

Movement Disorders: Impact and Access to Treatment

Introduction

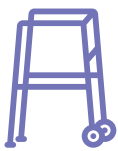
Movement disorders are neurological conditions that cause involuntary or abnormal voluntary body movements, or slow, reduced movements.¹

They afflict millions of people—patients themselves, and also families, caregivers, communities, the health care system, and the economy.

Many conditions fall under the umbrella of movement disorders, including Parkinson’s disease,

tardive dyskinesia, Huntington’s disease, dystonia, essential tremor, Tourette syndrome, ataxia, restless legs syndrome, and others.² Causes of various movement disorders range from nerve diseases (the cause of Parkinson’s) to injuries, autoimmune diseases, infections, and certain medications. Some are genetic disorders, passed on from one generation to the next.³

Though some movement disorders are relatively rare, collectively their prevalence is significant.



As many as 1 million Americans and 10 million people worldwide suffer from **Parkinson’s disease** alone, with 60,000 new cases being diagnosed each year.⁴



Essential tremor, in which patients experience uncontrollable shaking, affects about 10 million Americans.⁵



One out of every 100 U.S. children ages 5-17 have **Tourette syndrome**—which causes repetitive, involuntary movements and vocalizations—or a similar tic disorder.⁶



Thirty thousand people nationwide have **Huntington’s disease**, an inherited condition where the brain’s nerve cells deteriorate, causing movement, psychiatric and cognitive symptoms.⁷



Some studies indicate that up to half of all patients treated with some antipsychotic medications for mental illness will develop **tardive dyskinesia**, characterized by jerky, involuntary movements of the face and body.⁸

The prevalence of movement disorders increases with age, posing a growing challenge for older patients, their spouses and children, and the health care system.

Treatments vary for each condition, with some responding well to treatment. Many others have few treatments, and most all movement disorders have no cure. Research has produced innovative drugs in recent years, providing a source of hope and relief

to patients and families facing movement disorders.⁹ New treatment options continue to emerge.

Yet the ability of new treatments to reduce the burden of movement disorders pivots on one critical question: Can patients get the medication their doctor orders?



Impact of Movement Disorders

COST

The financial cost of movement disorders is staggering. Parkinson's creates a U.S. economic burden of about \$25 billion a year, including missed work or job loss for patients and their caregivers, Social Security payments, and the cost of treatment.¹⁰ Nursing home services make up 57 percent of additional medical costs for Parkinson's patients.¹¹

Meanwhile, people diagnosed with tardive dyskinesia can rack up total health care costs of more than \$55,000 a year.¹² And a study ending in 2009 found that some Huntington's patients had annual health care costs of almost \$40,000.¹³

The personal costs are also profound. Movement disorders may hinder patients' ability to work, travel, exercise, engage in leisure activities, and interact with friends and family. Older patients in particular may find their independence fading as they increasingly rely upon caregivers for day-to-day support.

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MENTAL HEALTH ISSUES

Movement disorders often coexist with other ailments, especially psychiatric conditions that overlap with patients' neurological symptoms.

As many as 40 percent of people with medically serious movement disorders also have some sort of mental disorder.¹⁴

Many times mental conditions complicate the symptoms of movement disorders. Parkinson's disease patients, for instance, may develop psychosis as a side effect of their disease, medications, or both. In other cases, the treatment for one condition can cause the emergence of a different condition.

Patients being treated for schizophrenia or other psychiatric conditions with some antipsychotic drugs, for example, may develop a movement disorder known as tardive dyskinesia as a result of their treatment. Tardive dyskinesia is characterized by grimacing, lip smacking and other involuntary facial movements, as well as

involuntary movements in the trunk and limbs. Similarly, some antipsychotic drugs widely used to treat schizophrenia and other psychotic disorders can cause other movement disorders such as bradykinesia, limb stiffness, and facial symptoms sometimes seen in Parkinson's patients.¹⁵

Moreover, depression and anxiety may coexist in movement disorder patients, exacerbating their conditions. For example, symptoms of Parkinson's can be worsened by anxiety.¹⁶ In other instances, drugs used to treat Parkinson's can exacerbate anxiety or depression.

