroid hormone replacement medication, despite concerns about the risk of thyrotoxicosis associated with DTE use. It is unclear why many patients prefer the use of DTE as a thyroid hormone replacement formulation over guideline-concordant therapies such as levothyroxine (LT4).

**Methods:** We conducted a mixed-methods study by analyzing patient-reported information from patient online forums to better understand patient preferences for and attitudes toward the use of DTE to treat hypothyroidism. We searched the 10 most popular patient forums based on number of users (WebMD, Topix, Health questions, Patients like me, Drugs.com, Endocrine Web, Everyday Health, Talk Health Partnership, Spark People and Patients.info) using the key terms: desiccated thyroid extract, desiccated thyroid treatment, thyroid USP, commercial names of DTE (Armour Thyroid® or Natural Thyroid®), thyroid extract, AND hypothyroidism. Unique posts were retrieved from those websites between each forum's inception to March 2018. From these posts, we extracted descriptive information on patient demographics and clinical characteristics and qualitatively analyzed posts' content to further explore patient perceptions on DTE and other thyroid hormone replacement therapies.

**Results:** Unique 1,235 posts were initially retrieved from the included patient forums. After the initial screening, we selected data from three of these forums (WebMD, Patients Like Me, and Drugs.com) based on the completeness of the available information (673 posts). Nearly half (45%) of patients reported that a clinician initially drove their interest in trying DTE. Patients described many reasons for switching from a previous therapeutic approach to DTE, including lack of improvement in symptoms (58%) and the development of side effects (22%). Among a majority of patients, DTE was described as moderately-to-majorly effective overall (81%) and more effective than the previous therapy (77%). The most frequently described benefits associated with DTE use were an improvement in clinical symptoms (56%) as well as a change in overall well-being (34%). One-fifth of patients described side effects related to the use of DTE. Qualitative analysis of posts' content supported these findings and raised additional issues around the need for individualizing therapy approaches for hypothyroidism as well as difficulties obtaining DTE.

**Conclusions:** Among patients with hypothyroidism, a subset may prefer DTE over guideline-concordant therapies for many reasons, including perceived effectiveness, despite the risks associated with DTE. Future work should incorporate patient-reported outcomes to better elucidate the mechanisms responsible for therapy preferences in this subset of patients.