More Than Twisting: An In-Depth Look at the Non-Motor Symptoms of Dystonia

November 9, 2021

Presented by:

Dr. Davide Martino, Ph.D. MD, Director of the Movement Disorders Program at the University of Calgary

Dystonia Medical Research Foundation Canada
Fondation de Recherche Médicale sur la Dystonie Canada

serving all dystonia-affected persons
désservant toutes personnes atteintes de dystonie

- This is a webinar presentation that aims to provide dystonia patients and caregivers with information about dystonia, as well as tips and tools for how to live your best life with dystonia.

- DMRF Canada is not recommending any specific course of treatment for dystonia.

- Any new or experimental treatment mentioned here today may still be relatively new or exploratory at this time.

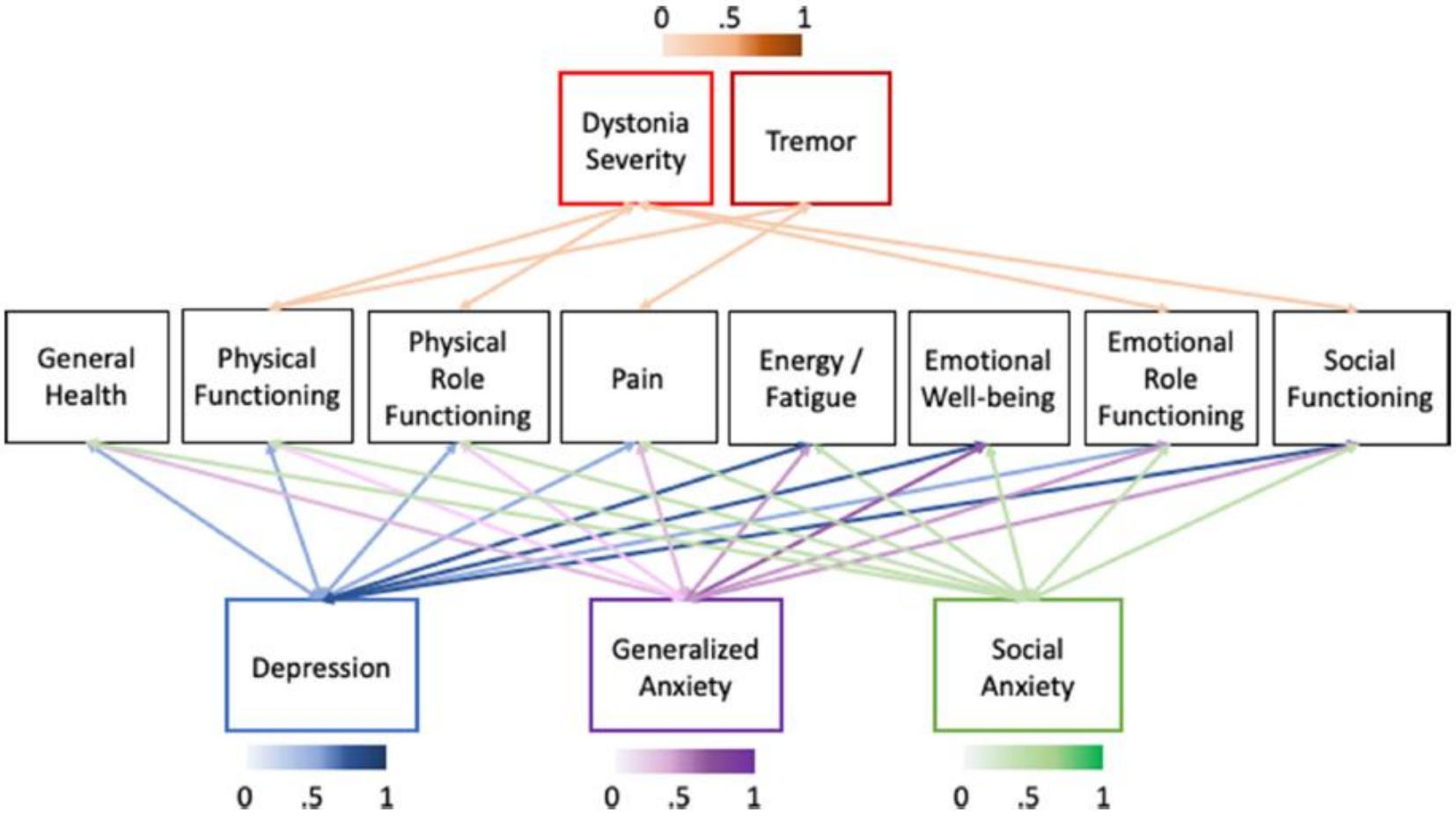
- Please speak with your Movement Disorder Specialist or General Practitioner about any course of treatment to ensure it is right for you.

Disclaimers & Reminders:

TALK OUTLINE

- **The spectrum of non-motor symptoms in cervical dystonia and other adult-onset isolated dystonias: pain, depression, anxiety, sleep, fatigue**
- **Other functional domains in isolated dystonia: physical function, gait, balance, falls and vision**
- **Screening and management of non-motor symptoms in dystonia:**
  - Barriers and facilitators
  - Towards a new pathway of care
- **Rehabilitation & CAMs in dystonia**

What impacts quality of life in dystonia?



- Degree of depressive symptoms
- Generalised and social anxiety
- Dystonia severity
- Tremor severity: only worse physical functioning and pain
- Younger age: emotional well-being and vitality
- No differences between sexes

Junker et al. *J Neurol Neurosurg Psychiatry* 2021

What causes disability in dystonia?

More data on cervical dystonia

Despite motor improvements with botulinum toxin, many patients still experience difficulties with performing daily life activities

Psychiatric features (depression, anxiety) and pain → largest contribution to disability

Much more than physical functioning and dystonia severity

[van den Dool et al., Parkinsonism Relat Disord 2016]

Non-motor symptoms

Many people living with dystonia experience non-motor symptoms contributing to disability and reducing participation in daily activities (Smit et al. 2017a; Stamelou et al. 2012; Torres and Rosales 2017),

Non-motor symptoms include: **pain, depression, anxiety, apathy, impaired sleep, fatigue, catastrophizing, sensorimotor disturbances, olfactory and visual problems**

Non-motor symptoms are important when considering the overall management of dystonia as they play a significant role in quality of life (Smit et al. 2017a; Torres and Rosales 2017; Tomic et al. 2016).

Pain

- **55-89% of people** with cervical dystonia (68% in neck and shoulders → spreads to upper back, up to the head on the bent side and down to the ipsilateral upper limb)
- 10-20% have **chronic daily headache** (occipital 79%, cervical 73%, temporal 43%, frontal 36%, vertex 25%, retroorbital 11%)
- “exhausting”, “radiating”, “prickly”, “pulling the neck”
- **38%** of people with focal hand dystonia have pain
- 36% of people with focal lower limb dystonia have pain
- People with blepharospasm have **painful photophobia**
- Are there different types of dystonia-related pain? Can we measure pain in dystonia accurately?

Pain: what are the risk factors?

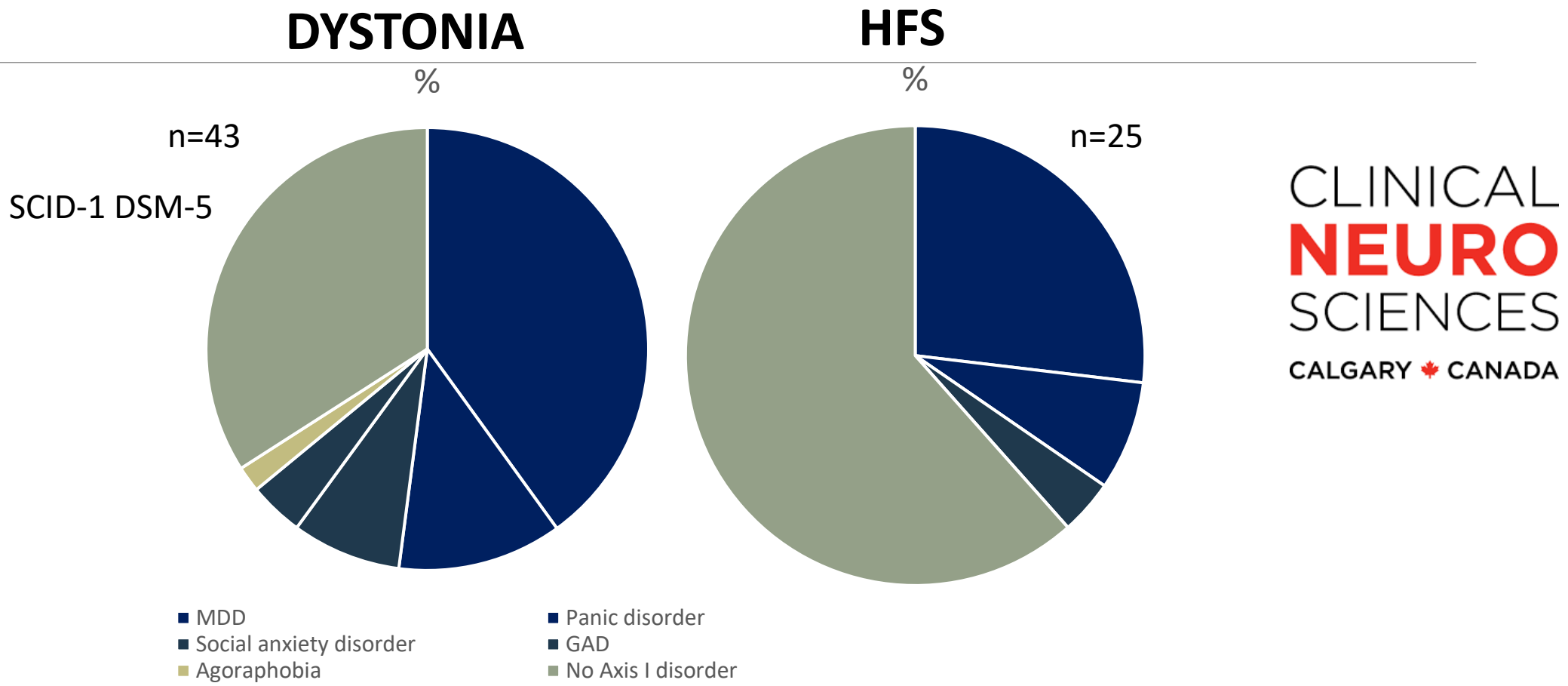
- Hypothesized mechanisms include:
  - prolonged contraction of the “dystonic” muscles
  - prolonged contraction of the “compensating” muscles
  - altered brain processing of painful stimuli

- Likely a multifactorial, yet incompletely understood, origin

Pain: how can we treat it?

