Educational Needs in the Management of Children and Adolescents With Tourette Syndrome: Results of a Survey of US Practicing Physicians

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INTRODUCTION

- Tourette syndrome (TS) is a childhood-onset neurodevelopmental disorder defined by motor and vocal tics lasting ≥1 year[1]
- Individuals with TS or a persistent tic disorder may experience impairment in multiple dimensions of functioning, including quality of life, academic attainment, and social and family dynamics,[2-5] as well as an increased risk of suicidality versus those without tics[6]
- Gaps in understanding of the management of TS by pediatric physicians remain, including how their attitudes, knowledge, and beliefs impact clinical decisions

AIM

- To identify educational needs and assess current US practice patterns, perspectives, and barriers to optimal management of individuals with TS

METHODS

- Online survey study (yes/no, free-text, and categorical response options [eg, Likert scale]) incorporating a clinical case vignette and questions developed in collaboration with a board-certified psychiatrist experienced in treating TS
  - Case consisted of a 16-year-old boy with TS who began aripiprazole 10 mg/day for treatment of tics 6 weeks ago after behavior therapy was ineffective and currently was reporting sadness, decreased interest in activities, insomnia, low energy, and impaired concentration
- Survey targeted US pediatric neurologists, pediatric psychiatrists, and pediatricians who previously engaged with a continuing medical education research firm
  - Eligibility criteria included weekly pediatric clinical services and caring for ≥1 individual with TS per month
- Data were collected between June and July 2025 and analyzed using descriptive statistics

RESULTS

- A total of 200 physicians (pediatric neurologists [n=41], pediatric psychiatrists [n=38], pediatricians [n=121]) completed the survey
- The median monthly caseload of individuals with TS receiving care was 14, 10, and 2 for pediatric neurologists, pediatric psychiatrists, and pediatricians, respectively (**Table**)

Table. Respondent Characteristics

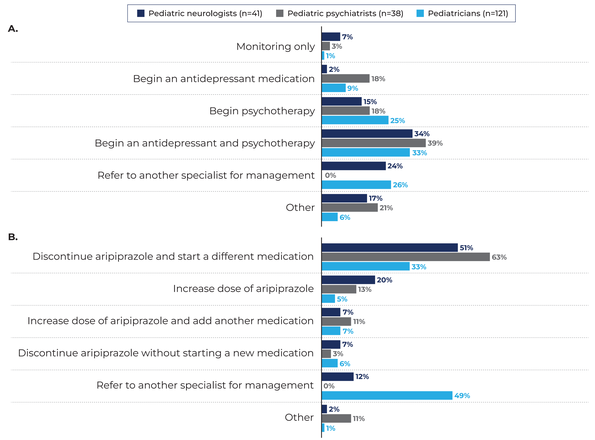
Parameter	Pediatric neurologists (n=41)	Pediatric psychiatrists (n=38)	Pediatricians (n=121)
Number of patients seen per week, median	50	40	80
Monthly caseload of individuals with TS receiving care, median	14	10	2
Years since graduation from medical school, median	23	20	27
Practice location, %			
Urban	61	61	35
Suburban	37	31	51
Rural	2	8	14
Practice type, %			
Academic	80	61	23
Group single specialty	5	8	49
Group multispecialty	10	11	16
Nongovernment community hospital	0	0	5
Solo practice	5	18	6
Other	0	2	1

TS = Tourette syndrome.

RESULTS

- When presented with a case of an adolescent with TS who began taking aripiprazole 10 mg/day 6 weeks ago for tics and meeting diagnostic criteria for major depressive disorder, 35% of physicians indicated they would initiate both an antidepressant and psychotherapy for mood symptoms; however, no overall consensus emerged (**Figure 1A**)
  - There was agreement across specialties that this individual would have a higher risk of suicide compared with an individual without TS
  - When asked what changes they would make to the individual's medication for tics, 43% of physicians overall would discontinue aripiprazole and start a different medication (**Figure 1B**)
    - However, only one-third of pediatricians would pursue this course of management, and almost half (49%) would refer to a specialist
- When asked how they would manage this individual who now reported good tic reduction after an increase in aripiprazole to 20 mg/day but with adverse effects of vague discomfort that improved with movement and difficulty sitting (ie, akathisia), 46% of pediatric neurologists and 42% of pediatric psychiatrists would reduce the dose of aripiprazole; 37% of pediatric psychiatrists would continue on aripiprazole and add propranolol
  - In contrast, 14% of pediatricians would reduce the dose of aripiprazole, while 51% would refer to a specialist

Figure 1. Management of (A) Mood Symptoms and (B) Medication for Tics in Adolescent With TS and Co-occurring Mood Disorder*



TS = Tourette syndrome.

*16-year-old boy with TS who received aripiprazole 10 mg/day for 6 weeks for tics with no improvement and currently reports sadness, decreased interest in activities, insomnia, low energy, and impaired concentration.

