Rehabilitation and Multidisciplinary Approach in Dystonia

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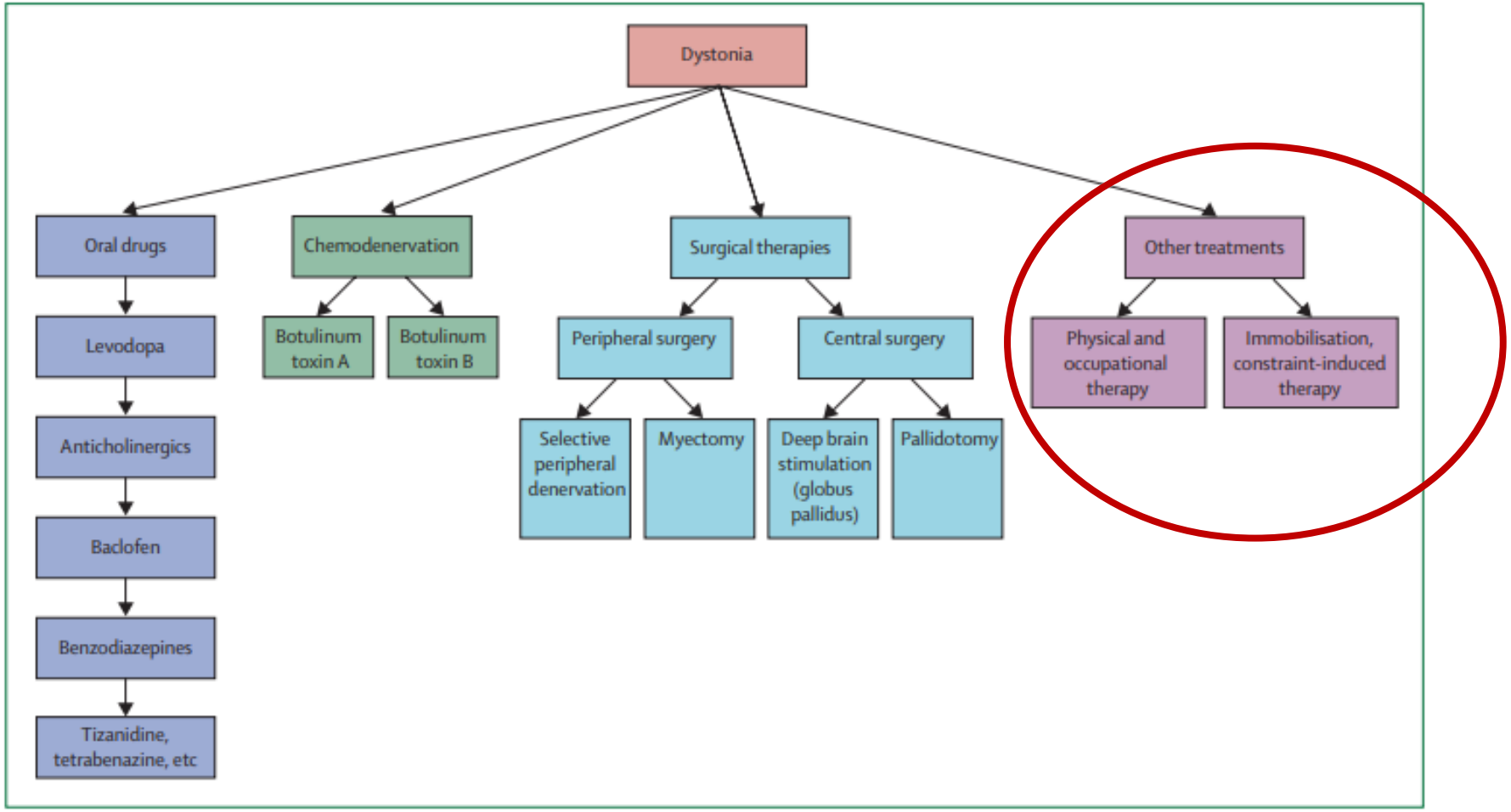
International Parkinson and Movement Disorder Society European Section

Dystonia: Bridging Theory and Hands-On Expertise- İstanbul



Jankovic J. Treatment of dystonia. Lancet Neurol. 2006

European Journal of Neurology 2011, **18:** 5–18

EFNS guidelines on diagnosis and treatment of primary dystonias

A. Albanese[a,b], F. Asmus[c], K. P. Bhatia[d], A. E. Elia[a,b], B. Elibol[e], G. Filippini[a], T. Gasser[c], J. K. Krauss[f], N. Nardocci[a], A. Newton[g] and J. Valls-Solé[h]

Physical therapy and rehabilitation

Recently, there have been an increased number of publications showing that physical therapy and rehabilitation procedures have an important role in the care of patients with dystonia [167,168]. A number of studies have reported motor improvement in patients with writer's cramp and other forms of focal dystonia following physical treatment, and sensory and motor retraining [169–171].

A class II study showed that transcutaneous electrical nerve stimulation caused a significant beneficial effect in patients with writer's cramp [172]. A class IV study of patients with primary writing tremor showed beneficial effect of writing after training with a device that supported the hand and held the pen [173]. This evidence adds to the already reported class III study [117] where physical therapy was combined with BoNT/A injections in patients with cervical dystonia.