- Oral meds for dystonia are non-specific (Marciniec et al. 2019; Siongco et al. 2020)
- Botulinum toxin injections relieve pain in cervical dystonia, even before relaxing muscles (Marciniec et al. 2019; Siongco et al. 2020)
- Deep brain stimulation of the globus pallidus internus is likely to reduce pain
- Kinesiotaping and cerebellar neuromodulation: preliminary results

Depression and natural history of CD



CLINICAL NEURO SCIENCES
CALGARY CANADA

No obvious difference in dystonia spread between those with and those without depression

RESEARCH ARTICLE

Association and Familial Coaggregation of Idiopathic Dystonia With Psychiatric Outcomes

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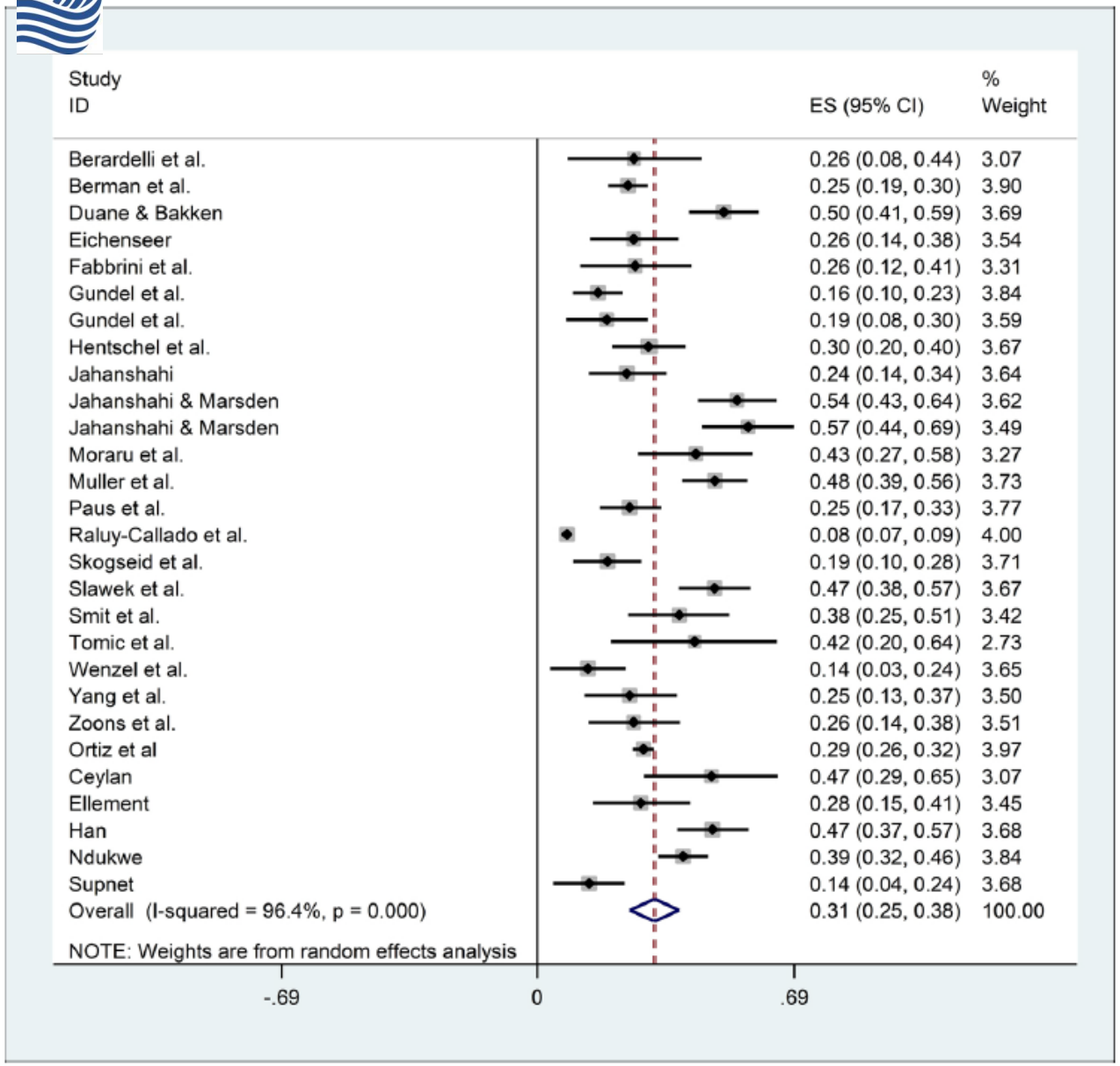
2-fold increased risk of dx of depressive disorder
2.13 of anxiety disorder
80% greater risk of suicide attempts/death by suicide

FULL SIBLINGS

	OR (95% CI) Adjusted for Sex and Birth Year	OR (95% CI) Adjusted for Sex, Birth Year, and Idiopathic Dystonia Status in the Outcome Sibling
Psychiatric Disorders of Primary Interest		
Depressive disorders	**1.21 (1.06–1.39)**	**1.20 (1.05–1.38)**
Anxiety disorders	**1.31 (1.15–1.49)**	**1.30 (1.14–1.47)**
Any suicidal behavior	**1.22 (1.02–1.47)**	**1.22 (1.01–1.46)**
Suicide attempts	**1.27 (1.04–1.54)**	**1.26 (1.04–1.53)**
Deaths by suicide	0.86 (0.51–1.44)	0.86 (0.51–1.45)
Psychiatric Disorders of Secondary Interest		
Attention deficit hyperactivity disorder	1.06 (0.71–1.58)	1.05 (0.71–1.56)
Autism spectrum disorders	0.76 (0.36–1.59)	0.74 (0.35–1.56)
Schizophrenia and other psychotic disorders	**1.45 (1.14–1.84)**	**1.44 (1.14–1.83)**
Bipolar disorder	1.12 (0.83–1.52)	1.12 (0.82–1.51)
Obsessive-compulsive disorder	1.07 (0.61–1.88)	1.06 (0.60–1.87)
Eating disorders	1.53 (0.85–2.75)	1.50 (0.83–2.70)
Substance use disorders	**1.29 (1.12–1.49)**	**1.29 (1.12–1.48)**
Any neurodevelopmental or psychiatric disorder	**1.24 (1.13–1.36)**	**1.24 (1.13–1.36)**

Statistically significant odds ratios are highlighted in bold.
Abbreviations: OR, odds ratio; CI confidence interval.



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The prevalence of depression in adult onset idiopathic dystonia: Systematic review and metaanalysis

Alex Medina Escobar [a], Tamara Pringsheim [a,b,c,d], Zahra Goodarzi [a,b,c,d,1], Davide Martino [a,c,d,*,1]

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- Overall pooled prevalence of any depressive symptoms or disorders: 31.4% for cervical dystonia, 29.2% for cranial dystonia, and 30.9% for studies examining mixed forms of AOID.
- Major depressive disorder more prevalent than dysthymia across all forms of AOID.
- Prevalence of MDD higher in cervical dystonia than in other forms, whereas prevalence of dysthymia higher in cranial dystonia.

