

# MDF ANNUAL CONFERENCE

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## PHYSICAL THERAPY IN DM

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# Physical Therapy in DM

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DM is a multi-systemic disorder

2 genotypes/phenotypes – DM1 and DM2

DM1 has 3 sub phenotypes –

Congenital, Juvenile/Pediatric and Adult onset

# Physical Therapy in DM

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Data from the literature regarding

- Symptoms/problems/concerns
- Use of rehabilitation therapies
- Use of orthotics and assistive devices

***If you build a rare disease registry, will they enroll and will they use it?***  
**Methods and data from the National Registry of Myotonic Dystrophy (DM)  
and Facioscapulohumeral Muscular Dystrophy (FSHD)**

Hilbert JE, Kissel JT, Luebke EA, Martens WB, McDermott MP, Sanders DB, Tawil R,  
Thornton CA, Moxley, RT III.

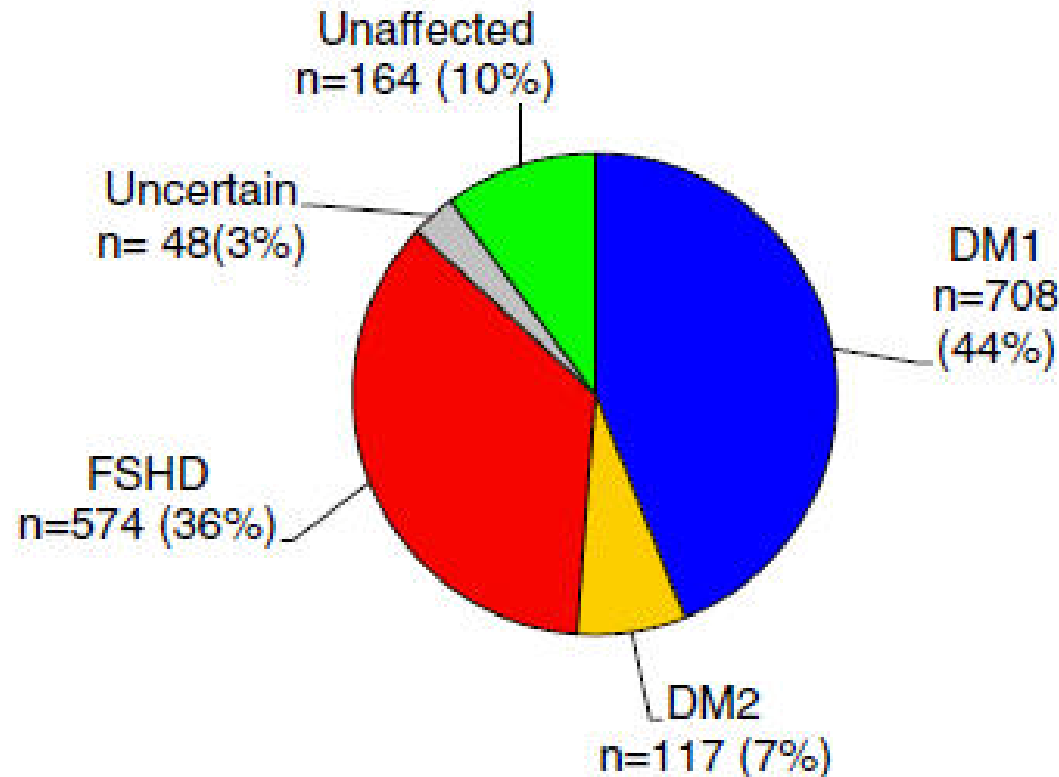
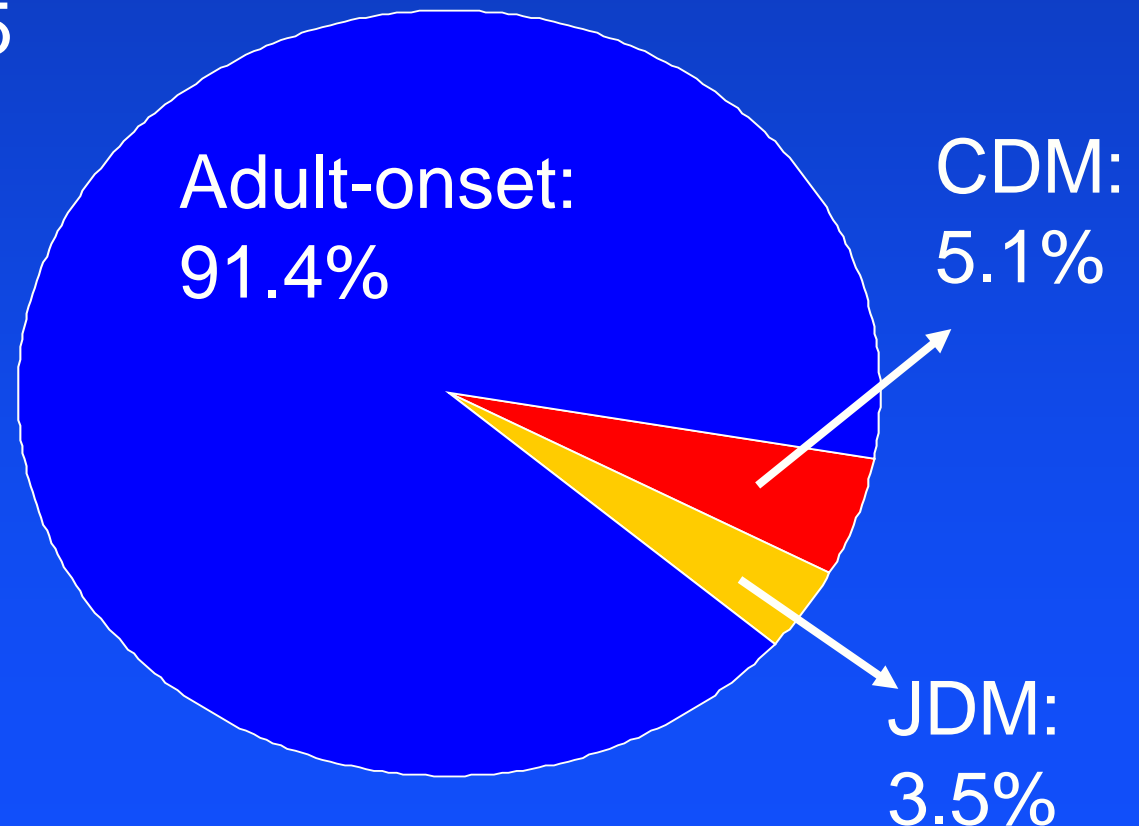