Musicians with dystonia may have specific benefit from motor retraining. A class IV study reported the long-term subjective outcome in a large series of musicians with focal dystonia after treatment with different medical and physical options: 54% of patients reported an alleviation of symptoms, 33% improved with trihexiphenidyl, 49% with BoNT, 50% with pedagogical retraining, 56% with unmonitored technical exercises and 63% with ergonomic changes [167].

Recommendations and good practice points

1. Transcutaneous electrical nerve stimulation to forearm flexor muscles administered is probably effective in patients with writer's cramp [172] (level B).

2. We encourage the conduction of new randomized controlled studies on these potentially useful interventions, particularly for patients with upper limb dystonia (good practice point).

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Jean-Pierre BLETON

Physiotherapy of focal dystonia: a physiotherapist's personal experience

J.-P. Bleton

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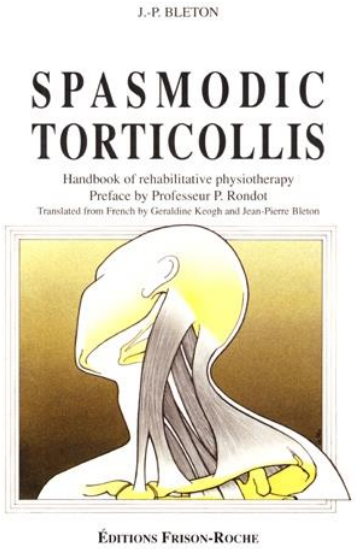
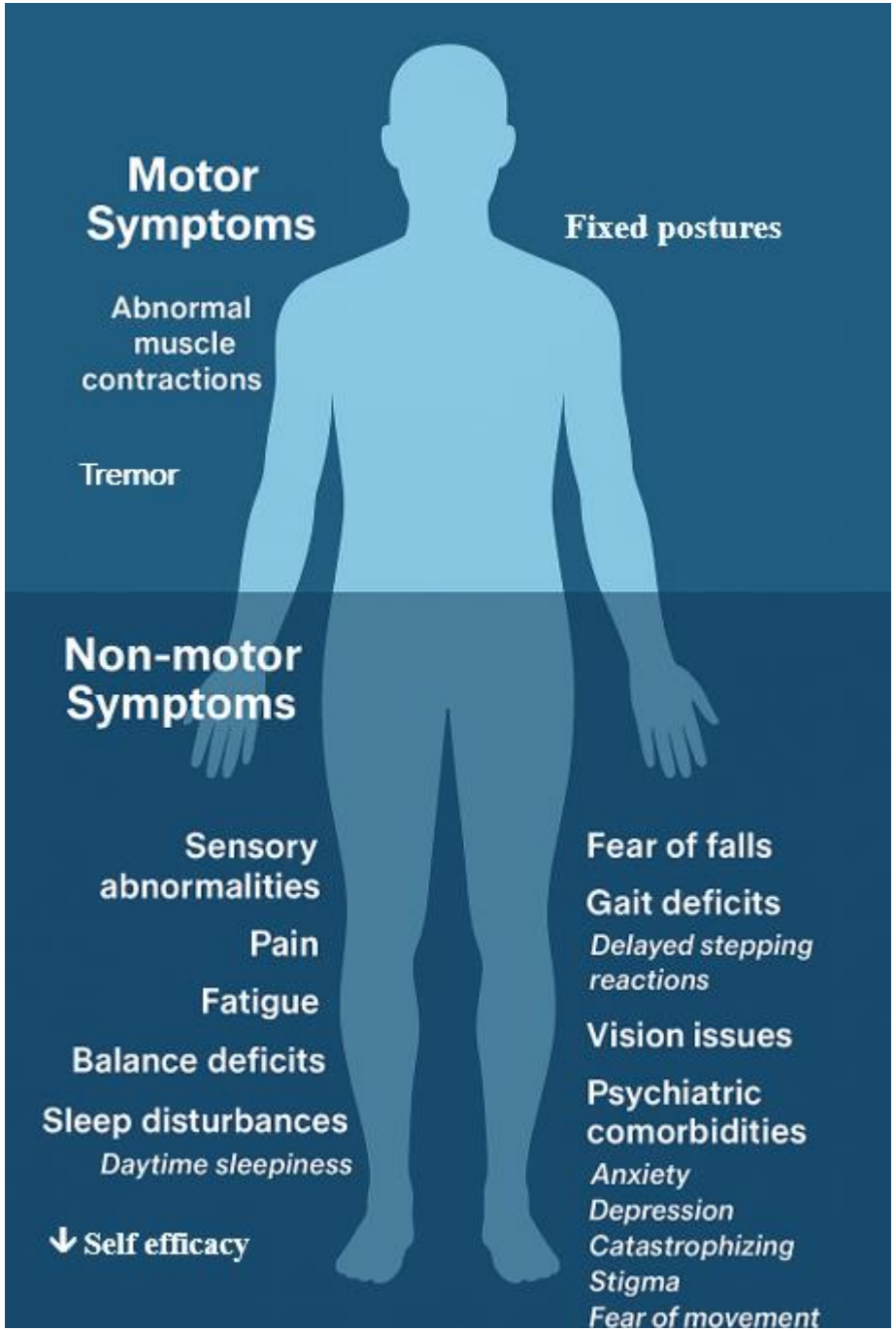