DOI: 10.1111/ene.15050

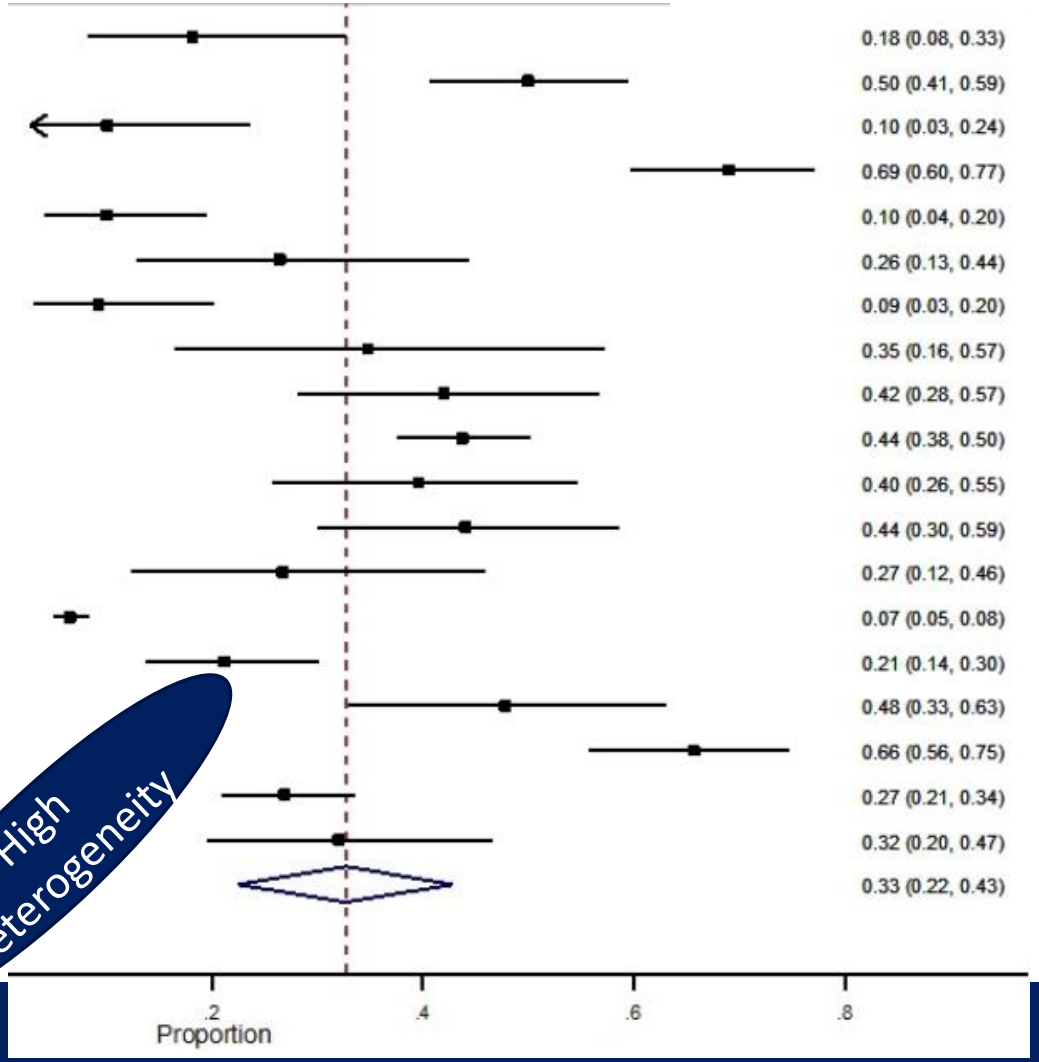
ORIGINAL ARTICLE

european journal of neurology

The prevalence of anxiety in adult-onset isolated dystonia: A systematic review and meta-analysis

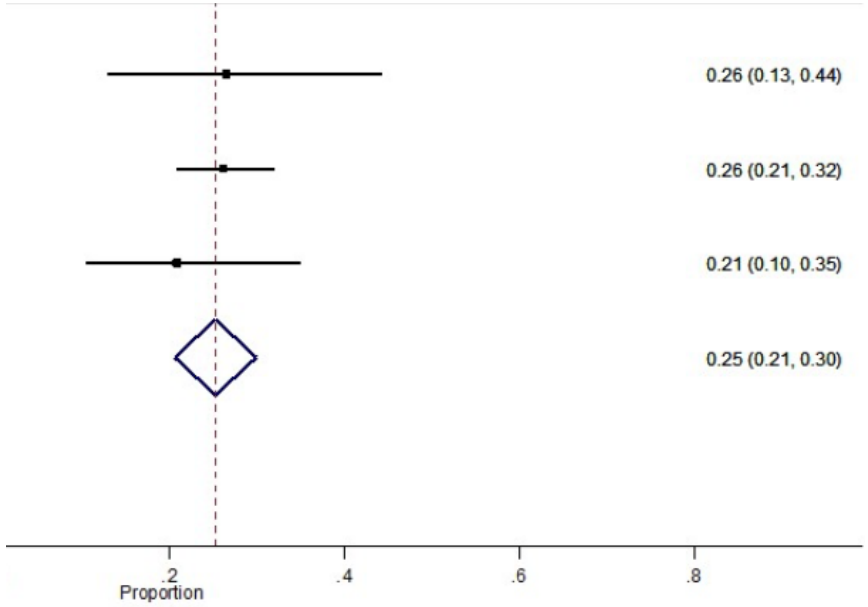
Alex Medina Escobar[1] | Davide Martino[1,2,3] | Zahra Goodarzi[2,3,4,5,6]