Fig. 1. Data summarizes the classification of the 1611 affected members of the Registry (frequency and percent of total enrollment).

# Frequency of different forms of DM1 in the National Registry

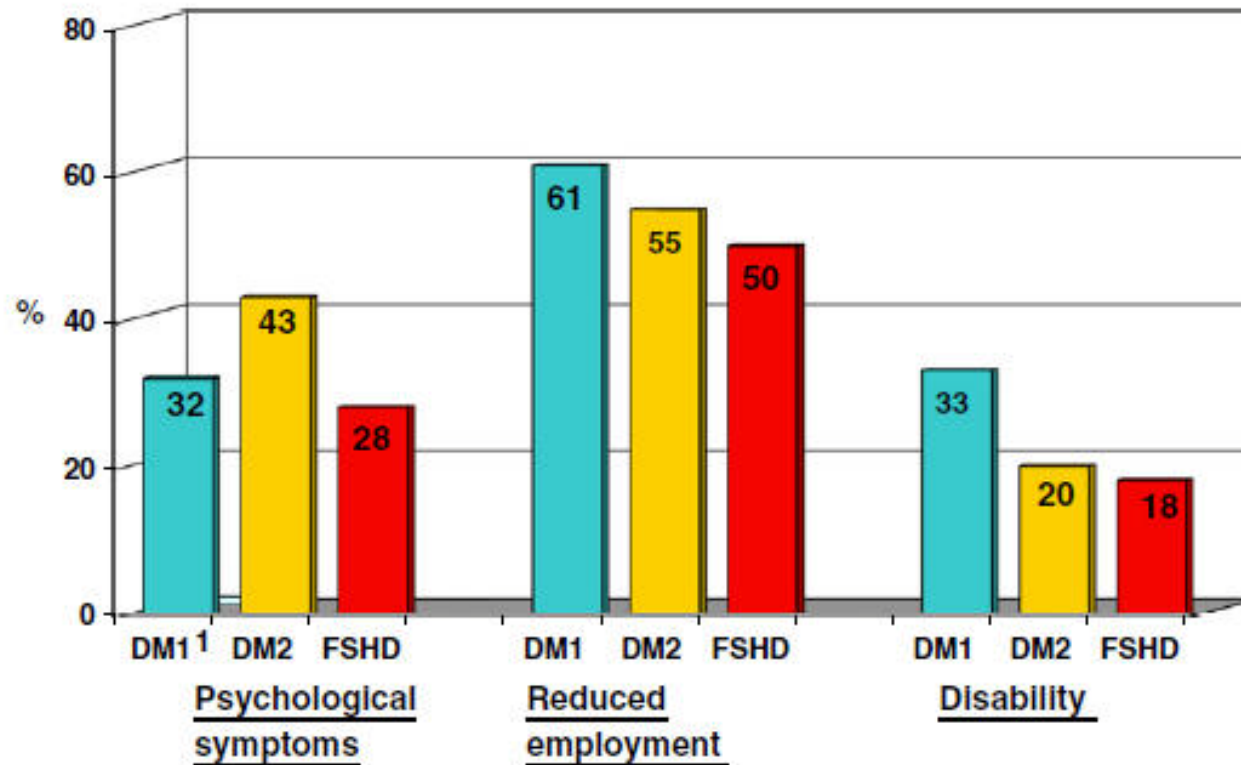
651 DM1 members currently enrolled in the Registry