DISCLOSURES:
GWM has received consultant fees or honoraria from AbbVie, Inc., Acadia Pharmaceuticals, Alkermes, Avanir Pharmaceuticals, Inc., Axsome Therapeutics, Boehringer Ingelheim, Eisai, Emalex Biosciences, Inc., Intra-Cellular Therapies, Ironshore Pharmaceuticals, Inc., Janssen Pharmaceuticals, Lundbeck, Medgenics, Inc., Neos Therapeutics, Inc., Neurocrine Biosciences, NLS Pharmaceutics, Otsuka Pharmaceuticals, Redx Pharma, Rhodes Pharmaceuticals, Roche Pharmaceuticals, Sage Therapeutics, Shire, Sunovion Pharmaceuticals, Inc., Supernus Pharmaceuticals, Takeda Pharmaceuticals, Teva Pharmaceuticals, and Tris Pharma.

GDS and BC are employees of CE Outcomes.

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JS, JAF, and GBK are employees of and have personal equity interest in Emalex Biosciences, Inc.

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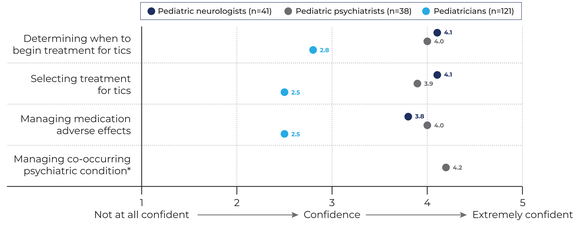
- Pediatric neurologists and pediatric psychiatrists reported high confidence in managing TS, including treatment initiation, tic management strategies, and handling medication adverse effects, whereas pediatricians reported slightly to moderately lower confidence (**Figure 2**)
  - As expected, pediatric psychiatrists reported very to extremely high confidence in managing co-occurring psychiatric conditions in individuals with TS

Figure 2. Physician Confidence in Managing TS and Co-occurring Psychiatric Conditions



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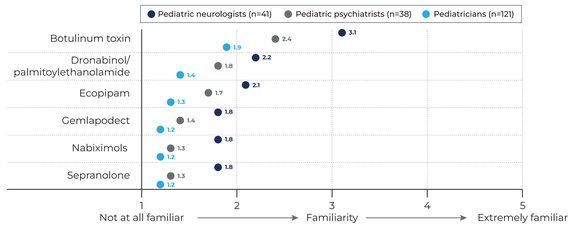
*Survey option posed to pediatric psychiatrists only.

- Choice of TS management guidelines varied by specialty: 80% of pediatric neurologists preferred American Academy of Neurology (AAN) guidelines, whereas 89% of pediatric psychiatrists preferred American Academy of Child and Adolescent Psychiatry (AACAP) guidelines
  - Among pediatricians, guidelines were primarily split between AAN (42%) and AACAP (50%)
  - Physicians rated the helpfulness of guidelines in managing patients with TS as moderate (mean, 3.2; range, 3.1-3.3 on a scale from 1 ["not helpful at all"] to 5 ["extremely helpful"])
- Physicians were generally not at all or only slightly familiar with new or emerging therapies for TS, with pediatric neurologists reporting comparatively greater familiarity (**Figure 3**)

Figure 3. Physician Familiarity With New or Emerging Therapies for TS



TS = Tourette syndrome.

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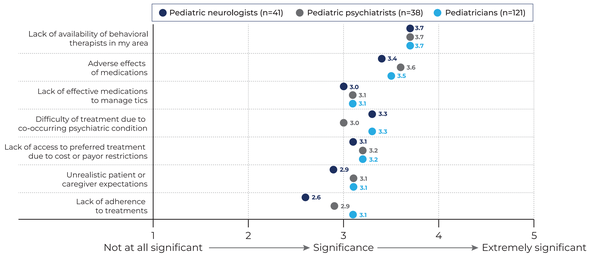
- Pediatric neurologists, pediatric psychiatrists, and pediatricians reported similar levels of concern regarding key barriers to optimal TS management, including limited access to behavioral therapists and medication adverse effects (**Figure 4**)

Figure 4. Barriers to Optimal Management of TS



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- Most (71%) physicians cited inadequate training among providers treating adults as a key challenge in transitioning individuals with TS from pediatric to adult care
  - Beyond limited training and experience with TS, many providers may also be unfamiliar with managing the complex co-occurring psychiatric conditions often associated with TS, leaving them uncertain or uncomfortable developing and overseeing a comprehensive treatment plan for an individual with TS
  - Some regions face shortages of trained providers, resulting in limited appointment availability, and as a result, patients who require follow-up care may be redirected to their family physician

CONCLUSIONS

- Management of TS with co-occurring mood disorder varied across pediatric physician groups, although almost all recommended initiating some form of therapy
- Pediatric neurologists and pediatric psychiatrists reported greater confidence than pediatricians in determining when to initiate tic treatment, selecting therapies for tics, managing medication adverse effects, and addressing co-occurring psychiatric conditions
- Across specialties, familiarity with new or emerging medications for TS was relatively low
- A shortage of qualified adult providers was identified as a key challenge in transitioning individuals with TS from pediatric to adult care
- Education regarding the treatment of co-occurring psychiatric conditions, current expert recommendations and guidelines, management of medication adverse effects, new TS therapies, and transitioning to adult care may improve outcomes in individuals with TS

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