Cervical dystonia



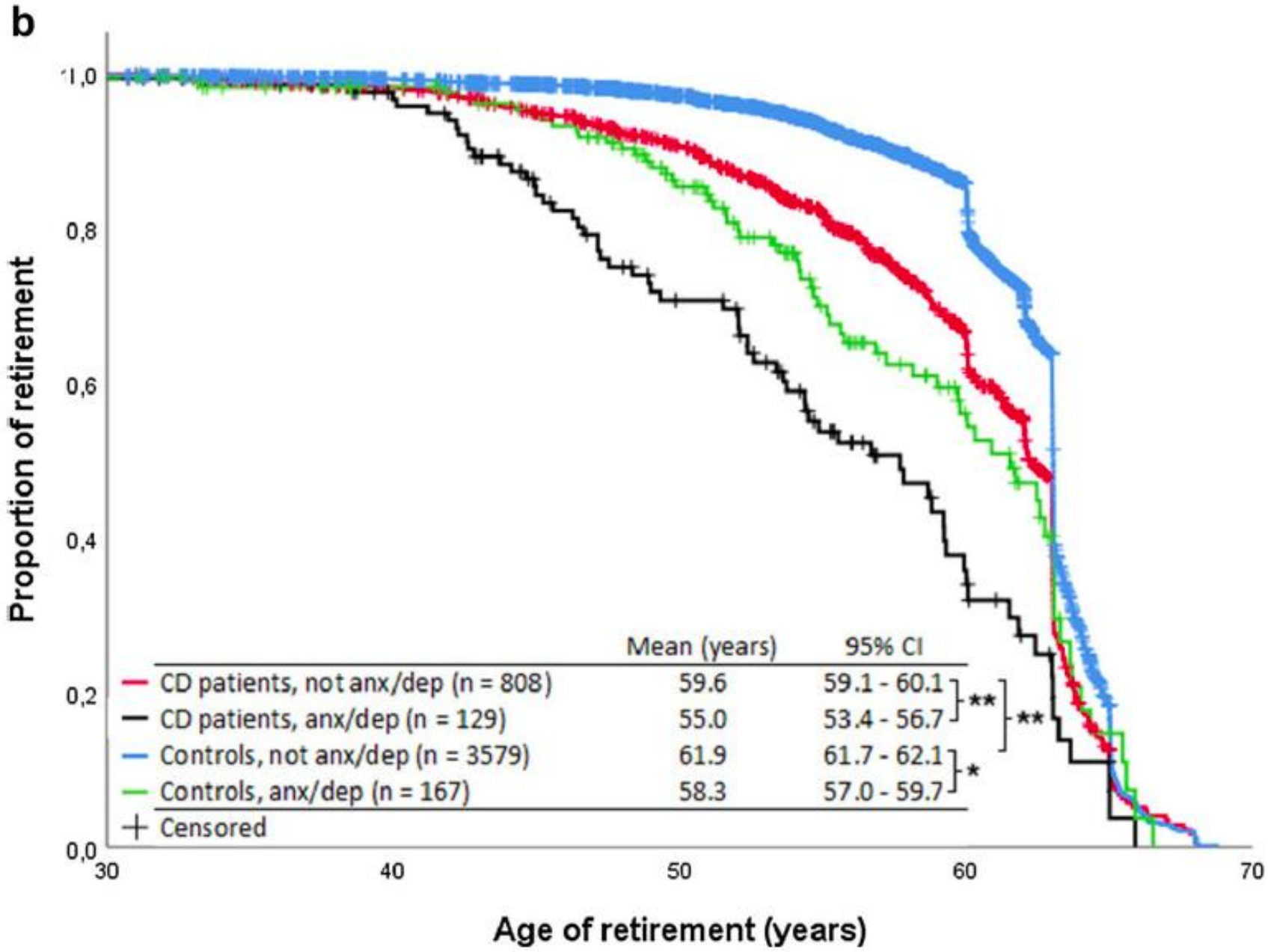
High heterogeneity

Cranial dystonia



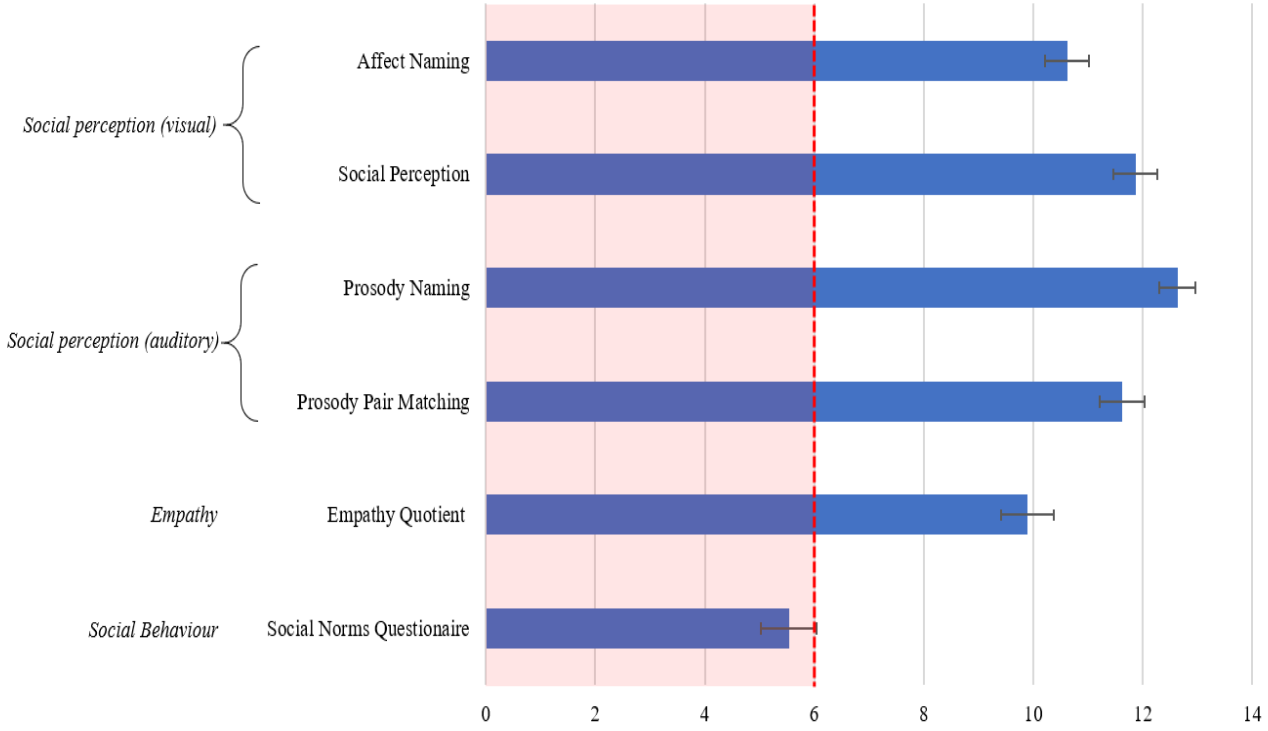
GENERALIZED ANXIETY DISORDER: 18%

SOCIAL PHOBIA: 25%



Ortiz et al. *J Neurol* 2019

SHI-CD
(Social cognition and Habituation to social stimuli In Cervical Dystonia)



ORIGINAL ARTICLE

Social cognition in cervical dystonia: phenotype and relationship to anxiety and depression

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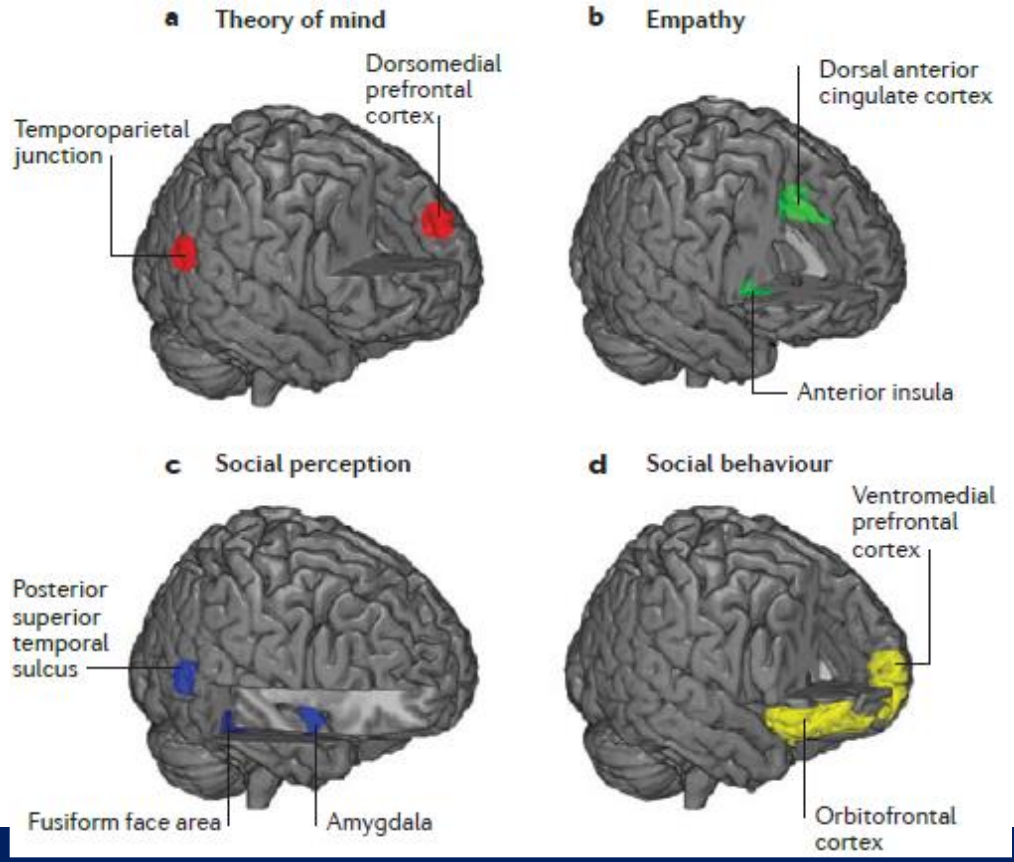


Are people with dystonia who also have depression and anxiety more prone to use meds?

Dystonia coalition cross-sectional study → 37 centres in US, Canada, Europe and Australia → 2,026 participants (76% focal [61% cervical, 12% laryngeal, 10% limb, 9% cranial, 8% blepharospasm]

If anxiety/depression was present, patients were ***twice as likely to be taking oral medications*** (also useful) for dystonia

Particularly:

BENZODIAZEPINES

OTHER SLEEP-INDUCING MEDS (e.g. zopiclone)

MUSCLE RELAXANTS

ANTICHOLINERGICS (e.g. trihexyphenidyl)

[Pirio Richardson et al. Neurology 2017]

May/should people with dystonia who also have depression and anxiety be treated with antidepressants?

There is no valid reason to be extra cautious to treat depression and anxiety with antidepressants (SSRIs) in patients with cervical dystonia

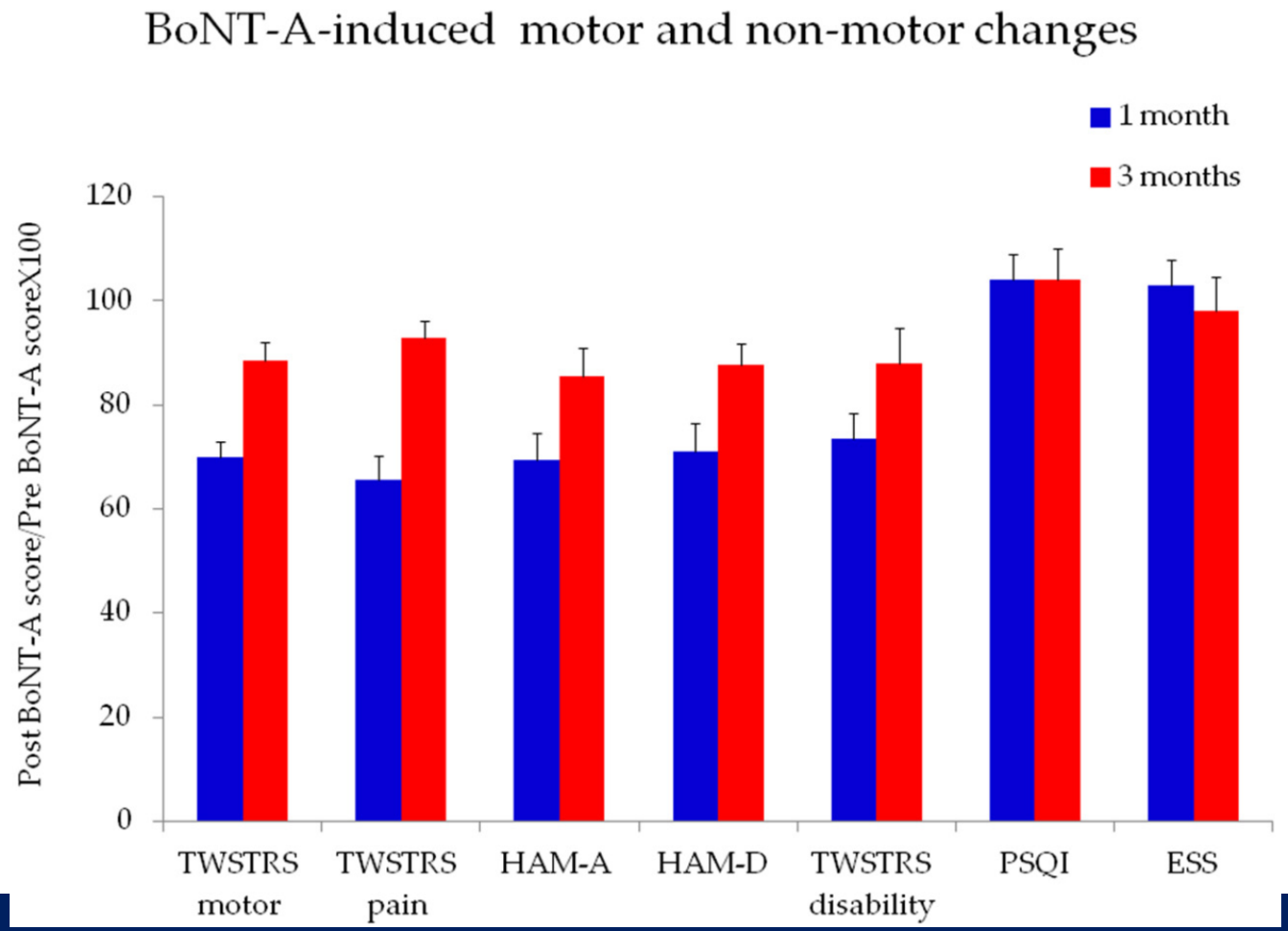
Still no clear evidence confirming that antidepressants improve depression in patients with dystonia, compared to placebo, but evidence is limited

Placebo matters in dystonia → high expectation rates for good effects and adverse effects (e.g. with BoNT-A)

[Zoons et al. J Neurol Neurosurg Psychiatry 2018; Duarte et al., Parkinsonism Relat Disord 2018]

Can BoNT-A improve depression and anxiety in AOID?

