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Original article:
Assessment and management of Tic Disorders and Tourette Syndrome by Australian Paediatricians

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Assessment and management of Tic Disorders and Tourette Syndrome by Australian Paediatricians

Abstract

Aim: The diagnosis and management of Tic Disorders and Tourette Syndrome (TS) can be challenging. A better understanding of current approaches by paediatricians is important to inform research and education, so as to improve patient outcomes. We aimed to investigate current assessment and management practices for tics/TS by Australian paediatricians.

Method: An online survey was sent to members of the Australian Paediatric Research Network. Primary outcomes of interest included assessment processes, referrals, behavioural interventions and pharmacological management. Four scenarios were presented to elicit information regarding treatment of different types of cases.

Results: One hundred and thirty nine (41%) of 340 eligible paediatricians responded, with 116 (84%) reporting that they diagnose and manage tics/TS as part of their practice. Questionnaires were used more to identify comorbidities (43%) than to quantify tics (12%). Referrals were most likely to be made to psychologists. Medication was considered important in the management of TS by 45% of respondents, with clonidine identified as the first choice medication by 69%. There was wide variation in both pharmacological and behavioural management strategies reported.

Conclusion: There is substantial practice variation among Australian paediatricians in the assessment and management of patients referred with tics/TS. This may reflect insufficient evidence regarding best practice, as well as limited training in this area. There is a need for improved education of Australian paediatricians in the assessment and management of tics/TS, as well as further research to identify optimal treatments.

Keywords: Behavioural, Paediatric Acute-onset Neuropsychiatric Syndrome, Psychotropic medication, Tics, Tourette syndrome

Briefpoints:

What is already known on this topic:

- Developmental disorders including Chronic tic disorders / Tourette syndrome (TS) make up a large proportion of the casemix of Australian general and community paediatricians
- These patients suffer high morbidity from their tics and comorbidities, and management is often challenging.
- Evidence gaps remain in the optimal management of TS in children and adolescents

What this paper adds:

- There is substantial paediatric practice variation in the assessment and management of patients with tics and TS.
- Australian paediatricians need more education in the management of tics and TS.

Introduction

Tourette Syndrome (TS) is a neurodevelopmental disorder characterised by chronic vocal and motor tics causing distress and functional impairment. Diagnostic and Statistical Manual of Mental Disorders (DSM-5) criteria require the presence of two or more motor tics and at least one vocal tic occurring many times a day, nearly every day, for longer than a year, with onset before 18 years of age.[1] If only vocal or motor tics are present, then the term chronic tic disorder is used. Prevalence estimates for TS in childhood vary from 0.1% to 1%, with a male:female ratio of approximately 4:1.[2, 3] Onset is most common in the early primary school years, and the tics tends to follow an unpredictable waxing and waning pattern over time.

The majority of patients with TS have at least one comorbid disorder, the most common being Attention-Deficit/Hyperactivity Disorder (ADHD) and/or obsessive-compulsive disorder (OCD).[4] Anxiety disorders, learning disorders, externalising disorders and autism spectrum disorder are also often seen in patients with TS.[4] Individuals with TS are at higher risk of peer victimisation,[5] social ostracism and depression.[6]

Developmental disorders, including tic disorders and TS, now represent a substantial proportion of the caseload of Australian general and community paediatricians. Although there are some good clinical guidelines and practice parameters for TS,[7, 8] anecdotally there is wide variation in paediatricians' practice in relation to the assessment and management of children referred with tic disorders/TS. Therefore, we designed a survey to investigate current Australian paediatric practice in the assessment and management of tics and TS. We hypothesised that there would be substantial variation in assessment practices and treatment choices.

Methods

Participants

The Australian Paediatric Research Network (APRN) is a nationwide network of paediatricians established to facilitate multisite, secondary care research in Australian

paediatric outpatient settings. The APRN comprises more than 40% of paediatricians registered with the Royal Australasian College of Physicians, with representation from all Australian states and territories. APRN members and non-members are broadly similar, with the exception of minor differences in age, sex and practice location. All active APRN members were invited to participate in the survey. Active members were defined as those who had participated in an APRN activity within the preceding 5 years.

