

Impact of Tardive Dyskinesia on Physical, Psychological, and Social Aspects of Patient Lives: A Survey of Patients and Caregivers in the United States

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Introduction

- Tardive dyskinesia (TD) is an iatrogenic, hyperkinetic movement disorder that has substantial impact on patients' lives¹
- A recent expert consensus panel recommended that key domains for assessing the overall impact of TD should include social, physical, and psychological function as well as impact on the underlying condition treated with antipsychotic medications²
- Despite this, there is a lack of literature about the impact of TD within each of these domains

Objective

- To assess the impact of TD on social, physical, and psychological domains of patients' lives in the United States from the perspective of patients and caregivers of patients with TD, as well as the impact on treatment of the underlying condition

Methods

- A targeted literature review and interviews with patients, caregivers, and clinicians were conducted to develop 2 online English-language surveys to assess patient burden, 1 for patients with TD and 1 for caregivers providing unpaid care for patients with TD ≥3 months (there was no overlap between patient respondents and the patients for whom the caregivers were providing care)
- Patients and caregivers provided survey responses regarding impact of TD on physical (24 items), psychological (11 items), and social (31 items) domains of patients' lives rated from 1 (least impact) to 5 (most impact)
 - Proportions of respondents reporting severe TD impact (impact score ≥4 on ≥1 item within each domain) and mean impact scores (sum of responses divided by number of items) were calculated and summarized descriptively
- In addition, patients were asked about how TD impacted treatment of their underlying condition (major depressive disorder, schizophrenia or schizoaffective disorder, bipolar disorder)
 - Proportions of patients selecting each option were summarized descriptively

Results

- Patients represented the diversity of race/ethnicities present in the United States; however, patients with higher education may have been overrepresented (Table 1)
- The patients for whom caregivers were providing care were older and more likely to be male than patients who completed the survey directly; patients were more likely than caregivers to report that TD symptoms were very severe and very bothersome (Table 1)

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Disclosures

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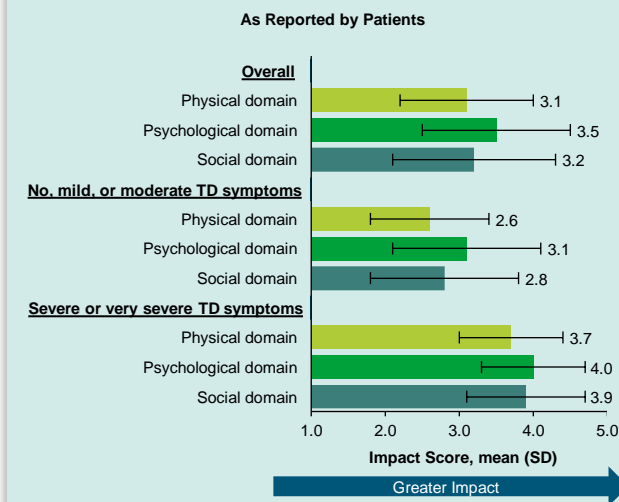
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Key Results

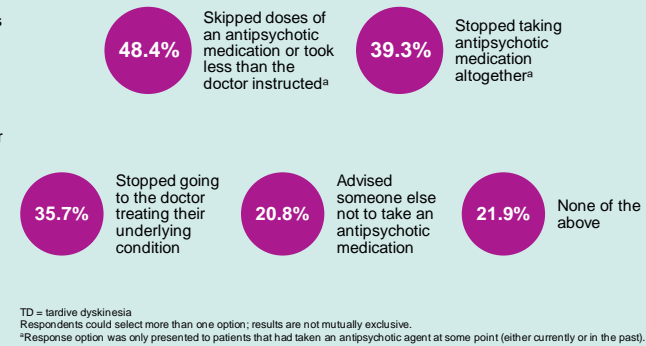
- Mean (SD) impact scores as reported by patients and caregivers were 3.1 (0.9) and 3.2 (0.7), respectively, for physical, 3.5 (1.0) and 3.5 (0.8) for psychological, and 3.2 (1.1) and 2.9 (0.7) for social domains, and increased with TD symptom severity (Figure 1)
 - For patients overall and patients with no, mild, or moderate TD symptoms, patients and caregivers rated impact fairly consistently on all 3 domains, with no obvious pattern between respondent groups; for severe or very severe TD symptoms, caregivers rated patient impact on all 3 domains lower than patients (Figure 1)
- Most patients and caregivers (75.1% and 82.7%, respectively) reported that TD has a severe impact (impact score ≥4 on ≥1 item within each domain), increasing from 61.5% and 75.2% for patients with no, mild, or moderate TD symptoms to 95.4% and 96.5% for patients with severe or very severe TD symptoms
 - Severe impact was reported by patients and caregivers with similar frequency for severe or very severe TD symptoms, but a greater proportion of caregivers reported severe impact for patients with no, mild, or moderate TD symptoms
- As reported by patients, the impact of TD was greatest for physical concerns about speaking, sleeping, and eating; psychological aspects of frustration and fear of being rejected; and social issues regarding comfort with appearing on camera in video conferences, taking public transportation, enjoying the things they do for fun, and reactions from family/friends, spouse/date, strangers, and employers (further results for individual survey items will be reported in separate publications)
- TD had a substantial impact on treatment of the underlying condition with >39% of patients skipping, stopping, or reducing their antipsychotic medication (Figure 2)