Costanzo et al., *Toxins* 2021



Promising evidence in favour of efficacy, but no change on TWSTRSpsych

Overall, still not uniform

No correlation between motor change and non-motor change (incl. pain and depression/anxiety) or between different NMS

Does deep brain stimulation surgery improve depression and anxiety in people with dystonia?

Overall, anxiety, mood and cognition seem to remain stable postoperatively

There may be some improvement if patients with moderate-severe depression are included (?due to different causes)

Caution for neuropsychiatric problems in the screening for DBS remains very important

[Eggink et al., Parkinsonism Relat Disord 2018]

Do people with dystonia have sleep problems?

Poor night sleep quality in at least half of the patients with cervical (and cranial) dystonia (increased sleep latency, decreased sleep efficiency, with more awakenings and less REM sleep)

Independent from the severity of dystonia

Poor sleep quality influenced by concurrent depression / may worsen quality of life in dystonia

Excessive daytime sleepiness less common complaint

[Hertenstein et al., Sleep Med Rev 2016; Antelmi et al., Sleep 2017]

Do people with dystonia have sleep problems?

Inverse relationship between quality of sleep and efficacy of sensory trick (→ poorer sleep leads to less effective tricks?→ vicious cycle of fatigue and diminished ability to exploit the trick?)

[Benadof et al., Trem Other Hyperkin Mov 2019]

BoNT-A, even if successful in reducing motor symptoms, may not eliminate sleep problems

Effect of GPi-DBS upon sleep: limited evidence (on Meige sdr)

How much can the use of other medications, e.g. benzodiazepines, explain these sleep disturbances?

[Hertenstein et al., Sleep Med Rev 2016]

Do people with dystonia suffer from excessive fatigue?

Moderate-severe fatigue: >40% of adults with dystonia

More fatigue correlates with poorer quality of life, regardless of depression and sleep problems

We don’t know whether this improves with treatment

Fatigue as significant barrier to engagement in exercise and physical activity

[Wagle Shukla et al., Int J Neurosci 2016; McCambridge et al., Front Neurol 2019]

Physical function, gait and balance

Proprioception, visual and vestibular feedback → maintaining upright posture → CD patients and impairments in physical function.

Gait deficits and slower walking speed in people with CD (Barr et al. 2017; Hoffland et al. 2014; Esposito et al. 2017).

Current treatment of CD is focused on the cervical region, however, the evidence highlights the value of **adding physical function assessments, and postural control and/or stepping reaction exercises along with gait rehabilitation into the therapeutic management of dystonia**.

Falling and fear of falling

International survey of a mixed dystonic population on falls experience → found 39% of the 122 respondents reported falling over in the previous 6 months (Boyce et al. 2017, 2020).

- Many of the fallers were living with isolated forms of dystonia such as CD, blepharospasm and focal hand dystonia, and not dystonia directly affecting the trunk and/or lower limbs.
- This suggests falling may be a consequence of the physical function impacts of dystonia, such as poor sensorimotor control, balance and gait function.

From the current research, it appears that people with dystonia report less fear of falling and higher balance confidence than people with other progressive neurological diseases, but similar fear of falling and balance confidence to older healthy people.

Importance of assessing balance and falls risk in the dystonia population during rehabilitation, even in isolated forms affecting the neck, face, voice or hand, and not just people with truncal or lower limb dystonia.

Vision and function

People living with CD exhibit increased postural sway with their eyes open compared to control adults, indicating vision is not used to maintain centre of gravity within the base of support to the same degree as normal (Barr et al. 2017).

This may arise due to the abnormal head posture in CD, meaning vision cannot be relied upon to provide reference points for spatial orientation and balance.

These quotes point to a relationship between head posture, vision and functional impairments, including balance, which may help to explain the incidence of falls and high fear of falling in the dystonia population

Vision impairment secondary to dystonic postures and its impact on physical function, visual compensation and oculomotor fatigue along with potential neurological impairments like spatial neglect should be considered important components of holistic rehabilitation of dystonia.

Vision and function

Participant quotes supporting reduced vision-related quality of life in a powerful way:

- ✓ *'blurriness, tired eyes, eyes not facing what I want to see due to twisted head—have to look out of the corner of my eye or not look at all';*
- ✓ *'focusing difficult judgement of distance in regard to steps and narrow walk ways. I become unbalanced easily';*
- ✓ *'my field of vision is affected when walking by head pulling to right';*
- ✓ *'the only difficulty I have is looking at things directly because my head turns. That is, I find I have to look at some things with my peripheral vision'*

Depression and anxiety: barriers and facilitators to screening and management

Health professionals recruited from 4 Canadian MD clinics in Calgary, Edmonton, Vancouver and Montréal

All experience of >1 AOID patient with co-morbid depression and/or anxiety

Patients with AOID + current/past anxiety or mood disorder from DMRF Canada local support groups and MD clinics

[Martino et al., submitted 2021]

Depression and anxiety: barriers and facilitators to screening and management

Focus groups and interviews: 45 participants (31 F): 10 MD neurologists, 4 psychiatrists, 5 MD nurses, 8 allied health/primary care practitioners, 18 patients

Framework analysis approach → summarizing and classifying data within a thematic framework approach

Indexed based on the Theoretical Domains Framework and the Capability, Opportunity, Motivation and Behaviours (COM-B) system

Behaviour change techniques identified to overcome the identified barriers and promote the implementation of facilitators

[Martino et al., submitted 2021]

Theme 1: Gaps in Knowledge

"The worst part is not knowing whether it is normal or abnormal to feel depressed with my dystonia. Probably anyone would feel depressed walking around with their head on their shoulder. So, I always thought that it was inevitable feeling like this when you have dystonia and that I had to pull myself together with my own resources".
→ PRECONCEPTION OF MOOD ISSUES AS SECONDARY TO OTHER 'PHYSICAL' SYMPTOMS

"An excellent seminar was put on just a few years ago in my city. They did a really good job at describing many of the aspects of dystonia, including depression, and how you could mitigate them by activities, exercise, diet. etc. If the opportunity to follow similar events were available again, I would certainly take it." → DEARTH OF COMPREHENSIVE EDUCATIONAL INTERVENTIONS

"The neurologist is very busy, and the time is very short, but it is almost like after you see the neurologist it would be nice to go to another person who can give you more information or something to read or direct you towards information online". *[Martino et al., submitted 2021]*

Theme 2: Self-isolation and stigma
Theme 3: Beliefs on the origin of emotional symptoms in AOID

"I will have the odd person that will come up to me and ask me if I have Parkinson's, if I am under a lot of stress, or even if I have just come out of rehab […] I have learned over time that people are inquisitive or simply commiserate you, and as a result have become quiet and withdrawn".

"Well, there is always difficulty in getting help for mood symptoms because usually most people, as you know, especially as they grow older, are reluctant to discuss that." → ACCESSING SOCIAL SUPPORT WITHIN PATIENTS' ORGANIZATIONS [Morgan et al., *Disabil Rehabil* 2021]

"What is it that you are anxious about?" Participant [Patient 6]: *"The pain, the people staring, questions, but mostly the pain"*. [Martino et al., *submitted* 2021]

Theme 4: Physicians' communication skills

"And he kept giving me pills. And he did not have the time to talk. That level could be looked at. I think it is not the doctors' fault. The way we pressure doctors to see a patient every 10 minutes. They haven't got the time. And nurses maybe have more time […] to talk to the patient for half an hour and then have the doctor come in for 10 minutes."

[Martino et al., submitted 2021]

Theme 5: Organization of activities at the level of the MDC

"And I think one of the challenges is that our patients are mixed in in our movement disorders clinic, or the patients that come every three months for toxin treatment. For sure having a screening tool with a few questions that they can fill out would make everything easier. So, I would love to have a good conversation with them, but time is limited". [Neurologist]

[Martino et al., submitted 2021]

Theme 6: Local networks of providers

"Around the time of my diagnosis of dystonia, I started feeling anxious around people and often tearful and depressed. My GP told me it was because I had dystonia and to talk to my neurologist. My neurologist disagreed and threw the ball's back into the GP's court. I lived like this for more than 3 years, feeling increasingly hopeless".