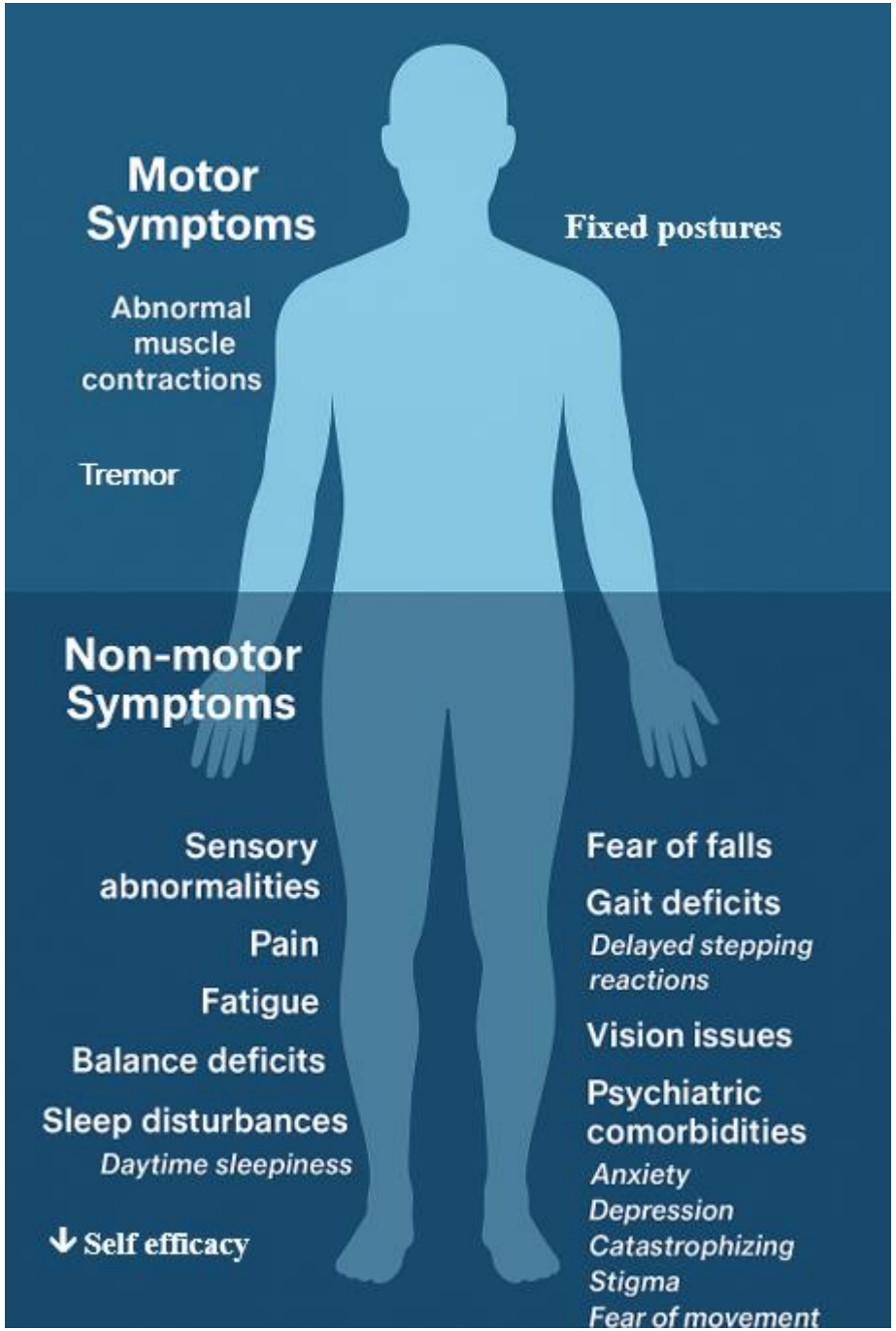
- Recent evidence has revealed that patients with dystonia experience a range of functional and non-motor deficits that have a detrimental effect on their ability to engage in daily activities and their overall health-related QoL
- assessment and management involve non-motor signs and symptoms and not only the dystonic body part
- In Cervical Dystonia, and in this population:

reduced postural control and walking speed,

high fear of falling and actual falls,

visual compensation for the impaired neck posture,

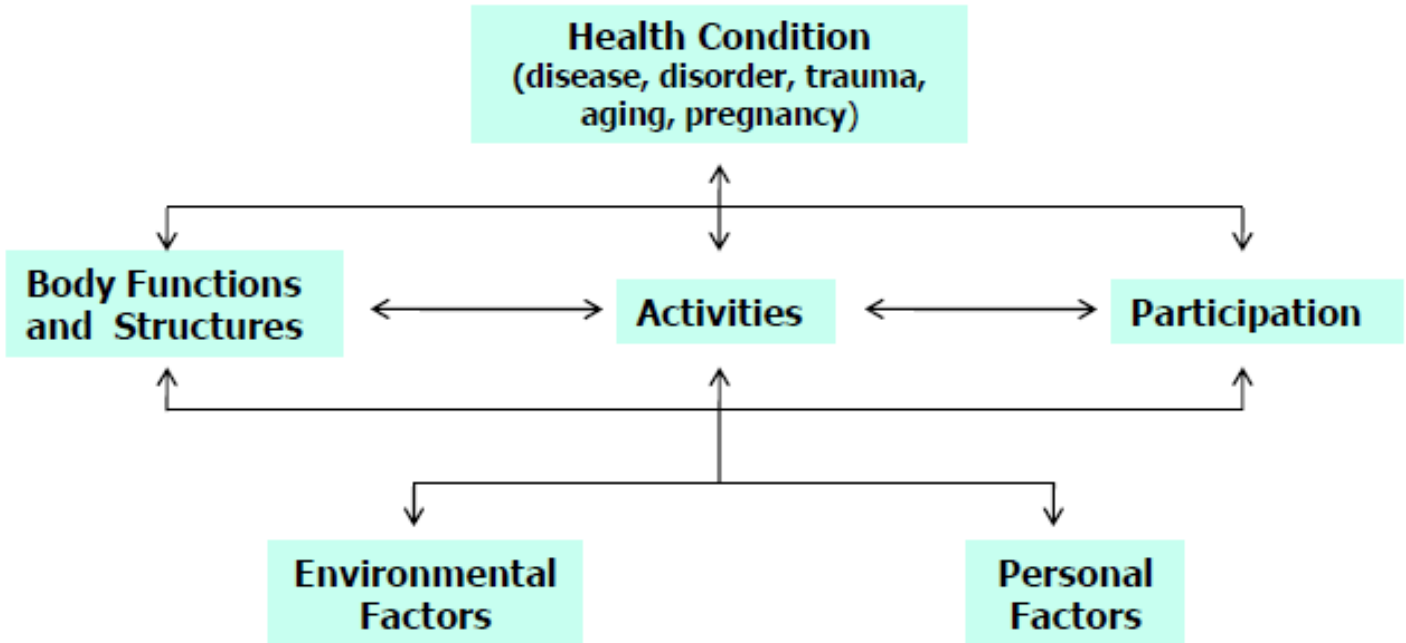
a myriad of non-motor symptoms including pain, fatigue, sleep disorders and anxiety and depression



- Motor symptoms are visible and recognized
- Non-motor symptoms are often hidden but equally impactful
- Both require attention for effective management of dystonia
- Although rehabilitation has its place in dystonia, a **holistic approach** is needed to manage the wide range of symptoms, both motor and non-motor, and to improve the quality of life experienced by people living with dystonia

REHABILITATION

ICF: International Classification of Functioning, Disability and Health (WHO-2001)



ICF: Contextual Factors

Environmental Factors

1. Products and technology (assistive products and technology; design-construction-building products)
2. Natural environment and human-made changes to environment
3. Support and relationships (family, friends, health professionals, others)
4. Attitudes (family, friends, health professionals, others)
5. Services, systems and policies

Personal Factors

Age, sex, educational status, personality, behaviour

Functioning: An umbrella term encompassing all body functions & structures, activities and participation

Disability: An umbrella term including impairments of body functions & structures , activity limitations or participation restrictions

Holistic approach to person with (*DYSTONIA*) a health condition

Biomedical Model → Bio-psycho-social Model

REHABILITATION

A process aimed at enabling persons with disabilities to reach and maintain their optimal physical, sensory, intellectual, psychiatric and/or social functional levels, thus providing them with the tools to change their lives towards a higher level of independence...

United Nations

Rehabilitation is defined as “a set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment”.

World Health Organization

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Rehabilitation is a set of interventions that assist individuals with health conditions , who experience or are likely to experience disability, to achieve and maintain optimum functioning in interaction with their environments

Rehabilitation requires multiprofessional team work.

Multiprofessional rehabilitation team works in an interdisciplinary, holistic approach.
Individualised management plan is set in a shared-decision making process between the patient and the team.

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- There is significant disability associated with focal dystonia due to pain and impairment, reduction in participation of activities of daily living (ADLs), and employment problems.
- Focal dystonia's impact extends beyond motor symptoms, often leading to loss of confidence, depression, social withdrawing, insomnia and fatigue.
- The disability associated with focal dystonia is within the scope of rehabilitation interventions, but these interventions are rarely used as an adjunct to standard treatment.

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- In a survey in 24 European countries, rehabilitation was easily accessible in only half of the countries surveyed.

Valadas A, et al. Management of dystonia in Europe: a survey of the European network for the study of the dystonia syndromes. Eur J Neurol. 2016

- In Sweden, where physical therapy is more commonly used in the management of cervical dystonia, it is the second most effective intervention after BoNT according to patients.

Silfors A, et al. Living with dystonia. A questionnaire study among members of the Swedish Dystonia Patient Association. L€akartidningen 2002

- People with cervical dystonia have reported physical therapy to be one of the most effective adjunct therapies to standard care, but only 31% of patients have ever received rehabilitation.

