Caregiver Burden of Tardive Dyskinesia in the United States: A Survey of Impact on Caregiving Tasks, Psychological Well-Being, and Daily Activities

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Introduction

- Tardive dyskinesia (TD) is an iatrogenic, hyperkinetic movement disorder that disrupts various aspects of life for not only patients with TD but also for their caregivers[1]

Objective

- To assess experiences and concerns of caregivers for patients with TD in the United States

Methods

- A literature review and interviews with patients, caregivers, and clinicians were conducted to develop an online English-language survey for caregivers of patients with TD to assess caregiver burden
- Surveyed caregivers were required to be providing unpaid care for a patient with TD for ≥3 months
- Caregivers provided responses regarding impact of TD on caregiving tasks, psychological well-being, and daily activities rated from 1 (least impact) to 5 (most impact); impact on caregivers' professional lives was also assessed with the Work Productivity and Activity Impairment Questionnaire
- Proportions of respondents reporting severe impact (score ≥4 on ≥1 item within each domain) and impact scores were calculated for each domain and summarized descriptively; the distributions of responses for each item within the domains and overall work impairment are presented descriptively

Results

- The surveyed caregivers (N=162) represented the diversity of race/ethnicities present in the United States; however, caregivers with higher education may have been overrepresented (**Table 1**)
- 35.2% of caregivers reported that the patient's TD symptoms were severe or very severe, and 69.7% described patients as being either quite a bit or very much bothered by their TD symptoms (**Table 2**)
- Caregivers experienced 46.4% activity impairment because of caring for the patient; caregivers who were employed missed 13.8% of work time (ie, absenteeism) and experienced 44.0% impairment while working (ie, presenteeism), representing 49.5% overall work impairment

Table 1. Key Caregiver Characteristics

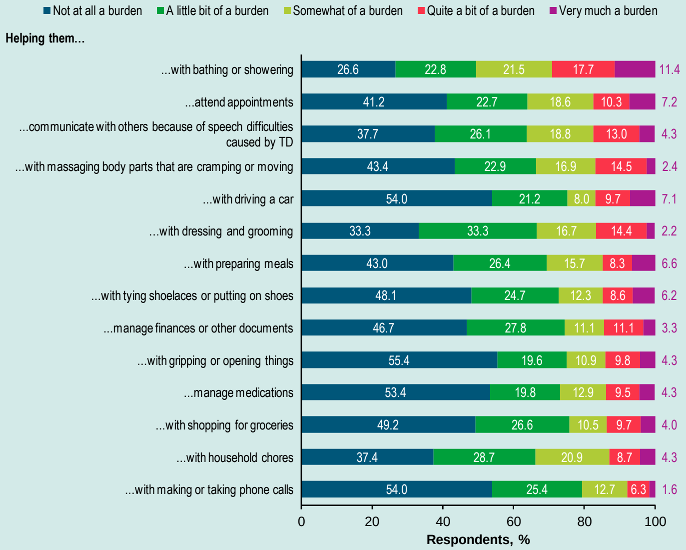
		Caregivers N=162
Age, years, mean (SD)		40.0 (9.8)
Male, n (%)		106 (65.4)
Race/ethnicity,[a] n (%)	White or Caucasian	124 (76.5)
	Latino, Hispanic, or Chicano	31 (19.1)
	Black or African American	17 (10.5)
	Asian	9 (5.6)
	Other	2 (1.2)
Education, n (%)	High school diploma or equivalent	10 (6.2)
	Some college, no degree	13 (8.0)
	Associate degree	18 (11.1)
	Bachelor's degree	69 (42.6)
	Graduate degree	52 (32.1)
Currently employed, n (%)		136 (84.0)

[a]Respondents could select more than one option; results are not mutually exclusive.