Data collection

In October 2017, active APRN members were invited to participate via email. Members were asked to complete a brief online questionnaire as part of a larger multi-topic survey. Study data were collected and managed using REDCap secure, electronic data capture application[9] hosted at the Murdoch Children's Research Institute. Ethics approval was obtained from the Royal Children's Hospital Human Research Ethics Committee (#37180).

Survey

The survey content was generated based on literature review and author expert consensus. The domains of practice included assessment processes (including use of standardised measures, allied health assessments), referrals, non-pharmacological management, pharmacological management and approach to Paediatric Acute-onset Neuropsychiatric Syndrome (PANS). Additionally, four scenarios were presented to elicit typical management of patients with common tic/TS presentations: 1. TS and ADHD; 2. TS and OCD; 3. TS and generalised anxiety; and 4. possible PANS (without using these descriptors):

1. *An 8 year boy presents with a long-standing history of untreated moderate-severe ADHD (causing academic and social impairments), with a 2-3 year history of fluctuating but increasingly problematic vocal and motor tics which are causing increasing problems both at home and school. He has some defiant and aggressive behaviour*
2. *A 10 year old boy presents with a 9-12 month history of severe vocal and motor tics, on a background of language delay and poor social cognition. He also has many obsessive thoughts and compulsive behaviours.*

3. *A 12 year old girl presents with a 3-4 month history of worsening vocal and motor tics with severe generalised anxiety. She is doing well academically but she is being teased at school for her tics.*
4. *A previously well 12 year old boy presents with a 4-6 week history of severe vocal and motor tics. Their onset occurred within a week of a very sore throat, for which he had no treatment.*

For each scenario respondents were asked to indicate their first to third line medication choices, and how useful they would consider each of three listed non-medication strategies (parental and school education, psychological management and occupational therapy management).

Data analysis

We used descriptive statistics and frequency analyses to present the data. For the medication choices, percentages for each rank were derived using the total number of possible responses as the denominator. All analyses were conducted using Stata Version 15.

Results

Participant demographic characteristics are presented in Table 1. One hundred and thirty nine of 340 (40.9%) active APRN members responded to the survey. Twenty-three (16.6%) respondents reported that they did not see any patients with tics, and were excluded from the analysis. Compared to non-responders, responders were older but there were no differences in sex or practice location (metropolitan or regional/rural).

Assessment

In the assessment of a child with severe tics/possible TS, the use of tic-specific questionnaires was considered important or very important by 14 (12%) respondents, whereas comorbidity-related questionnaires were considered important or very important by 49 (43%; Table 2).

Referral to a psychologist for assessment of TS was considered important or very important by 23 (20%) respondents, and for assessment of comorbidities by 43 (37%) respondents. Referral to an occupational therapist (OT) was considered important or very important by 7 (6%) respondents. Twenty respondents (17%) considered referral to a neurologist important or very important. The use of a standardised measure of tic severity for diagnosis was reported by only 4 (4%) respondents, and for evaluating response to treatment by 2 (2%) respondents.

Management

Education of patient and parents was considered important or very important by 91%, and paediatrician-delivered management strategies by 80% (Table 2). In patients with severe tics/TS, improvement in comorbidities was rated as important or very important by 97% of respondents, reduction of tics by 84%, and elimination of tics by 20%. To assist with management 50% reported often or always referring to a psychologist, compared with 7% to an OT. Access to a psychologist or OT with "specific training and expertise in TS management" was reported by 27% and 8% of respondents respectively.

Overall, medication was rated as important or very important in the management of patients with severe tics/TS by 45% of respondents. The three most common reasons for paediatricians to consider prescribing medication to target tics were *tics are causing functional problems at school* (92%), *tics causing pain* (74%) or *the child is embarrassed about the tics* (69%).

The ranking of medications for treating tics is presented in Table 3. Clonidine was the most frequently-reported first line medication for treating tics (69%), followed by SSRIs (7%) and risperidone (5%). The most frequent second line choices were risperidone (28%), SSRI (21%) and haloperidol (12%). Stimulants were selected to reduce tics by 16% of respondents, including 3% as first choice.