Comella C, Bhatia K. An international survey of patients with cervical dystonia. J Neurol 2015

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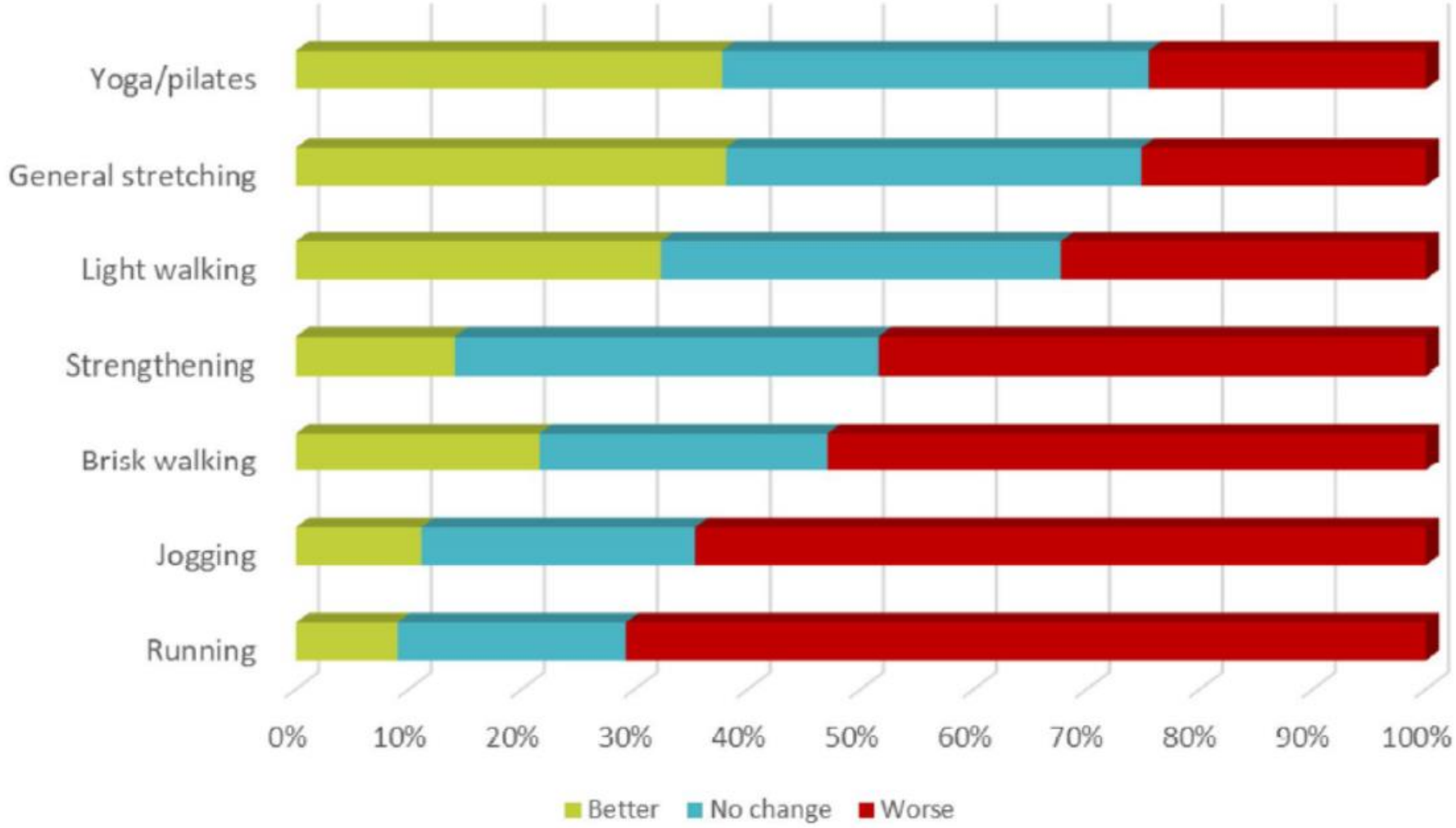
Reasons for the inadequate use of rehabilitation approaches are:

- There is a *belief and/or awareness* that rehabilitation interventions may worsen the current situation

- The lack of definitive evidence regarding their effectiveness!

McCambridge A et al. Physical activity, sedentary behavior, and barriers to exercise in people living with dystonia. Front Neurol 201910:1121



Obvious higher impact exercise tended to worsen dystonia, while low impact exercise may be beneficial, or at least not aggravating for around 2/3 of dystonia

European Journal of Neurology 2010, **17** (Suppl. 1): 107–112

Physiotherapy of focal dystonia: a physiotherapist's personal experience

J.-P. Bleton

The approach of the physiotherapist to each form of dystonia is individual and has to be specific. There is not one single method but several strategies related to the different clinical forms. Although there is no standard programme applicable to all forms of

There is no standart programi but main steps are:

- to stop abnormal movements by specific relaxation techniques
- to reinforce the corrective muscles by bringing about the head to the opposite side to the torticollis attitude
- to avoid muscular overflow and co-contractions by precise and analytic activation of the corrective muscles
- then, to replace spasms by voluntary and adapted movements of the head

muscles involved in the correction of dystonic postures are trained by drawing loops, curves and arabesques. The aim of rehabilitation is not to enable patients with writer's cramp to write as they used to, but to help their dysgraphia evolve towards a fast, fluid and effortless handwriting. A reshaping of the sensory cortical hand representation appears to be associated with clinical improvement in patients with dystonia after rehabilitation.