Key Results

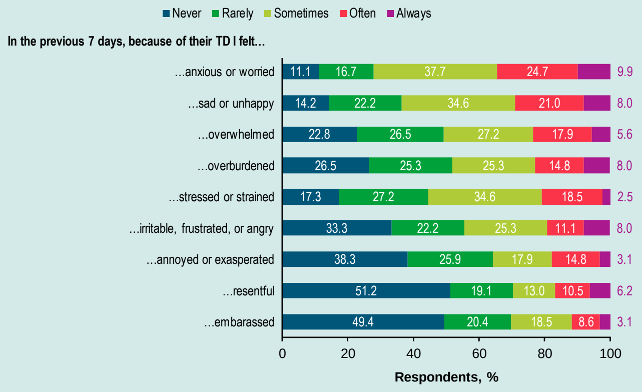
- 23.5% of caregivers reported that the patient's TD has a severe impact (score ≥4 on ≥1 item within each domain) on the caregiver's life; among caregivers of patients with no, mild, or moderate TD symptoms, 18.1% reported severe impact, whereas 33.3% of caregivers of patients with severe or very severe TD symptoms reported severe impact
  - Mean (SD) impact scores were 2.1 (1.1) for caregiving tasks, 2.5 (0.9) for caregiver psychological well-being, and 2.7 (0.9) for caregiver daily activities, increasing with TD symptom severity–for caregivers of patients with no, mild, or moderate symptoms, scores were 2.0 (1.0), 2.3 (0.9), and 2.6 (0.9), respectively, and for caregivers of patients with severe or very severe TD symptoms, scores were 2.4 (1.2), 2.7 (1.0), and 2.9 (1.0), respectively
- The most burdensome task was helping patients with bathing or showering; however, the majority of caregivers did not consider helping patients with any individual task overly burdensome (**Figure 1**)
- 34.6% of caregivers reported feeling anxious or worried often or always because of the patient's TD, and 29.0% felt sad or unhappy, 23.5% overwhelmed, 22.8% overburdened, and 21.0% stressed or strained (**Figure 2**)
- Approximately 30% of caregivers reported that the patients' TD often or always impacted their ability to enjoy the things they do for fun, to join social activities, to socialize with friends, and/or to date or meet new people (**Figure 3**)

Figure 1. Burden of Caregiving Tasks



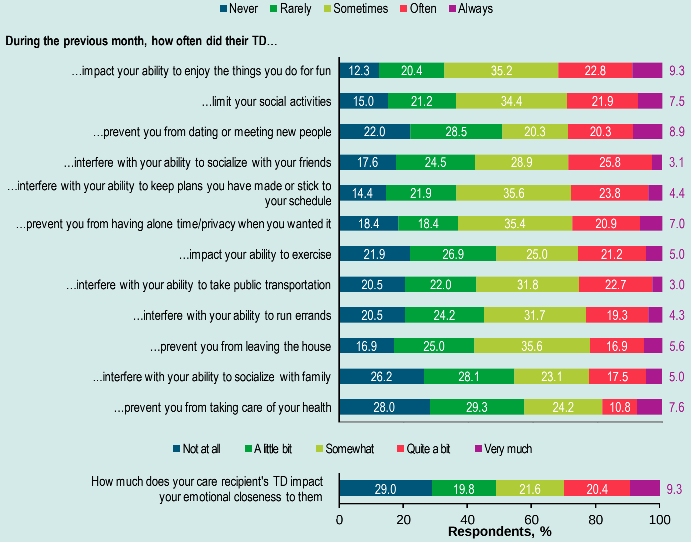
TD = tardive dyskinesia
Respondents only provided the burden of tasks for which they indicated they support the patient.

Figure 2. Impact on Caregiver Psychological Well-Being



TD = tardive dyskinesia

Figure 3. Impact on Caregiver Daily Activities



TD = tardive dyskinesia
Respondents could select "not applicable" for all but the last item. Results are based on respondents who did not select "Not applicable."

Table 2. Key Caregiver-Patient Relationship and Patient Characteristics

		Reported by Caregivers N=162
Relationship to patient, n (%)	Patient is my parent or guardian	91 (56.2)
	Spouse or partner	19 (11.7)
	Sibling	11 (6.8)
	Friend	6 (3.7)
	Patient is my child	2 (1.2)
	Other relative	33 (20.4)
Living with patient, n (%)		96 (59.3)
Length of time as caregiver, n (%)	≥3 months to ≤1 year	22 (13.6)
	>1 year to ≤3 years	78 (48.1)
	>3 years to ≤10 years	53 (32.7)
	>10 years	9 (5.6)
Severity of patient's TD symptoms in previous 7 days, n (%)	None	2 (1.2)
	Mild	9 (5.6)
	Moderate	94 (58.0)
	Severe	47 (29.0)
	Very severe	10 (6.2)
Extent to which patient was bothered by TD symptoms in previous 7 days, n (%)	Not at all	1 (0.6)
	A little bit	12 (7.4)
	Somewhat	36 (22.2)
	Quite a bit	83 (51.2)
	Very much	30 (18.5)
Underlying condition,[a] n (%)	Bipolar disorder	67 (41.4)
	Major depressive disorder	48 (29.6)
	Schizophrenia or schizoaffective disorder	47 (29.0)

TD = tardive dyskinesia
[a]If a caregiver reported that the patient had more than one underlying condition, then underlying condition was assigned based on the condition that was reported as having the greatest impact on the patient's life. Patients with bipolar disorder and major depressive disorder were classified as BD..

Conclusions

- Although most caregivers did not consider helping patients with individual tasks burdensome, responses regarding impact on their own activities and psychological well-being reflect a cumulative burden of supporting patients with TD
- These results highlight the importance in recognizing incremental impact of TD on caregivers

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Disclosures

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Reference

1. Cutler AJ, et al. *J Am Psychiatr Nurses Assoc.* Published online ahead of print June 22, 2021. doi: 10.1177/10783903211023565.