Paediatric Acute-onset Neuropsychiatric Syndrome (PANS)

Over three-quarters (77%) of respondents indicated that when taking a history for a patient referred with tics they "inquire about temporally-related triggers, such as sore throat or other infections". Although 71% indicated that they would order investigations in a patient presenting with severe tics following a sore throat, including a throat swab (46% of those who would order investigations) and streptococcal serology (98% of those who would order investigations), only 20% reported feeling comfortable making a diagnosis of PANS.

Scenarios

Responses to the four scenarios indicated marked practice variation in relation to medication choice (Figure 1), and also to some extent in relation to the expected benefits from allied health professional input (Table 4).

Discussion

In this survey we found substantial variation in Australian paediatricians' practice in relation to the assessment and treatment of children with tics/TS. The findings are best interpreted in the context of published evidence and clinical practice guidelines.

Only a minority of respondents reported using standardised measures of tics for diagnosis or evaluation of treatment response. As with most developmental disorders, the most important component in the diagnosis of TS is history.[10] However, the use of tic-specific measures such as the clinician-rated Yale Global Tic Severity Scale (YGTSS)[11] can enrich initial assessment and also inform evaluation of response to treatment.[8] The YGTSS includes an important rating of impairment attributable to the tics.[7] Given that tic-related impairment was reported by respondents as a key indication for medication treatment, increased use of such standardised measures is strongly recommended. The barriers to its use are unclear however familiarity and time required to administer it may be contributing factors.

Less than half of respondents reported using standardised questionnaires to screen for comorbidities, and just over one third reported referring to a psychologist to assess for comorbidities. As comorbidities are usually present, screening for comorbid psychiatric

disorders is recommended as part of the assessment of TS.[7, 8] The use of standardised rating scales can provide detailed information to supplement the clinical history, and can increase the reliability of identifying comorbid problems. Children with TS and comorbid conditions (particularly ADHD) are at risk of academic underachievement, and psychoeducational testing[8] or neuropsychological testing (executive function, attention, memory, social cognition)[7] is recommended to inform an individual learning program. Occupational therapy sensory profile assessment may be indicated in some cases, and clinical psychology input can be helpful for assessment and also intervention for anxiety, obsessive compulsive behaviours, oppositional behaviour and family dynamic difficulties, which often develop in these patients over time.

Over 90% of respondents endorsed the value of psychoeducation regarding TS as an important element of management, consistent with recommended best practice.[8, 12] This includes providing information to the patient, family and teachers about tic types, tic management, the importance of comorbidities and the natural history. Families may also be directed to useful websites such as the Tourette Syndrome Association of Australia (http://www.tourette.org.au/).

The American Academy of Child and Adolescent Psychiatry (AACAP) recommends that behavioural interventions for TS be considered when tics cause impairment and are moderate in severity.[8] Unfortunately, this survey indicates that few Australian paediatricians have access to psychologists with specific training and expertise in TS management, which may impact on management decisions. Comprehensive Behavioral Intervention for Tics (CBIT) is an effective treatment for cognitively normal children with TS over 10 years of age.[13] CBIT involves habit reversal training (recognition of the premonitory urge and use of competing responses incompatible with the tic) and "exposure with response prevention" (increasing tolerance of the premonitory urge). Behavioural intervention can also be useful to address maladaptive coping strategies such as avoidance and withdrawal which sometimes exacerbate the impairments of TS.[8] It is hoped that specific training in the management of tics and Tourette Syndrome will become more widely available to clinical psychologists in Australia.