Figure 1. Patient Impact Overall and by TD Symptom Severity



TD = tardive dyskinesia

Figure 2. Impact of TD on Treatment of Underlying Condition(s)



TD = tardive dyskinesia
 Respondents could select more than one option; results are not mutually exclusive.
^aResponse option was only presented to patients that had taken an antipsychotic agent at some point (either currently or in the past).

Table 1. Key Patient Characteristics

	Reported by Patients N=269	Reported by Caregivers N=162
Age, years, mean (SD)	40.6 (9.9)	62.6 (15.4)
Male, n (%)	162 (60.2)	87 (53.7)
Race/ethnicity, ^a n (%)		
White or Caucasian	211 (78.4)	126 (77.8)
Black or African American	38 (14.1)	16 (9.9)
Latino, Hispanic, or Chicano	27 (10.0)	30 (18.5)
Other	19 (7.1)	11 (6.8)
Education, n (%)		
High school diploma (or equivalent) or less	47 (17.5)	35 (21.6)
Some college, no degree	39 (14.5)	23 (14.2)
Associate degree	28 (10.4)	19 (11.7)
Bachelor's degree	77 (28.6)	64 (39.5)
Graduate degree	78 (29.0)	21 (13.0)
Employment, n (%)		
Working full-time	161 (59.9)	3 (1.9)
Short-/long-term disability from work	35 (13.0)	39 (24.1)
Working part-time	31 (11.5)	5 (3.1)
Not employed (not looking for work), retired, or homemaker	31 (11.5)	27 (16.7)
Self-employed or other	13 (4.8)	0
Not employed (looking for work)	9 (3.3)	4 (2.5)
Student	5 (1.9)	1 (0.6)
Duration of TD diagnosis, ^b years, mean (SD)	5.4 (5.1)	5.5 (6.3)
Duration of TD symptoms, ^c years, mean (SD)	5.8 (5.5)	5.3 (6.0)
Severity of patient's TD symptoms in previous 7 days, n (%)		
None	5 (1.9)	2 (1.2)
Mild	36 (13.4)	9 (5.6)
Moderate	120 (44.6)	94 (58.0)
Severe	61 (22.7)	47 (29.0)
Very severe	47 (17.5)	10 (6.2)
Extent to which patient was bothered by TD symptoms in previous 7 days, n (%)		
Not at all	8 (3.0)	1 (0.6)
A little bit	25 (9.3)	12 (7.4)
Somewhat	70 (26.0)	36 (22.2)
Quite a bit	86 (32.0)	83 (51.2)
Very much	80 (29.7)	30 (18.5)
Underlying condition, ^a n (%)		
Bipolar disorder	134 (49.8)	67 (41.4)
Major depressive disorder	61 (22.7)	48 (29.6)
Schizophrenia or schizoaffective disorder	74 (27.5)	47 (29.0)

TD = tardive dyskinesia
^aRespondents could select more than one option; results are not mutually exclusive.
^bDuration of TD diagnosis is calculated only for patients (n=258) and caregivers (n=153) who reported year of TD diagnosis. The duration of TD diagnosis is approximated, as only the year of diagnosis was reported.
^cDuration of TD symptoms is calculated only for patients (n=257) and caregivers (n=144) who reported year of TD symptom onset. The duration of TD symptoms is approximated, as only the year of symptom onset was reported.

Conclusions

- TD imposes a substantial burden on patients' physical functioning, mental well-being, and social activities, even in patients with self-assessed mild-to-moderate TD symptoms
- TD also impacts how patients manage the underlying condition, suggesting that better TD symptom control may reduce patient burden by reducing antipsychotic treatment disruptions and nonadherence
- These results reinforce the need for health care providers to assess impact to patients when assessing TD movements