When mental and movement disorders occur in combination, diagnosis and treatment become more complicated.¹⁷ Patients deserve to be able to achieve stability quickly and they, their physicians, and their families often face complex decisions concerning which condition should be given priority and whether the potential side effects of a given treatment outweigh its benefit.



MOVEMENT DISORDERS



BURDEN OF DISEASE

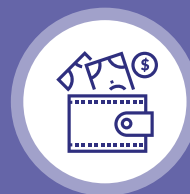
DISEASE SYMPTOMS

TREATMENT
SIDE EFFECTS

LOSS OF
INDEPENDENCE

IMPACT ON
RELATIONSHIPS

IMPACT ON WORK &
DAY-TO-DAY ACTIVITIES



COST

MISSED WORK

JOB LOSS

TREATMENT COSTS

NURSING HOME COSTS

HEALTH CARE
EXPENSES



CAREGIVER IMPACT

PHYSICAL TOLL

FINANCIAL EXPENSES

DEPRESSION

LOSS OF JOB
OPPORTUNITIES

MISSED WAGES

CAREGIVERS

The impact of movement disorders, both financial and emotional, also fall on caregivers, who are often family and friends.

The Caregiver Action Network estimates that more than a quarter of the U.S. population—65 million people—provide care for a family member or friend during any given year, spending an average of 20 hours per week meeting their needs.¹⁸ Adult patients without a child, spouse, or close friend who can provide care may be at a severe disadvantage in managing their conditions. Caregivers provide essential support, such as taking patients to medical appointments, overseeing the use of prescribed medications, supporting day-to-day care needs and, increasingly, acting as advocates for access to treatment. About 70 percent of family caregivers manage medications for their loved ones.¹⁹ In some cases, the toll of movement disorders requires that extended family members also play a role.

Yet the demands of caregiving can directly impact the physical, economic, and mental wellbeing of the caregiver. As many as 70 percent of family caregivers exhibit clinically significant symptoms of

depression, and 11 percent report that caregiving has caused their physical health to decline.²⁰ They may lose out on job opportunities and leisure pursuits.²¹ One study found that more than half of family caregivers feel overwhelmed by the amount of care family members need.²² Parents of children with movement disorders may have to alter their work schedule, scale back or even leave their jobs to help manage their child's disease.

Caregiving also has financial implications. Caregivers over 50 years of age have average losses of \$303,880 in lifetime income and benefits.²³ Women who are family caregivers are 2.5 times more likely to live in poverty and five times more likely to receive Supplemental Security Income from the Social Security Administration.²⁴

The mental, physical, and financial problems that caregivers endure can compound the issues facing the patients under their care. The imperative of making treatment accessible to patients with movement disorders, therefore, is doubly important. Both patients and their caregivers benefit from the ability to manage the debilitating symptoms caused by movement disorders.





Treatment Options

How physicians treat movement disorders varies from condition to condition and patient to patient. Physicians continually evaluate ongoing treatment results to decide what is appropriate.

Treatment options can include physical and occupational therapy, speech-language therapy, oral medications, biologics, injections, or surgery in some instances.²⁵

Historically, however, there have been limited treatment options for movement disorder patients and their physicians. Investment and research into new treatments remains a primary concern for the patients and families affected by movement disorders and the physicians who treat them.

Meanwhile, many of the medications prescribed to treat movement disorders are used off-label, meaning that even though there is some evidence they may be effective, they have not been approved by the Food and Drug Administration for that purpose.²⁶ For example, some anti-psychotic drugs are prescribed off-label for

Tourette syndrome.²⁷ Off-label lithium can be used to help some symptoms of Huntington's disease,²⁸ and several different drugs, including acetylcholinesterase inhibitors and atypical antipsychotic medications are used for Parkinson's.²⁹

Off-label prescribing is legal and quite common, but more evidence is needed. It's estimated that about 20 percent of all outpatient prescriptions written in the U.S. are for off-label therapies.³⁰

Physicians who rely upon off-label prescribing to treat their patients, however, may have difficulty getting complete information about these therapies' uses. Federal laws limit the information that drug manufacturers can provide regarding off-label use of their products. While the restrictions are designed to encourage safe and appropriate treatment decisions, they may have the unintended effect of limiting physicians' knowledge about what are sometimes the only treatment options available for a given movement disorder.