The reasons indicated by survey respondents for prescribing medication in TS were generally consistent with the AACAP recommendation that medications "should be considered for moderate to severe tics causing severe impairment in quality of life or when medication responsive psychiatric comorbidities are present that target both tic symptoms and comorbid conditions."[8] The medication choices for treating tics in this study partly reflected the available evidence. Clonidine was indicated as the first choice medication treatment by the majority of respondents. The alpha-2 adrenergic agents clonidine or guanfacine have been shown to be moderately effective in reducing tics, although the effect size appears to be less in patients without comorbid ADHD.[14] These medications are generally well-tolerated, although they can cause sedation, and are recommended as first-line treatment for treating tics of moderate severity. Antipsychotics (both first and second generation) have the strongest evidence in treating tics, with a moderate effect size,[14, 15] however they have a high risk of significant side effects including sedation, weight gain, metabolic disturbances, acute dystonias and chronic movement disorders.[16] They are therefore often recommended as second-line treatment. Among the antipsychotics, risperidone has been the subject of the most trials in treating TS and is usually the preferred agent in this class. A minority of respondents selected first line treatments which have no supportive evidence in the treatment of tics, including SSRIs and stimulants. This suggests that further education of paediatricians is needed, both in the pharmacological treatment of tics and the effects of these medications.

Responses to the scenarios 1-3 indicate that many paediatricians target comorbidities in preference to tics. This is consistent with best practice recommendations that when comorbidities cause more functional problems than tics they should be the priority treatment targets.[8] The scenarios also identified substantial practice variation in the management of common clinical presentations involving tics. In scenario 1 (comorbid ADHD) the selection of clonidine may have been to reduce both tics and ADHD symptoms. Both methylphenidate and clonidine have been shown to be effective in the treatment of ADHD in patients with tics.[17] SSRIs were the most frequently selected medication treatment in both scenarios 2 (comorbid OCD) and 3 (comorbid generalised anxiety disorder). These drugs have supportive evidence for treating both OCD[18] and generalised anxiety disorder[19] in children and

adolescents, although they may be less effective in treating OCD in patients with tics compared to those without tics.[20]

In scenario 4 (acute onset of florid vocal and motor tics soon after a sore throat), over half of respondents indicated they would prescribe antibiotics first-line, and almost one quarter would treat with intravenous immunoglobulin. The term paediatric acute neuropsychiatric syndrome (PANS), has been used to describe patients who present with an acute and sudden onset of tics, OCD and emotional lability, often following a group A streptococcal or other infection.[21] Although this entity is controversial, there are some patients who have a well-documented acute onset of OCD and/or tics, often associated with sudden behavioural change and other functional deterioration. There is some evidence that these patients may respond to antibiotics,[22] or, in severe cases, to immune therapy with steroids or intravenous immunoglobulin,[23, 24] although more research is needed to be definitive. Until there is clear evidence of benefit, standardised measures of assessment such as the Children's Yale-Brown Obsessive Compulsive Scale and YGTSS should be used to objectively evaluate response to treatment.

In summary, this survey found evidence of both practice variation and deviation from recommended best practice in the assessment and management of children referred with tics/TS by Australian paediatricians. The findings suggest that Australian paediatricians need more education and training in relation to the assessment and management of tics/TS. There are however a number of aspects of the management of this condition for which evidence to guide best practice is not conclusive. This is particularly notable in relation to the best medication to treat tics, and the role of antibiotics and immune therapies in the treatment of PANS. There is a need for more research into the optimal management of tics/TS, so as to improve outcomes and minimise treatment-associated harms for these patients.

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Table 1. Sample characteristics of responding and non-responding APRN members.

	Responders (n=139)		Non-responders (n=201)	
Characteristic	n	%	n	%
Male	60	43.2	104	51.7
Age in years				
<44	29	20.9	68	33.8
45–54	48	34.5	74	36.8
55–64	40	28.8	35	17.4
65+	22	15.8	19	9.5
Practice location				
Metropolitan	107	77.0	151	75.1
Regional/Rural	31	22.3	41	20.4
Practice setting †				
Private practice	66	47.5	58	28.7
Public Outpatients	107	77.0	109	54.2
Community Health Centre	9	6.5	20	10.0
Academic post	15	10.8	26	12.9
State / Territory				
Australian Capital Territory	5	3.6	7	3.5

New South Wales	35	25.2	63	31.3
Northern Territory	2	1.4	2	1.0
Queensland	28	20.1	25	12.4
South Australia	7	5.0	1	0.5
Tasmania	3	2.2	1	0.5
Victoria	49	35.3	74	36.8
Western Australia	10	7.2	28	13.9