[Martino et al., submitted 2021]

Theme 6: Local networks of providers

"I think that behavioural treatments (like mindfulness-based or cognitive-behavioural) are under-used in these patients, and family physicians may not always have great training in non-medical modalities of treatment." [Psychiatrist]

[Martino et al., submitted 2021]

Code	Domain in the Theoretical Domain Framework	Behaviour change technique
Under-diagnosis of depression/anxiety	Skills	Yearly screening with self-rated tools
Lack of nurses' involvement	Professional role	Nurses act as case managers
Lack of coordination of local resources	Environmental and Context Resources	Neurologists act as coordinators of local network of providers
Limited communication with family physicians	Environmental and Context Resources	Timely documentation on screening and treatment
Limited patients' and family physicians' knowledge on mood/anxiety issues in AOID	Knowledge	Multimodal educational package

[Martino et al., submitted 2021]

Moving towards improvement in screening

- In Calgary, symptoms charted only for 20% of patients screened positive for depression/anxiety (in a research study – clinical screening is random)
- Only 31% received active treatment (>80% by family physicians)
- Under-detected without rigorous screening, under-treated when diagnosed
- BDI-II and PHQ-9 highest sensitivity for depression
- BAI and STAI highest sensitivity for anxiety

[Martino et al., *submitted* 2021]

	YES	NO
1. Do you feel NOT refreshed after an overnight sleep?		
2. Do you have difficulties falling or staying asleep?		
3. Do you experience light - headedness or dizziness?		
4. Does fatigue (tiredness) or lack of energy limit your daytime activities?		
5. Do you feel nervous, worried or frightened for no apparent reason?		
6. Do you feel sad or depressed?		
7. Do you suffer from loss of self-confidence due to stigma of visible (cervical) dystonia?		
8. Do you have flat moods without the normal "highs" and "lows"?		
9. Do you have difficulty while eating such as chewing or swallowing?		
10. Do you experience unpleasant sensation such as numbness, tingling or pins and needles in the body area or nearby the body area of your dystonia?		
11. Do you have any speech problems?		
12. Does your dystonia affect your vision for instance when your head is turning to one side?		
13. Do you suffer from pain (painful tension) of the body area or near to the body area of your dystonia (without any other condition in this body area that could cause the pain)?		
14. Do you suffer from any walking difficulty or balance problem?		

ANNALS of Clinical and Translational Neurology
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RESEARCH ARTICLE

Validation of a self-completed Dystonia Non-Motor Symptoms Questionnaire

Lisa Klingelhoefer[1,*], Kallol R. Chaudhuri[2,*], Christoph Kamm[3,4], Pablo Martinez-Martin[5], Kailash Bhatia[6], Anna Sauerbier[2], Maximilian Kaiser[1], Carmen Rodriguez-Blazquez[5], Bettina Balint[6,7], Robert Untucht[1], Lynsey J. Hall[2], Lauritz Mildenstein[3], Miriam Wienecke[1], Davide Martino[8], Olaf Gregor[9], Alexander Storch[3,4] & Heinz Reichmann[1]

Movement Disorders
CLINICAL PRACTICE
RESEARCH ARTICLE

Reliability of DNMSQuest as a Screening Tool for Mood Disorders in Cervical Dystonia

Shameer Rafee, MRCPI, Ihedinachi Ndukwe, MBBS, Sean O'Riordan, MD, FRCPI, and Michael Hutchinson, FRCPI

Assessment tool (total = 88)	Men (27)	Women (61)
BAI ≥ 10	10 (37%)	30 (49%)
BDI ≥ 14	11 (41%)	24 (39%)
HADS-A ≥ 8	9 (33%)	30 (49%)
HADS-D ≥ 8	9 (33%)	29 (48%)
HADS-Total ≥ 16	10 (37%)	29 (48%)

- 88 CD patients, tested within 1 week of previous BoNT-A treatment
- 70% women and 52% men met criteria for mood disorder on ≥1 assessment tool

Movement Disorders
CLINICAL PRACTICE
RESEARCH ARTICLE

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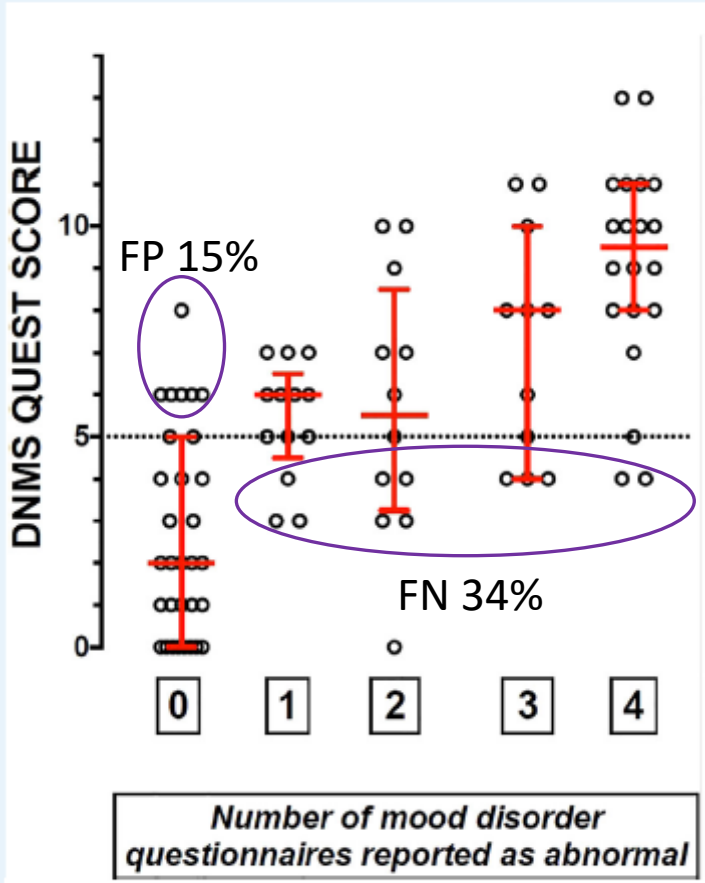


Tool	Sensitivity	Specificity
BAI ≥ 10	85%	60%
BDI-II ≥ 14	85.7%	56.6%
HADS-Anx ≥ 8	76.9%	53.1%
HADS-Dep ≥ 8	78.9%	54%

CAVEATS:

- DNMSQuest cumulative score reflects the whole NMS spectrum
- BAI, BDI and HADS may not be equivalent in detecting anxiety/depression in CD (rigorous validation studies missing)

Depression and anxiety: recommendations for screening and management

Survey development meeting

Delphi survey: 41 expert professionals invited → 23 participated

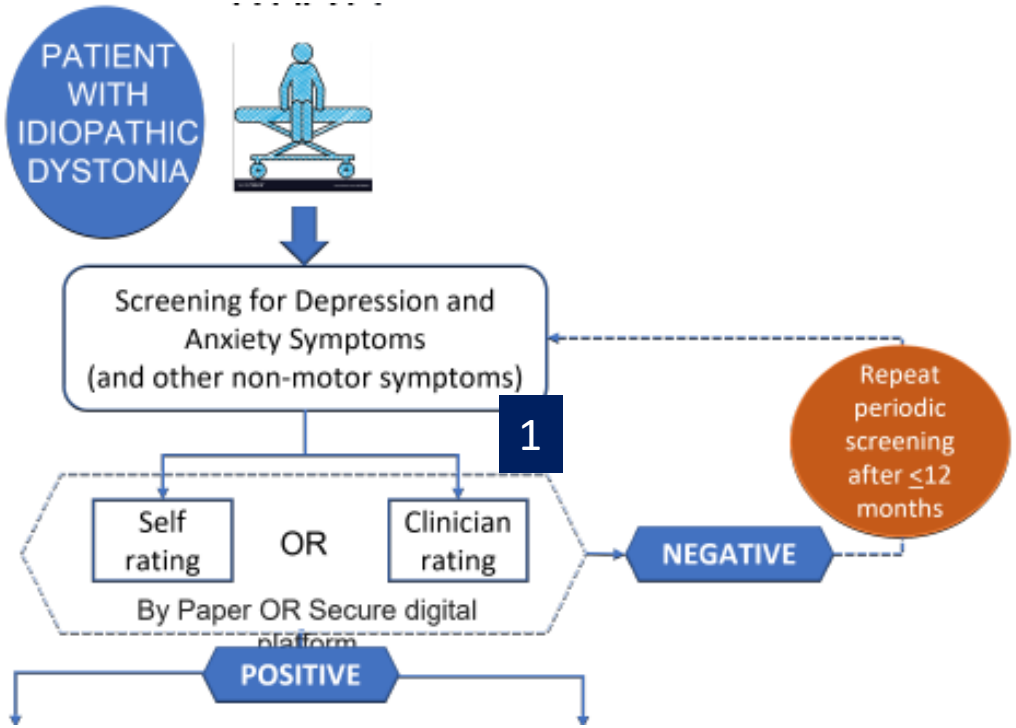
14 F, 9 M

Neurologists, psychiatrists, clinical psychologists, family physicians and nurses

Consensus meeting

[Martino et al., submitted 2021]