Movement Disorders
Vol. 24, No. 15, 2009, pp. 2187–2198

Review

Paramedical Treatment in Primary Dystonia: A Systematic Review

Cathérine C.S. Delnooz, MD,[1] Martin W.I.M. Horstink, MD, PhD,[1] Marina A. Tijssen, MD, PhD,[2] and Bart P.C. van de Warrenburg, MD, PhD[1]*

J Neurol (2014) 261:1857–1865
DOI 10.1007/s00415-013-7220-8

REVIEW

The effectiveness of physiotherapy for cervical dystonia: a systematic literature review

Joke De Pauw · Kevin Van der Velden · Jill Meirte · Ulrike Van Daele · Steven Truijen · Patrick Cras · Rudy Mercelis · Willem De Hertogh

Systematic Review of Rehabilitation in Focal Dystonias: Classification and Recommendations

Cecília N. Prudente, PT, PhD,[1] Lena Zetterberg, PT, PhD,[2] Annika Bring, PT, PhD,[2] Lynley Bradnam, PT, PhD,[3] Teresa J. Kimberley, PT, PhD[1,4,]*

Evidence of rehabilitation therapy in task-specific focal dystonia: a systematic review

Arne HAUTEKIET [1] *, Katrien RAES [1], Sybille GEERS [1], Patrick SANTENS [2], Kristine OOSTRA [1]

European Journal of Physical and Rehabilitation Medicine 2021

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MDPI

Systematic Review

Physiotherapy for Cervical Dystonia: A Systematic Review of Randomised Controlled Trials

Dana Loudovici-Krug [1,*], Steffen Derlien [1], Norman Best [1] and Albrecht Günther [2]

Movement Disorders
Vol. 24, No. 15, 2009, pp. 2187–2198

Review

Paramedical Treatment in Primary Dystonia: A Systematic Review

Cathérine C.S. Delnooz, MD,[1] Martin W.I.M. Horstink, MD, PhD,[1] Marina A. Tijssen, MD, PhD,[2] and Bart P.C. van de Warrenburg, MD, PhD[1]*

- There were no class A1 or A2 studies and therefore, level 1 or 2 practice recommendations for a specific intervention could not be deducted.
- Many papers were case reports, mostly with a very limited number of patients and a clear publication bias for beneficial effects of a particular paramedical intervention.
- Some potentially interesting interventions come from class B studies, which include physical therapy in addition to botulinum toxin injections (BoNT-A) in cervical dystonia; sensorimotor training and TENS in writer's cramp; and speech therapy added to BoNT-A injections in laryngeal dystonia.
- Good quality clinical studies are therefore warranted.

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The effectiveness of physiotherapy for cervical dystonia: a systematic literature review

J Neurol (2014) 261:1857–1865

Joke De Pauw · Kevin Van der Velden ·

- After screening, **16 studies** were retained.
- The methodological quality of most studies was low.(small sample sizes, lack of randomization or blinding, and diversity in therapeutic techniques and outcome measures).
- **Only 7**studies were clinical trials
- The reported physiotherapy treatments: EMG biofeedback training, muscular elongation, postural exercises and electrotherapy.
- Improvements in head position, pain, cervical ROM, QoL and ADL
- Cautious interpretation on the effectiveness of physiotherapy as an adjuvant therapy
- Additional high quality trials are needed

Systematic Review of Rehabilitation in Focal Dystonias: Classification and Recommendations

MOVEMENT DISORDERS CLINICAL PRACTICE 2018; 5(3): 237–245

Cecília N. Prudente, PT, PhD,[1] Lena Zetterberg, PT, PhD,[2] Annika Bring, PT, PhD,[2] Lynley Bradnam, PT, PhD,[3] Teresa J. Kimberley, PT, PhD[1,4,*]

- The search revealed 1207 publications. 45 were included in the final review: randomized controlled trials (8), quasi-experimental studies (5), single subject design studies (4), case series (21), and case reports (7).
- This systematic review is the first to classify rehabilitation studies in focal dystonias based on the theoretical basis of the interventions to help to bring together seemingly diverse approaches for improved comparison across studies.
- The GRADE level for each category ranged from very low-to-low. Despite a lack of high-level evidence, intensive movement practice and neuromodulation combined with motor training should be further explored.
- The most frequent limitation observed in the studies reviewed was small sample sizes
- There is a need for more objective and specific assessment tools for measuring changes in disease status

Categories of Intervention Approaches

Movement Practice	Intensive motor practice and training to recover voluntary control of the affected body part
Training with Constraint	Constraining compensatory movements in unaffected joints during motor training to support improvements in motor performance
Sensory Reorganization	Focus on reorganization of the cortical sensory map to induce motor improvements
Normalization of Muscle Activity with External Techniques	Application of external methods (active or passive) to normalize muscle activity levels and regain function
Neuromodulation with Training	Use of neuromodulation methods combined with motor practice to alter brain excitability and recover voluntary control
Compensatory Strategies	Use of compensatory or new movement strategies to replace the abnormal motor program and improve motor function

Systematic Review of Rehabilitation in Focal Dystonias: Classification and Recommendations

Cecília N. Prudente, PT, PhD,[1] Lena Zetterberg, PT, PhD,[2] Annika Bring, PT, PhD,[2] Lynley Bradnam, PT, PhD,[3] Teresa J. Kimberley, PT, PhD[1,4,*]

- The key component of each category is distinct (i.e., movement practice vs. use of biofeedback).
- Utilization of the proposed classification system allows improved comparison between studies, invites further exploration for the strongest evidence, and allows future meta-analyses.
- Theoretical basis and identification of the intervention category within the classification will promote a hypothesis-driven approach, which is essential for progress in the field.
- The majority of studies used impairment-based assessments while a few evaluated patients' activity and participation levels.
- Specific recommendations for clinical applications are premature. Intensive movement practice and neuromodulation combined with motor training for rehabilitation of cervical and hand dystonias have the strongest level of evidence and should be further explored.

toxins

MDPI

Systematic Review

Physiotherapy for Cervical Dystonia: A Systematic Review of Randomised Controlled Trials

Dana Loudovici-Krug [1,*], Steffen Derlien [1], Norman Best [1] and Albrecht Günther [2]

- This systematic review emphasizes physical therapy and evaluates it by including 6 studies.