[†]Not mutually exclusive

Table 2. Paediatricians rating of the importance of assessment tools and management strategies for severe tics/Tourette Syndrome

	Not at all important		Not important		Neutral		Important		Very Important	
	n	%	n	%	n	%	n	%	n	%
Assessment										
History	-	-	-	-	-	-	25	21.6	91	78.5
Observation of tics	-	-	3	2.6	14	12.1	70	60.3	29	25.0
Examination	-	-	5	4.4	27	23.5	62	53.9	21	18.3
Questionnaires										
Tic-specific	22	19.3	31	27.2	47	41.2	9	7.9	5	4.4
Comorbidity-specific	15	13.0	18	15.7	33	28.7	36	31.3	13	11.3
Broad band (non-condition specific)	19	16.7	26	22.8	48	42.1	17	14.9	4	3.5
Referrals for assessment										
Psychologist										

Tourette Syndrome	11	9.5	30	25.9	52	44.8	22	19.0	1	0.9
Cognitive function	16	13.8	25	21.6	55	47.4	19	16.4	1	0.9
Comorbid condition	9	7.8	15	13.0	48	41.7	39	33.9	4	3.5
Occupational therapist	28	24.4	43	37.4	37	32.2	7	6.1	-	-
Neurologist	12	10.4	31	27.0	52	45.2	17	14.8	3	2.6
Management										
Management goals										
Elimination of tics	11	9.6	35	30.4	46	40.0	19	16.5	4	3.5
Reduction in tics	1	0.9	1	0.9	17	14.7	68	58.6	29	25.0
Improvement in comorbidities	-	-	-	-	4	3.5	67	57.8	45	38.8
Improvement in overall function	-	-	-	-	1	0.9	35	30.2	80	69.0
Managing severe tics/Tourette Syndrome										
Verbal and/or written education for patient/parents	-	-	2	1.7	8	6.9	50	43.1	56	48.3

Strategies provided to help the child manage tics	-	-	3	2.6	20	17.2	71	61.2	22	19.0
Medication	4	3.5	14	12.1	46	39.7	47	40.5	5	4.3

Table 3. Medications ranked from 1 to 8 in preference for reducing tics

	Ranking (1 to 8)															
	1		2		3		4		5		6		7		8	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Clonidine	80	69.0	8	6.9	6	5.2	4	3.4	-	-	-	-	-	-	-	-
Haloperidol	4	3.4	14	12.1	6	5.2	3	2.6	3	2.6	2	1.7	-	-	-	-
Risperidone	6	5.2	32	27.6	12	10.3	11	9.5	1	0.9	1	0.9	-	-	-	-
Other 2nd generation anti-psychotic	-	-	1	0.9	5	4.3	7	6.0	6	5.2	1	0.9	1	0.9		
SSRI	8	6.9	24	20.7	19	16.4	5	4.3	2	1.7	-	-	-	-	-	-
Stimulants	4	3.4	1	0.9	5	4.3	3	2.6	3	2.6	1	0.9	1	0.9	1	0.9
Atomoxetine	4	3.4	5	4.3	5	4.3	3	2.6	2	1.7	2	1.7	1	0.9	-	-
Antibiotics	1	0.9	2	1.7	1	0.9	2	1.7	-	-	2	1.7	1	0.9	2	1.7
Total responses[†]	107	92.2	87	75.0	59	50.9	38	32.8	17	14.7	9	7.8	4	3.4	3	2.6

[†] Percentages for each rank are based on the overall denominator (n=116). SSRI: selective serotonin reuptake inhibitors

Table 4. Non-medication strategies likely to be helpful by scenario

	Occupational therapy management		Psychological management		School and parent education	
	n	%	n	%	n	%
Scenario 1	13	12.0	68	60.2	101	88.6
Scenario 2	21	19.6	91	80.5	100	89.3
Scenario 3	13	12.3	105	93.8	107	94.7
Scenario 4	4	4.3	34	34.7	83	78.3

