

Exploring Clinical Pathways for Tics and Tourette Syndrome: Perspectives from Healthcare Professionals and Patients

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“Focus on quality of life, not reducing frequency of tics”.
Advice from patient

Challenges

- Long waiting times, unclear clinical pathways, frustration at being passed between different healthcare professionals

Aim

- 1) Identify which healthcare professionals are involved in the treatment and management of patients with tics and Tourette Syndrome (TS), as well as the treatment options they offer across different countries
- 2) Examine initial referral, offered treatment and satisfaction with treatment for patients

Methods

- Two surveys: One for *professionals* and one for *patients*
- SurveyXact and shared with the help of European Society for the Study of Tourette Syndrome (ESSTS), Tics and Tourette Across the Globe (TTAG), Tourettes Action, and multiple patient associations across Europe

Results

Professionals

- 58 participants from 13 countries
- Most responses from physicians and psychologists
- Line of treatment → European clinical guidelines followed
- Treatment offered: Deep brain stimulation least (DBS) available (offered by 27%) followed by behavioral therapy (offered by 81%)

Patients

- 78 participants from 12 countries
- Initial referral: neurologist
- Most experienced treatment (medical treatment) → lowest satisfaction (40%)
- Behavioral therapy highest satisfaction (75%)

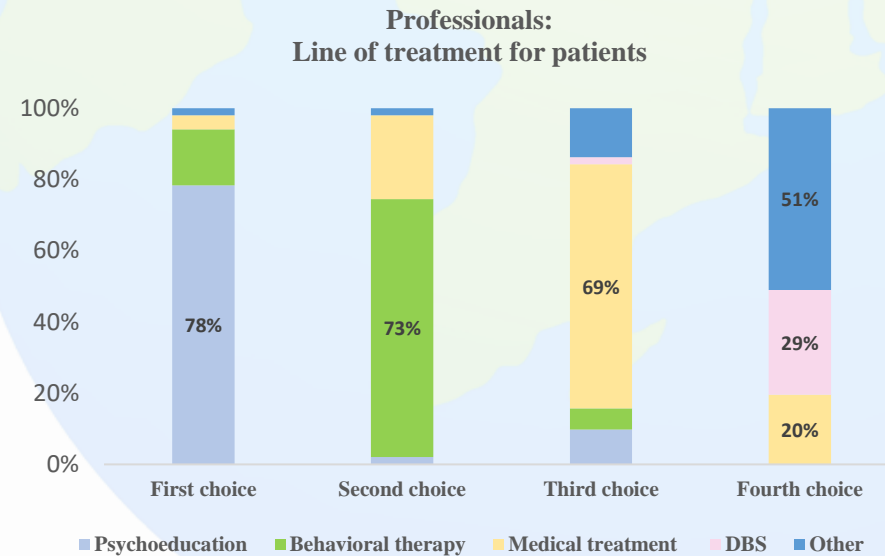


Figure 1: Line of treatment for patients with tics and TS

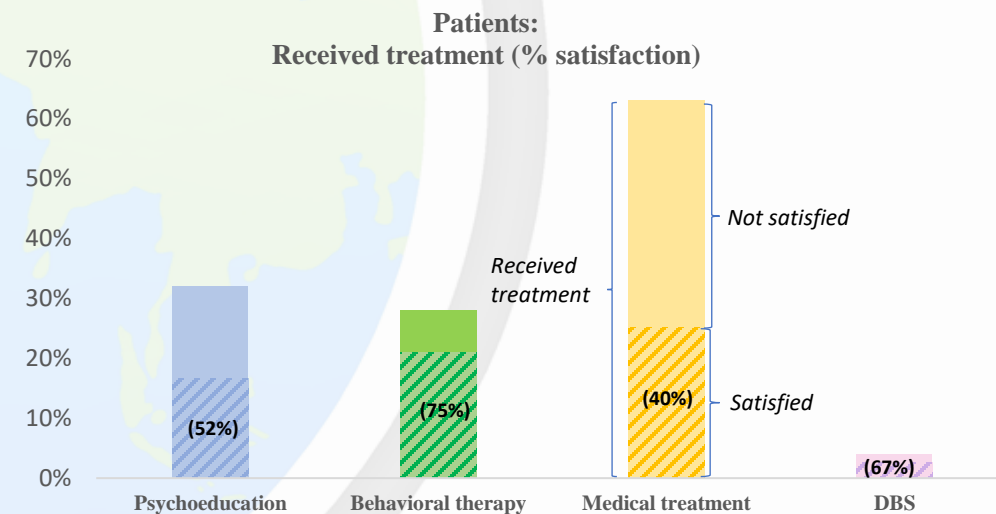


Figure 2: Received treatment and reported satisfaction

Conclusion

- Professionals follow the European clinical guidelines and offer the recommended treatment
- Treatment with the highest satisfaction (behavioral therapy) is not offered by 19% of the included participants
- Patients request more focus on quality of life, more follow-up appointments, and increased listening from their healthcare provider