I have felt a bit helpless in the past when I see people who experience TD. **We didn't have any treatment options approved by the FDA. But now we have two new tools** and I look forward to learning more about these medications from my patients' experiences and scientific literature.

KEN DUCKWORTH, MD
Medical Director,
National Alliance on Mental Illness

Access Challenges

After years of limited treatment options for movement disorders, exciting new therapies are emerging. In 2014, for example, U.S.

biopharmaceutical research companies were reported to be developing 37 different new medicines to help Parkinson's sufferers.³¹

Many of these medications are expensive, and getting patients access to them can be a challenge. Prior authorization, an insurance company cost-reduction strategy that requires patients and doctors to get prior approval from the health plan before the plan will pay for the medication, delays or prevents patient access to the medication and greatly increases paperwork. It may cause delays of days or even weeks in filling prescriptions for costly drugs like biologics. A 2010 American Medical Association survey of 2,400 physicians found that payers had rejected 20 percent of first-time prior authorization requests.³²

Another insurer cost-reduction strategy—step therapy—is often referred to as fail first because this onerous insurance company technique forces patients to try, and fail, on one or more less expensive drugs before payment is authorized for the medication the physician originally prescribed. Movement disorder sufferers may, ironically, even

be asked to fail first on off-label drugs even when an FDA-approved treatment exists.³³

Insurers sometimes completely block patient access to expensive medications by increasing the out-of-pocket expense beyond what the patient can afford. Breakthrough drugs, which can be costly, are frequently placed on specialty tiers. This significantly increases the portion of the medication's price that patients must cover. Patients who can't afford their portion of the cost simply can't receive the treatment. Some manufacturer programs and nonprofit organizations may offer patients assistance with paying for their medication. But access remains a challenge for many patients.

Health plans may also dictate that only specialists can prescribe some medications, making it more difficult and expensive for patients to utilize them. This can be especially burdensome for elderly or lower-income patients. Seeing a specialist can involve long wait times or travel, particularly for people who live in rural areas or a long distance from academic health centers. Veterans with movement disorders face the added challenge of navigating the Veterans Affairs health care system to access specialists and necessary treatment.



For veterans with movement disorders, accessing treatment through the VA is deeply challenging. You may have to wait six, even nine, months to see a specialist. Then there's the distance. You may have to drive hours to the clinic. Once you do see a doctor, the drug the prescribes may not be authorized. Congress has worked to improve veterans health care, but we still have a ways to go.

JERRY BOSTER
Veteran, U.S. Navy
Hawai'i Parkinson Association

Conclusion

Movement disorder patients have more hope and more treatment options today than ever before. New therapies can help to alleviate symptoms while others address common comorbidities such as mental health disorders. Moreover, there is an increased recognition of the important role caregivers play and the need to support their health as well.

But breakthrough treatments are beneficial only when patients have access to them. People suffering from movement disorders often face relentlessly progressive disability. They need the most effective treatments possible, and they need them quickly to lessen symptoms and improve quality of life.

Federal, state, and health plan policies should honor the promise of new therapies for movement disorders by prioritizing effective treatments over cost-cutting. That includes avoiding strategies that intentionally hinder or completely block access and balancing short-term expense with long-term considerations of cost and value.