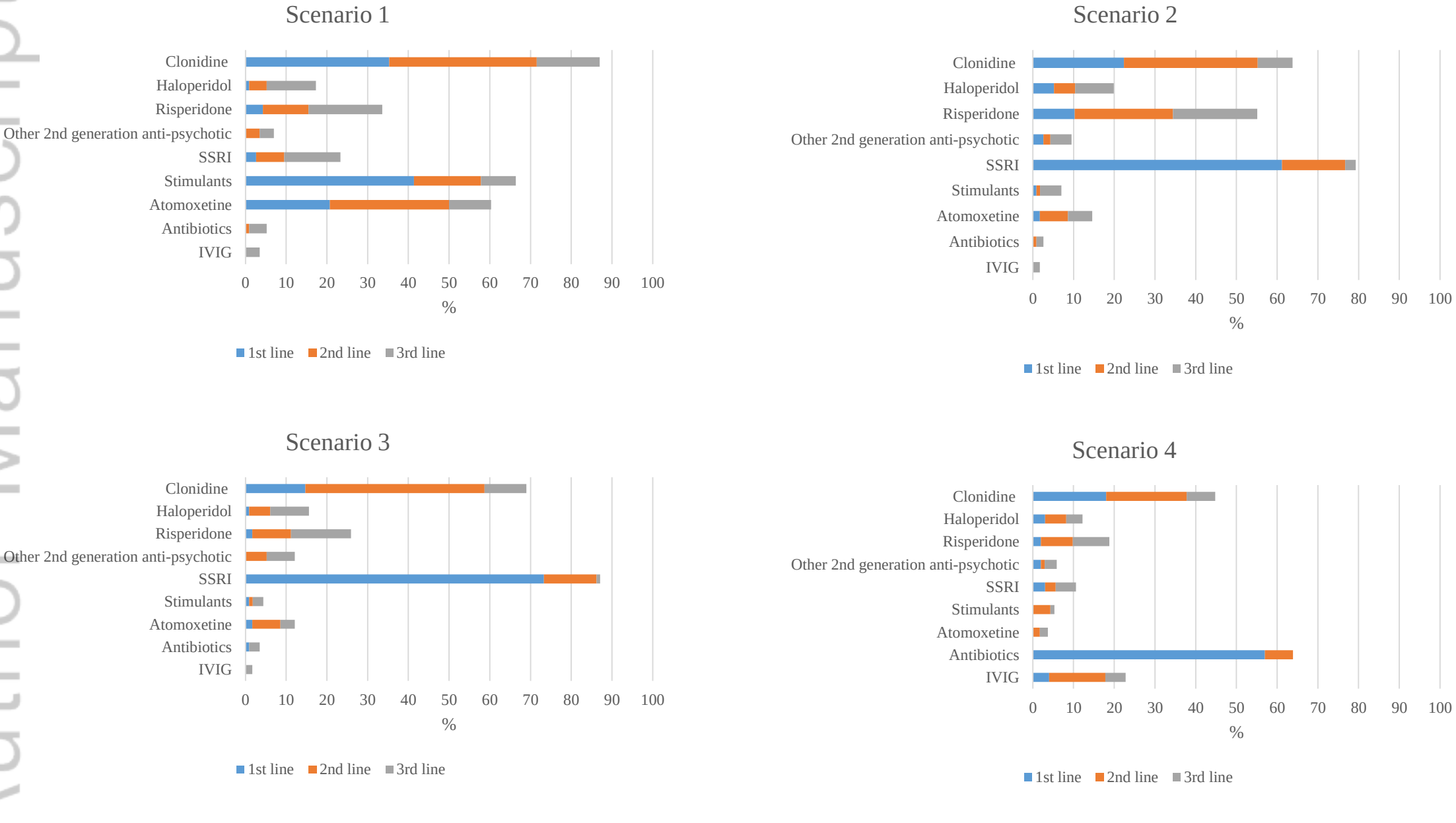

Figure 1. 1st – 3rd line medication preference for scenarios. SSRI: Selective serotonin reuptake inhibitors; IVIG: Intravenous immunoglobulin

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