

Learning Objectives

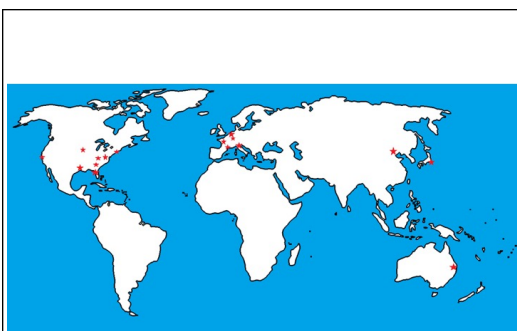
To inform the community as to the presence of the TSA database which should help further our knowledge

Introduction

Emerging evidence from clinical studies suggests that DBS is effective in treating the symptoms of refractory Tourette Syndrome (TS). The data, gleaned from multiple case reports and small case series, has been notable for significant variation in target selection, outcome measures, and length of follow-up. The International TS DBS Registry and Database is a central data repository for the worldwide experience.

Methods

The International TS Registry and Database currently consists of 31 participating institutions in Australia, Europe, China, Japan, Canada and the USA. To date, 16/31 sites have submitted data, reflecting 160 individual patients (Figure 1). Our own single-center experience in 13 patients, included in the registry, was compared to the entire worldwide experience.



Record Registration by Target

- 149/160 (93%) records have complete demographics
- Sorted by primary target implant:
 - 94 Thalamus (VO-CM/Pfc; CM/Pfc)
 - 23 Antero-medial GPi
 - 41 Postero-ventral GPi
 - 2 NA-ALIC



Figure 2. Target Selection

Results

The brain target structures utilized include 94 medial thalamus, 41 posteroventral GPi, 23 anteromedial GPi, and 2 nucleus accumbens region (Figure 2). Data collected includes demographics, clinical characteristics, surgical information, clinical outcome and adverse events (Figure 3). The mean age of disease onset is 7.8 years, and average at surgery was 29.6 years. 18% reported a history of self-injurious behavior. Mean Yale Global Tic Severity Scale was 74.1 at baseline, and 37.8 at 24-month follow-up. There were 80/160 records (50%) that contained information on specific adverse events. Device-related adverse events were noted in 15% of cases, the most common being device infection/erosion. The device explant rate was 17%, with the reasons for explant including device-related complications, lack of clinical response, as well as spontaneous improvement in tics (Figures 3-5). In our single-center experience of 13 patients with a median f/u of 23 months, mean patient age at surgery was noted to be 10 years younger (19.9 YO), with a slightly higher baseline YGTSS (85), but with a similar reduction at latest follow-up (51% reduction, 85->42) (Figures 6-7).

Data Summary

- Demographics
- Symptom onset
- Tic characteristics at baseline
- Surgical target
- Hardware used
- Programming parameters
- YGTSS scores
- YBOCS scores
- Auxiliary outcomes (HAM-D, BDI-II, CAARS, MADRS, GAF)
- Adverse events



Figure 3

General Patient Characteristics

	All Targets (n=160)	
	Mean	Range
Age at Onset	7.8	2-20
Age at Diagnosis	13.3	3-35
Age at DBS Surgery	29.6	13-58
	# of Patients	% of Cohort
History of OCD	94	54%
History of ADD	40	25%
History of Depression	67	42%
History of Anxiety	53	33%
History of Self-Injurious Behavior	29	18%



Figure 6

YGTSS Total – Records Submitted

YGTSS Total Records Submitted	Combined Cohort n	Mean
Baseline	142	74.1
6 Month	99	45.3
12 Month	95	41.3
24 Month	56	37.8

These numbers represent the total # of records which have a submitted value at the times listed. This data cut not used for analysis.



Figure 3

Adverse Events

Explants
27 reported across 6 sites (17% explanted)

Due to:	Occurrence
Dermal erosions	4%
Infection	3%
Inflammation	2%
Poor response	2%
Discomfort	2%
Tics improved	<1%
Patient compliance issues	<1%
Cable rupture	<1%
Obstructive hydrocephalus	<1%



Figure 4

Conclusions

Given the small number of DBS surgeries performed for TS, and variation in the field, more information will be necessary to plan next steps in this area. Though there are gaps in the data, encouraging collaboration and more standardization of data sets will drive the field and likely improve outcomes. Any individual or institution can join the collaborative effort.

NYU Center for Neuromodulation, DBS for Tourette's Syndrome, 2009-2016

- Single DBS team (two institutions)
- 15 patients, 7-year period
 - Age at diagnosis: 6.7 YO
 - Age at surgery: 19.9 YO, range 16-33 Y.O.
- Cases reviewed by institutional DBS for TS committee:
 - 2 neurologists, 2 neurosurgeons, 2 psychiatrists (child psychiatrist when appropriate), neuropsychologist
- Surgeries performed off-label after obtaining insurance approval and extensively discussion and documentation regarding level of evidence, risks and alternatives.
- IRB obtained for retrospective chart review – case series presented in abstract form (AANS, MDS), submitted for publication
- Mean f/u: 23 months: (minimum 6 months, range 6-58 months)



Figure 6

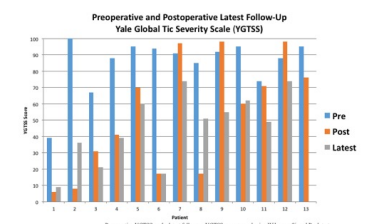


Figure 7