  It is difficult to make a clear PT recommendation based on the individual 6 RCTs

- Additional physical therapy and active home exercise programs appear to be useful.

- Further research should focus on the dose–response principle to emphasize physical therapy treatment modalities.

The effectiveness of physiotherapy for patients with isolated cervical dystonia: an updated systematic review and meta-analysis

Shimelis Girma Kassaye[1,2], Willem De Hertogh[2], David Crosiers[3,4], Esayas Kebede Gudina[1] and Joke De Pauw[2*]

Abstract

Background Cervical dystonia is a movement disorder typically characterized by a patterned and twisting movement of sustained or intermittent muscle contractions. Recently, new clinical trials are emerging, highlighting the potential benefit of physiotherapy (PT) on disease outcomes. Thus, the objective of this review is to update the effectiveness of PT on cervical dystonia disease outcomes and subsequently perform a meta-analysis.

Methods Interventional studies published in English with adult patients with isolated cervical dystonia following a physiotherapy program were included. Relevant articles were searched in PubMed (MEDLINE), Web of Science, and Scopus. Cochrane and Joanna Briggs Institute risk of bias checklists were used for quality reporting. Meta-analysis was done using Review Manager 5.3 statistical software and a pooled mean difference for pain was presented.

Results Fourteen articles were included in the review and two articles were included in the meta-analysis. The meta-analysis revealed that PT intervention had a significant effect on pain reduction scale (-5.00, 95% CI -6.26, -3.74) when used as an additional therapy with botulinum toxin (BoNT) injection. Additionally, findings indicate a possible positive effect of PT disease severity, disability, and quality of life.

Conclusions Physiotherapy in addition to BoNT is recommended to decrease pain. The findings suggest a reduction of disease severity, disability, and improvement in quality of life. The variety in the type and duration of PT interventions did not allow a clear recommendation of a specific type of PT.

Keywords Cervical dystonia, Torticollis, Physiotherapy, Physical therapy

Why is Rehabilitation Necessary?

A Critical Adjunct to BoNT

- BoNT addresses the muscle overactivity,
- Rehabilitation targets the underlying sensorimotor dysfunction and faulty movement patterns and activity participation- functioning
- A combined approach (BoNT + Rehab) has been shown to improve outcomes compared to BoNT alone, particularly for pain and quality of life.
- Rehab empowers patients to take an active role in their management.

Core Principles of Dystonia Rehabilitation

- **A Neurorehabilitation Framework**

➢ **Patient-Centered:** Treatments are highly individualized based on the patient's specific presentation and goals

➢ **Multimodal:** Combines various techniques (manual therapy, exercise, sensorimotor training, etc.).

➢ **Adjunctive:** Best used in conjunction with BoNT therapy.

Timing of Rehabilitation

The "Window of Opportunity"

- **Optimal Timing:** Initiate rehabilitation 1-2 weeks *after* BoNT injection.
- **Rationale:** The toxin has started to take effect, reducing muscle overactivity and making it easier for patients to participate in active, motor-retraining exercises.
- **Continuing Care:** Rehabilitation should be an ongoing process, including a consistent home exercise program, to maintain gains between injections.

Physical Therapy

A Step-by-Step Approach

Step 1: Assessment: Thoroughly evaluate posture, range of motion, motor control, and sensory perception.

Step 2: Inhibition: Use techniques like gentle stretching or manual pressure to temporarily reduce muscle spasm.

Step 3: Postural Re-education: Retrain the patient's awareness of a neutral head and neck position.

Step 4: Motor Learning: Facilitate new, non-dystonic movement patterns.

PT Modality: Stretching & Soft Tissue Work

Releasing Tension and Promoting Movement

- **Gentle Passive Stretching:** Release hypertonic muscles (e.g., SCM, trapezius).
- **Active Stretching:** Encourage patient-led stretching within their non-painful range.
- **Myofascial Release & Massage:** Improve tissue extensibility and reduce trigger points.
- **Goal:** Decrease pain and prepare the muscles for active re-education.

PT Modality: Strengthening

Targeting Antagonistic and Core Muscles

- **Weakness Post-BoNT:** Muscles injected with BoNT will be weakened.
- **Strengthening Antagonists:** Strengthen muscles opposite the dystonic pattern (e.g., strengthen neck flexors in a patient with retrocollis).
- **Core and Postural Muscles:** Focus on deep neck flexors and scapular stabilizers to provide a stable foundation for head control.
- **Goal:** Improve muscle balance and support more controlled movement.