References

1. Treating Movement Disorders: Parkinson's Disease, Essential Tremor and Dystonia. Available from: <https://brighamhealthhub.org/treating-movement-disorders-parkinsons-disease-essential-tremor-and-dystonia>
2. Types of movement disorders. Available from: <https://www.news-medical.net/health/Types-of-movement-disorders.aspx>
3. Movement Disorders: Available from: <https://medlineplus.gov/movementdisorders.html#summary>
4. Statistics on Parkinson's. Available from: http://www.pdf.org/parkinson_statistics
5. About Essential Tremor. Available from: <http://www.essentialtremor.org/about-et/>
6. Tourette Syndrome: An Overview. Available from: <https://www.tourette.org/about-tourette/overview/>
7. What is Huntington's Disease? Available from: <http://hdsa.org/what-is-hd/>
8. Tardive Dyskinesia. Available from: <https://www.nami.org/Learn-More/Mental-Health-Conditions/Related-Conditions/Tardive-Dyskinesia>
9. Movement Disorders. Available from: <https://medlineplus.gov/movementdisorders.html#summary>
10. Statistics on Parkinson's. Available from: http://www.pdf.org/parkinson_statistics
11. Two new studies highlight \$14.4-billion economic burden of Parkin's disease. Available from: <https://www.michaeljfox.org/foundation/news-detail.php?two-new-studies-highlight-14-billion-economic-burden-of-parkinson-disease>
12. Healthcare Utilization and Costs for Patients With Tardive Dyskinesia. Available from: <http://www.mdsabstracts.org/abstract/healthcare-utilization-and-costs-for-patients-with-tardive-dyskinesia/>
13. The Direct Medical Costs of Huntington's Disease by Stage. A Retrospective Commercial and Medicaid Claims Data Analysis. Available from: https://www.researchgate.net/publication/241690299_The_Direct_Medical_Costs_of_Huntington%27s_Disease_by_Stage_A_Retrospective_Commercial_and_Medicaid_Claims_Data_Analysis
14. Comorbid Movement and Psychiatric Disorders. Available from: <http://www.psychiatrictimes.com/geriatric-psychiatry/comorbid-movement-and-psychiatric-disorders>
15. Antipsychotic-Induced Movement Disorders. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3004713/>
16. Comorbid Movement and Psychiatric Disorders. Available from: <http://www.psychiatrictimes.com/geriatric-psychiatry/comorbid-movement-and-psychiatric-disorders>
17. Ibid.
18. Caregiver Statistics. Available from: <http://caregiveraction.org/resources/caregiver-statistics>
19. Ibid.
20. Ibid.
21. Understanding the Burden on Caregivers of People with Parkinson's: A Scoping Review of the Literature. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4179947/>
22. Profile of Caregivers in America. Available from: <http://www.nasud.org/sites/nasud/files/NASUAD%20Caregiver%20Infographic.pdf>
23. Ibid.
24. Caregiver Statistics. Available from: <http://caregiveraction.org/resources/caregiver-statistics>
25. Treating Movement Disorders: Parkinson's Disease, Essential Tremor and Dystonia. Available from: <https://brighamhealthhub.org/treating-movement-disorders-parkinsons-disease-essential-tremor-and-dystonia>
26. Off-label drug (Parkinson's disease). Available from: <http://what-when-how.com/parkinsons-disease/off-label-drug-parkinson-s-disease/>
27. A Treatment for Tourette Syndrome. Available from: <http://www.medscape.com/viewarticle/771465>
28. Off label use of lithium in the treatment of Huntington's disease: A case series. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3574462/>
29. Off-label drug (Parkinson's disease). Available from: <http://what-when-how.com/parkinsons-disease/off-label-drug-parkinson-s-disease/>
30. Off-Label Drug Use: What You Need to Know. Available from: <http://www.webmd.com/a-to-z-guides/features/off-label-drug-use-what-you-need-to-know#1>
31. Nearly 40 Medicines Are Being Developed to Treat or Diagnose Parkinson's Disease and Related conditions. Available from: <http://phrma-docs.phrma.org/sites/default/files/pdf/2014-parkinsons-report.pdf>
32. Standardization of prior authorization process for medical services white paper. Available from: <https://www.massneuro.org/Resources/Transfer%20from%20old%20sit/AMA%20White%20Paper%20on%20Standardizing%20Prior%20Authorization.pdf>
33. Frequently Asked Questions: Step Therapy & Forced Off-Label Prescribing. Available from: <http://www.uspainfoundation.org/us%20pain%20fact%20sheet%20forced%20off%20label.pdf>



The **Movement Disorders Policy Coalition** is a platform from which stakeholders, including health care providers and patients, inform policymaker about issues impacting patient access to approved therapies and appropriate clinical care.



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