Pathway of care – part 1



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MDC Neurologist

MDC Nurse

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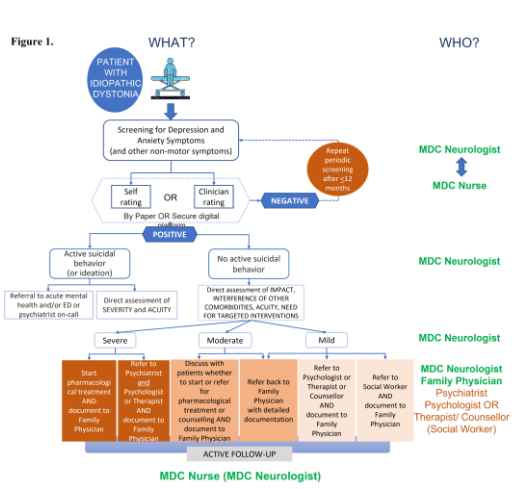
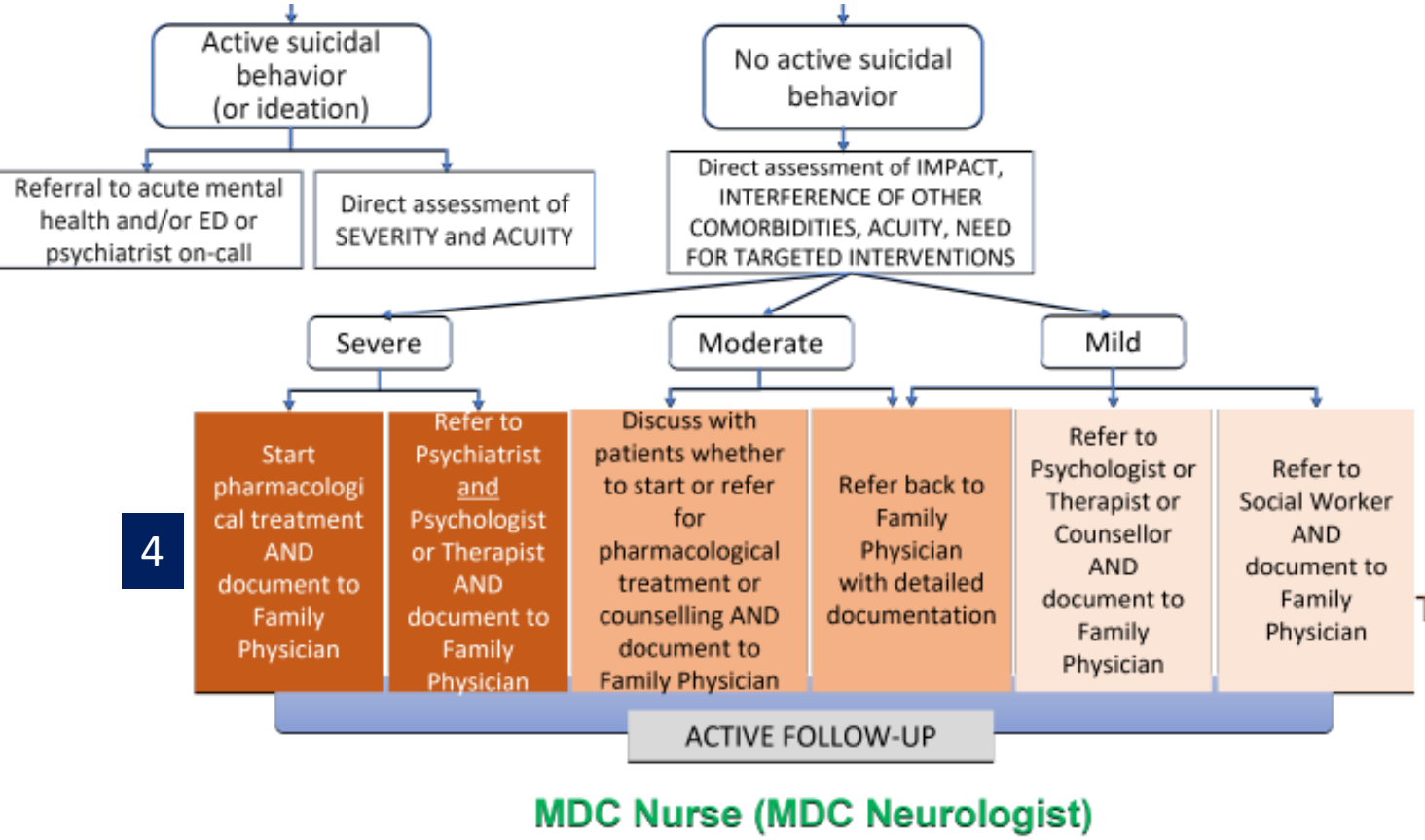


[Martino et al., submitted 2021]

Pathway of care – part 2



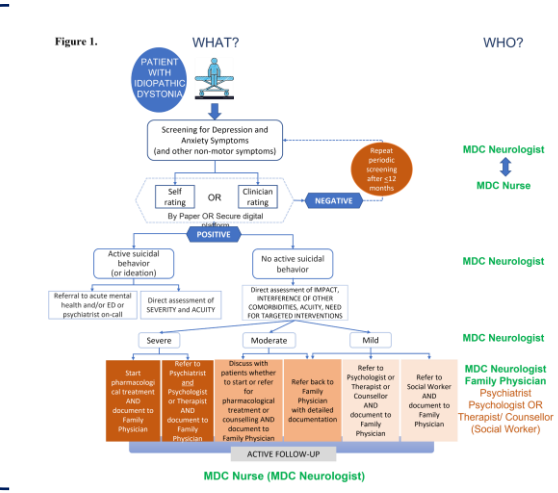
MDC Neurologist

MDC Neurologist

MDC Neurologist
Family Physician
Psychiatrist
Psychologist OR
Therapist/ Counsellor
(Social Worker)

5

6



[Martino et al., submitted 2021]

Rehabilitation in focal dystonias

Rate of utilization varies worldwide

In the US, few therapists see patients with dystonia regularly

In Europe, only half of 24 countries provide access (in Sweden it is second after BoNT-A)

People with CD report effectiveness of adjunct PT but only 31% ever received it

Lack of definitive evidence of effectiveness is a key factor

[Prudente et al., Mov Disord Clin Pract 2017]

Rehabilitation in focal dystonias

Same efficacy
SPT has lower cost

SPECIALIST PHYSIO

- PTs trained for 1 day
- Emphasis on motor training to correct the dystonic postures during ADL

Includes:

- Stretching of dystonic muscles for temporary relaxation to decrease possible contractures
- Passive mobilization to increase ROM and decrease possible joint limitations

2 x 30' sessions/week for 6 weeks
1 x 30' session/week for 6 months
1 session a month for other 6 months

Daily home 10'-15' exercises up to 5 times/day

REGULAR PHYSIO

- PTs not specifically trained in dystonia
- Massage
- Relaxation exercises
- Stretching
- General neck exercises

Current PT treatment remains based on the experience of individual therapists with no standardization.

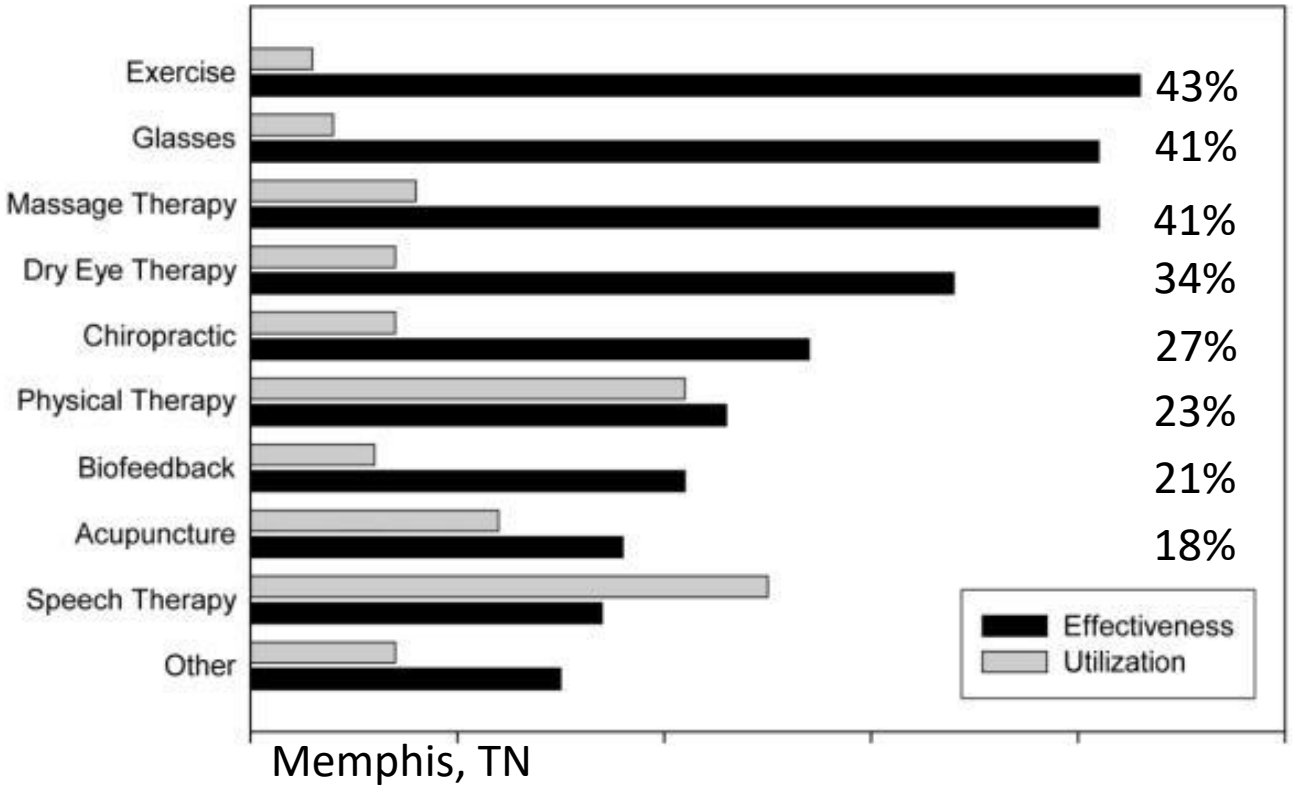
Since CD is relatively rare, experience among therapists is often lacking.