PT Modality: Sensorimotor Retraining

The core of neuroplasticity

Mechanism: Aims to improve the brain's "map" of the body.

- **Mirror Therapy:** Patients watch themselves in a mirror, which can help retrain perception and movement.
- **Proprioceptive Training:** Exercises with eyes closed to improve the sense of where the head is in space.
- **Motor Imagery:** Mental practice of normal head movements.
- **Dual-Task Training:** Performing head movements while completing another task to reduce conscious control and promote more natural movement

PT Modality: External Devices

Tools for Sensory Feedback

- **Kinesiotaping:** Provides continuous sensory input to the skin and muscles, helping to "remind" the brain of proper posture.
- ***Cervical Collars***: *Used cautiously and briefly to provide support and sensory feedback*.
- **Vibrotactile Stimulation:** Placing a small vibrating device on the neck to provide sensory input and modulate muscle activity.

PT Modality: Biofeedback

Making the Invisible Visible

- **EMG Biofeedback:** Uses surface electrodes to measure muscle activity.
- **How it Works:** Patients can see or hear a signal that corresponds to their muscle tension, allowing them to learn how to relax overactive muscles and activate underactive ones.
- **Goal:** Promote conscious motor control and relaxation.

Occupational Therapy

Bridging the Gap to Daily Life

- **Functional Assessment:** Evaluate how CD affects daily activities (e.g., dressing, driving, eating).
- **Adaptive Strategies:**
  - **Ergonomic Modifications:** Adjusting workstations, computer monitors, or car headrests.
  - **Assistive Devices:** Using adapted tools for writing or eating.
- **Task-Specific Training:** Practicing a specific task repeatedly with cues to improve efficiency and reduce the dystonic pattern.
- **Energy Conservation:** Teaching patients how to manage fatigue.

Recent Knowledge: Emerging Therapies

The Future of Rehabilitation

- **Transcranial Magnetic Stimulation (TMS):** Non-invasive brain stimulation that can modulate cortical excitability.
  - **Research:** Studies show promise in reducing dystonic symptoms and improving motor control.
  - **Status:** Still largely a research modality for CD.
- **Extracorporeal Shock Wave Therapy (ESWT):** Has been used to reduce muscle spasticity in other conditions and is being explored for CD.
- **Transcranial direct current stimulation**
- **……**
- **……**

Non-Motor Symptoms

A Holistic View

- **Pain Management:** Manual therapies, TENS, heat/cold packs, and relaxation techniques.
- **Psychological Support:** Cognitive-behavioral therapy (CBT) can help manage anxiety and depression, which often co-occur with CD.
- **Stress Reduction:** Mind-body techniques like meditation, deep breathing, and yoga can help

Patient Education & Home Program

Sustaining the Gains

- **Education is Key:** Patients must understand their condition and the goals of rehabilitation to be active participants.
- **Daily Practice:** A consistent, daily home exercise program is crucial for reinforcing new motor patterns.
- **Exercise "Snacks":** Encourage short, frequent practice sessions throughout the day.
- **Examples:** Gentle stretches, postural cues, and relaxation exercises.

Recent Knowledge: The Power of Multimodal Approaches

Evidence-Based Combination

- Recent systematic reviews and meta-analysis consistently show that a multimodal approach (BoNT + PT) is more effective than BoNT alone
- **Key Findings:**
  - Significant reduction in pain
  - Improvement in disease severity
  - Enhanced quality of life
- There is no single "best" rehabilitation approach; the key is a tailored, multi-faceted plan

Materials and Methods: A total of 46 cervical dystonia patients who received botulinum toxin type A injection and met the inclusion criteria at Ankara University Faculty of Medicine, Department of Neurology, Movement Disorders Outpatient Clinic were included in the study. The patients were randomized into two groups: 23 in the study group and 23 in the

Conclusion: This study demonstrated that personalized exercise programs in cervical dystonia patients who received botulinum toxin type A were particularly effective in reducing pain and also provided additional improvements in severity, disability, and quality of life. The literature on the effect of regular exercise programs after botulinum toxin type A injection is limited, and especially for long-term outcomes, further studies are needed.

Dystonia Questionnaire-24 (CDQ-24). In addition, the level of difficulty in performing the exercises, the perceived benefit of exercise after botulinum toxin type A injection, the level of limitation in daily living activities due to fatigue, and the discontinuation of exercise due to pain were questioned. All patients were evaluated at weeks 0, 6, and 12.

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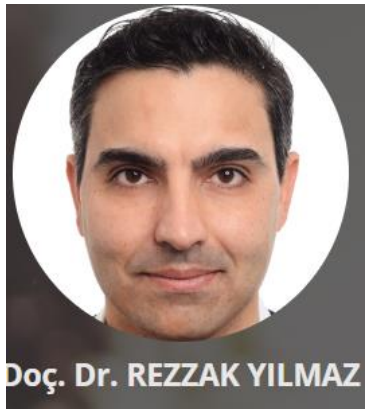
Torticollis, stretching exercise

Key Points

- Multimodal rehabilitation of dystonia is not something completely new
- Many clinicians are currently treating patients using a multimodal approaches.
- We need more studies not only RCT but real life situations
- The concept is of picking the therapies ideally suits best with patient's goal

Many thanks to you all and my colleagues

Prof. Dr. Muhittin Cenk Akbostancı'



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