

Rehabilitation

The way to make the guideline ready for use in the Dutch rehabilitation centres

Lotte Heutinck and Imelda de Groot

Disclosure

Lotte Heutinck	Nothing to disclose
Imelda de Groot Relevant activities:	Names involved companies
<ul style="list-style-type: none"> • International clinical trials • Advisory board • Educational courses • (Inter) National scientific studies 	<ul style="list-style-type: none"> • Santhera • Italfarmaco • Roche • PTC • Sarepta • Focal Meditech • Baat Medical • Hankamp Rehab • Intespring • Xsense • TMSI

Standard of Care: rehabilitation (I)

- Rehabilitation personnel include:
Physicians, physical therapists, occupational therapists, speech-language pathologists, orthotists, and durable medical equipment providers
- Team requires an understanding of DMD
- Multidisciplinary rehabilitation assessment includes:
measures of passive, ranges of motion, muscle extensibility, posture and alignment, strength, function, quality of life, and participation in all normal activities of everyday life

Standard of Care: rehabilitation (II)

Assessments

North Star Ambulatory Assessment (NSAA) and timed function tests are foundational clinical assessments of function during the ambulatory period and should be done every 6 months

Intervention

- Direct treatment of the multidisciplinary team
- Prevention of contracture and deformity: (K)AFO, position, casting, standing
- Exercise and activity: regular aerobic with or without assistance
- Falls and fracture prevention and management
- Management of learning, attentional, and sensory processing differences
- Participation: all stages
- Pain prevention and management

Care for DMD in the Netherlands (I)

- Academic hospitals
- Rehabilitation centres
- Home ventilation centres
- Primary health care



Care for DMD in the Netherlands (II)

- Yearly follow up in academic hospitals
- Follow up in rehabilitation centres including assessments
- Treatment in rehabilitation centres
- Treatment in primary health care in combination with rehabilitation centres



**Guidelines for the yearly academic follow up
and guidelines for the rehabilitation care**

Careful care

Care organization and guideline use for
Duchenne muscular dystrophy in the
Netherlands

Interviews with DMD professionals

Semi-structured interviews

3 topics:

1. How is the care for boys and men with DMD organized?
2. What do you think of the international guideline*?
3. What is your ideal situation?

(Half) yearly follow-up

Standard visits/assessments in all hospitals:

- ✓ Genetic counselling
- ✓ Neurologist
- ✓ Rehabilitation physician
- ✓ Care coordinator
- ✓ Pulmonary function tests
- ✓ Spinal assessment/radiograph
- ✓ Physiotherapist: timed and functional tests
- ✓ Cardiac function: ECG&Echo
- ✓ Anthropometry
- ✓ Corticosteroid management

Some hospitals include:

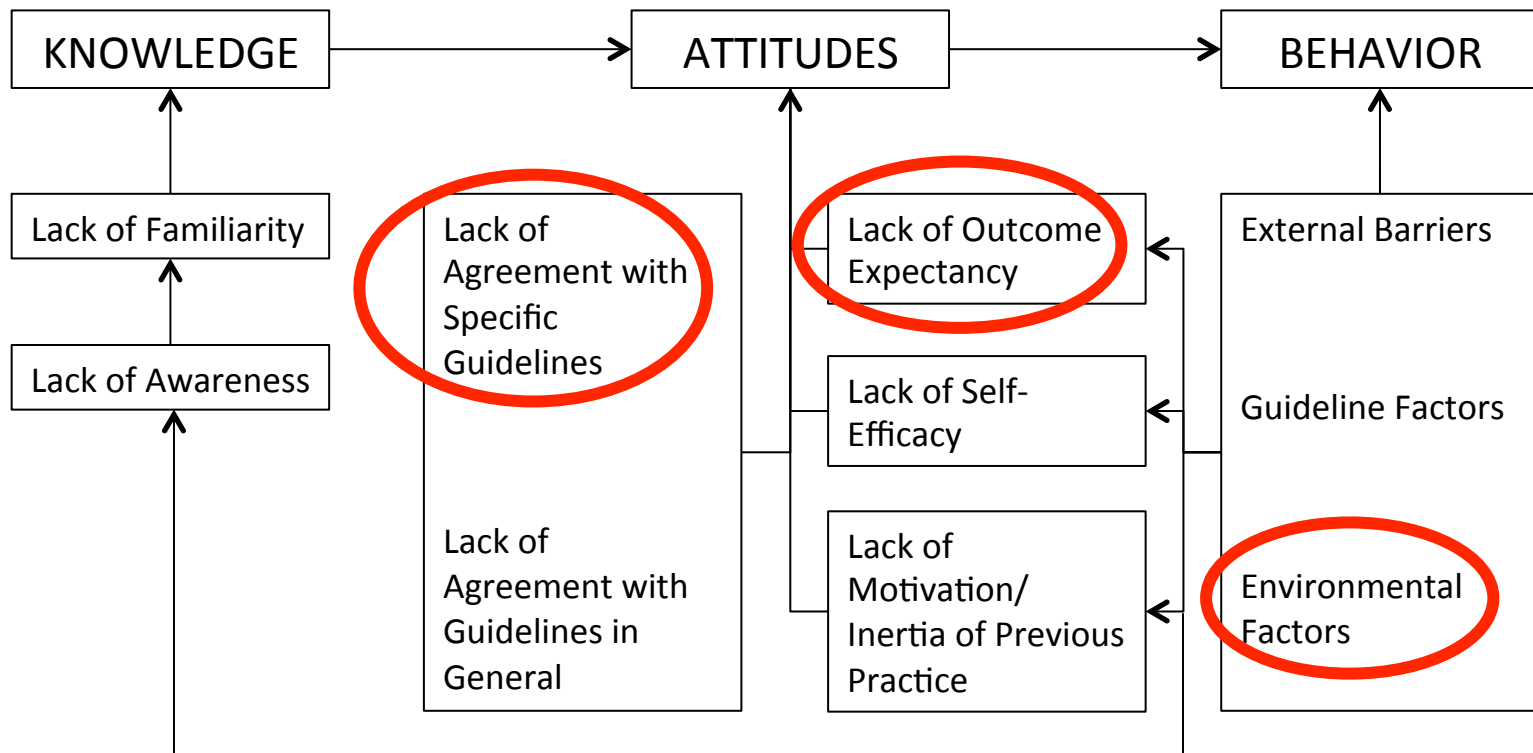
- ✓ Pediatrician
- ✓ Occupational therapist
- ✓ Speech therapist
- ✓ Dietician

**Multidisciplinary
outpatient
transition clinic**

Available on indication:

- ✓ Psychosocial management
- ✓ Orthopedic surgeon
- ✓ Radiologist
- ✓ Pulmonologist
- ✓ Urologist
- ✓ Endocrinologist
- ✓ Gastroenterologist
- ✓ Occupational therapist
- ✓ Speech therapist
- ✓ Dietician
- ✓ Intensivist

Barriers for guideline use (I)



Barriers for guideline use (II)

Lack of Agreement with Specific Guideline

Broad interpretation

- Depends on expertise

Need of more scientific proof

- Expert opinion

Incomplete information

- Contractures, splinting
- Spinal radiograph
- Height measurement

Lack of outcome expectancy

Overall

- Added value

Rehabilitation management

- Which timed and functional tests to use

Bone health

- Bone densitometry
- Little indication for treatment

Environmental factors

Finances

- Care coordinator
- Capacity

Time and logistics

- 1 day
- Structure

Communication

- Rehabilitation centres
- Between hospitals

The ideal situation (I)

Implementation of the new guideline

- Implement the guideline collectively
 - Good communication between professionals
 - Good communication with the field
- Form groups for each specialism
- Uniform care
 - Minimum care/basic set of tests

The ideal situation (II)

Expertise and logistics

- Minimum number of patients
- Yearly follow up in a limited number of hospitals
 - Throughout the country
- Expertise should be accessible on every care level

Open questions regarding rehabilitation

Uniformity for:

- Orthotic management
- Tests to perform for follow up
- Wheelchair seating
- Use of arm supports
- Physiotherapy
- Sports
- Transition
- Adult care
- etc



The way to proceed with the rehabilitation guideline

- Supported by a grant of the Medische Specialisten Federatie and organized by Kennis Instituut Medische Specialisten
- Starting in September 2018
 - Inventarisation of the topics to address
 - Organizing working groups on different topics
 - Literature update
 - Consensus agreement on topics in the guideline
 - Implementation



**THANKS
FOR
LISTENING**