Van den Dool et al. *Arch Phys Med Rehab* 2019

Complementary and alternative medicine:

diverse medical and health care systems, practices and products not generally considered part of conventional medicine

53% of 389 pts → use I-CAM → effectiveness rate 28%
90% of 389 pts → use BoNT-A → effectiveness rate 59%



[Fleming et al., Parkinsonism Relat Disord 2012]

- Lack of evidence
- Can traditional studies reflect accurately CAM effectiveness? problems of specificity and personalization
- Health insurance
- Need for national standards for certifying CAM practitioners or what qualifies as a specific therapy

Exercise and physical activity (PA)

Exercise is not only important for cardiometabolic health in general, but for neurological populations, it also has the potential to improve neuroplasticity and provide therapeutic benefits.

Several neurological populations (Parkinson's disease, Multiple Sclerosis, Stroke) have been extensively investigated for benefits of PA on disease-specific signs such as fatigue, depression and pain, and general cardiovascular and musculoskeletal health (Latimer-Cheung, et al. 2013a, b; Motl et al. 2018).

In these conditions, **remaining active can attenuate disease progression and physical deconditioning, and maintain or improve cognitive function**, and exercise guidelines have been published (Kim et al. 2019).

There **is little understanding of how PA and exercise engagement may affect physical and psychological health in people living with dystonia**.

Exercise guidelines specific to this patient cohort **are needed**.

Common barriers to engaging in PA that were identified were personal barriers, relating to **physical impairments**, and **financial barriers** and a **lack of trained exercise specialists** (McCambridge et al. 2019).

Exercise and physical activity (PA)

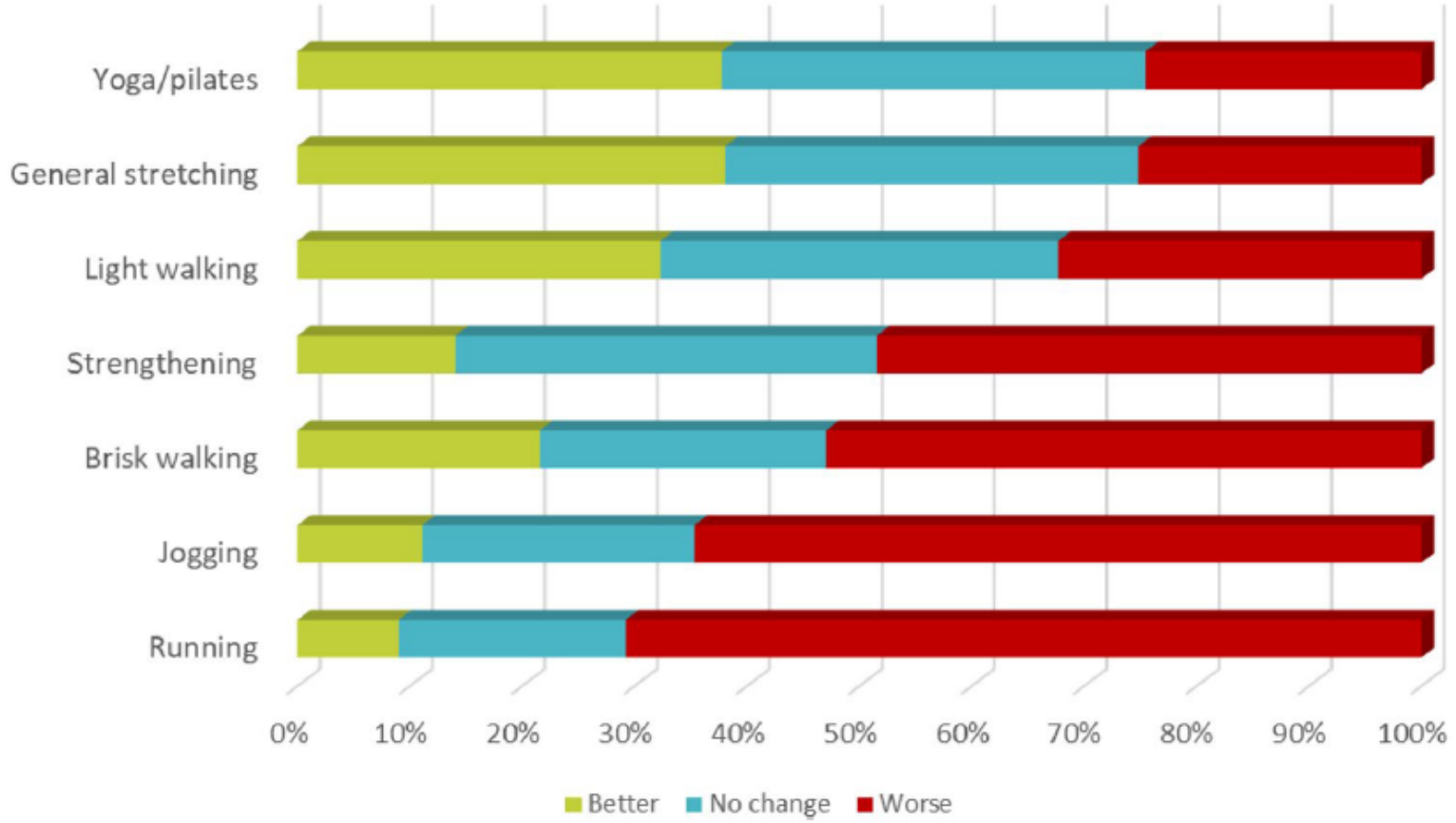
The most reported dystonic symptom barriers were pain, fatigue and poor balance.

Furthermore, many people with dystonia do not exercise as it tends to aggravate a range of dystonic symptoms (McCambridge et al. 2019).

However, a survey revealed that **lower intensity exercise** was less aggravating for dystonia symptoms than high-intensity exercise.

People with dystonia face extensive barriers to physical activity and exercise engagement and more effective tailored interventions are needed to reap the benefits of activity for overall health and well-being.

Exercise and physical activity (PA)



DYSTONIA RESEARCH PROGRAM IN CALGARY

Local PI collaborators

- Dr. Tamara Pringsheim
- Dr. Zahra Goodarzi
- Dr. Justyna Sarna
- Dr. Brandy Callahan
- Dr. Scott Patten
- Dr. Daniel Kopala-Sibley
- Dr. Fiona Clement
- Dr. Khara Sauro
- Dr. Tolulope Sajobi
- Drs. Na Li and Meng Wang
- Dr. Zelma Kiss
- Dr. Bruce Pike
- Dr. Nicholas Strzalkowski
- Dr. Tyler Cluff

Coordinators and scientists

- Ms Ela Nosrat
- Ms Beatrice Anghelescu
- Ms Yamile Jasaui
- Dr. Fil Cortese

CIHR IRSC
Canadian Institutes of Health Research | Instituts de recherche en santé du Canada

SEVENTH FRAMEWORK PROGRAMME

Parkinson Alberta

Dystonia Medical Research Foundation Canada
Fondation de Recherche Médicale sur la Dystonie Canada
serving all dystonia-affected persons
désservant toutes personnes atteintes de dystonie

Fellows and trainees

- Dr. Nicholas Cothros
- Dr. Alex Medina
- Ms Rachel Sondergaard
- Ms Eleanor Campbell
- Ms Janet Adeoti
- Dr. Gabriel Amorelli
- Dr. Ali Abusrair
- Dr. Cinthia Terrobi-Chamba
- Dr. Conrad Rockel
- Ms. Baeleigh Van der Zweeg

International collaborators

- Dr. Laura Avanzino (Genova)
- Dr. Mark Edwards (SGUL, London)
- Dr. Francesca Morgante (SGUL, London)
- Dr. Christos Ganos (Charitè, Berlin)
- Dr. Lorena Fernandez de la Cruz and coll. (Karolinksa, Stockholm)
- Dr. Hyder Jinnah (Atlanta)
- Dr. Joel Perlmutter (St. Louis)
- Dystonia Coalition

Tools and Resources:

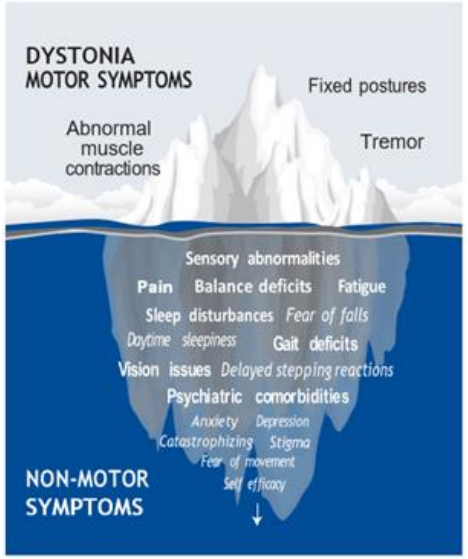


Image adapted from a figure in Bradnam, L.V., Meiring, R.M., Boyce, M. et al. Neurorehabilitation in dystonia: a holistic perspective. J Neural Transm (2020).

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www.dystoniacanada.org/nonmotor

Tools and Resources:

www.dystoniacanada.org/mental-health-resources

Tools and Resources:

www.dystoniacanada.org/support

DYSTONIA MEDICAL RESEARCH FOUNDATION CANADA

FONDATION DE RECHERCHE MÉDICALE SUR LA DYSTONIE CANADA

serving all dystonia-affected persons
désservant toutes personnes atteintes de dystonie

Thank you to Dr. Davide Martino for sharing this presentation

www.dystoniacanada.org