- Adult-onset: n=595
- CDM: n=33
- JDM: n=23



# ***If you build a rare disease registry, will they enroll and will they use it?*** **Methods and data from the National Registry of Myotonic Dystrophy (DM) and Facioscapulohumeral Muscular Dystrophy (FSHD)**

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**Fig. 4.** Data summarize percentages of Registry members who reported psycho-social burdens at baseline. A significantly higher percentage of DM2 members reported psychological problems compared to DM1 ( $p=0.03$ ) and FSHD ( $p=0.003$ ) members at baseline. Disease manifestations reduced employment opportunities in a significantly higher percentage of DM1 members compared to FSHD members at baseline ( $p=0.0008$ ). No other significant differences were apparent at baseline.

# ***If you build a rare disease registry, will they enroll and will they use it?*** **Methods and data from the National Registry of Myotonic Dystrophy (DM) and Facioscapulohumeral Muscular Dystrophy (FSHD)**

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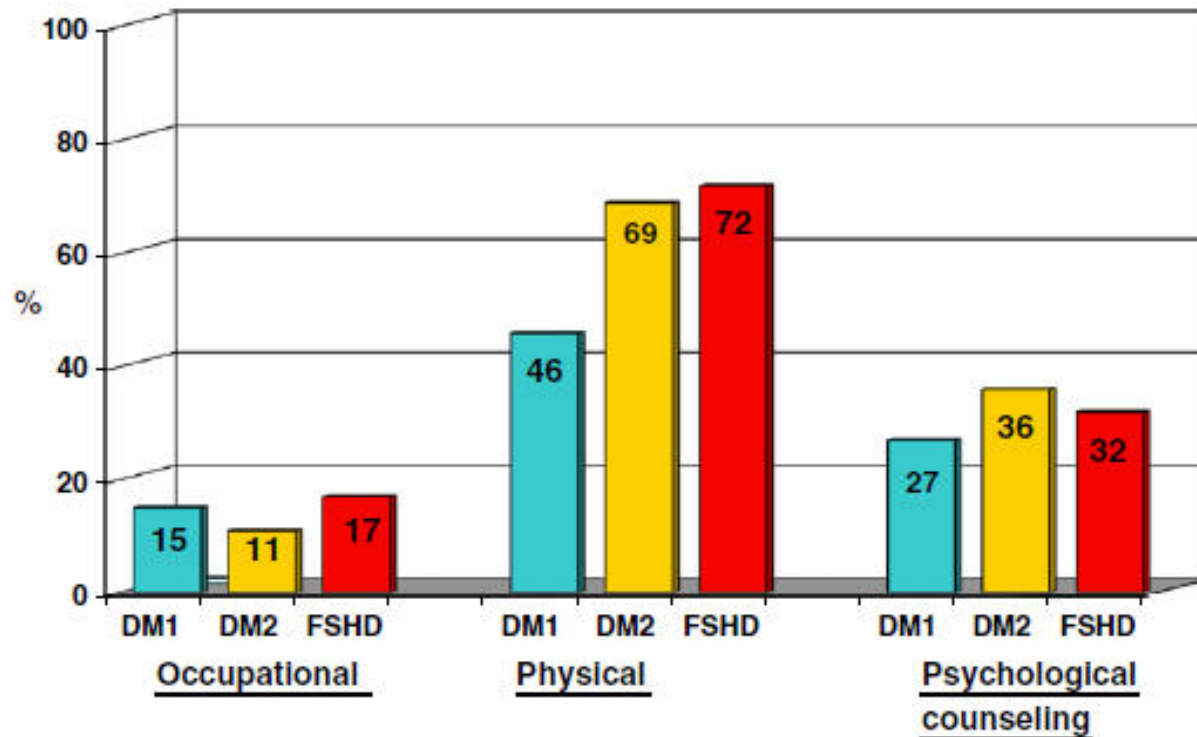
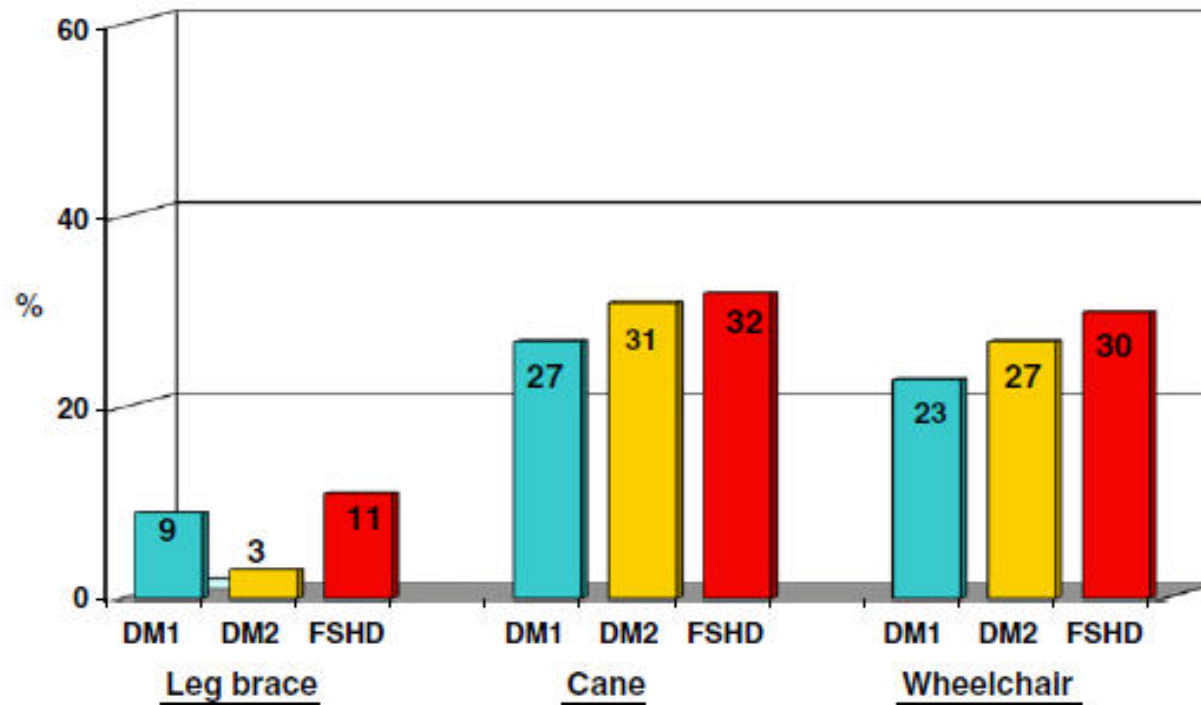


Fig. 3. Data summarize percentages of Registry members who reported use of various therapies at baseline. A significantly lower percentage of DM1 members reported use of physical therapy compared to DM2 ( $p < 0.0001$ ) and FSHD ( $p < 0.0001$ ) members at baseline. No other significant differences were apparent at baseline.

# ***If you build a rare disease registry, will they enroll and will they use it?*** **Methods and data from the National Registry of Myotonic Dystrophy (DM) and Facioscapulohumeral Muscular Dystrophy (FSHD)**

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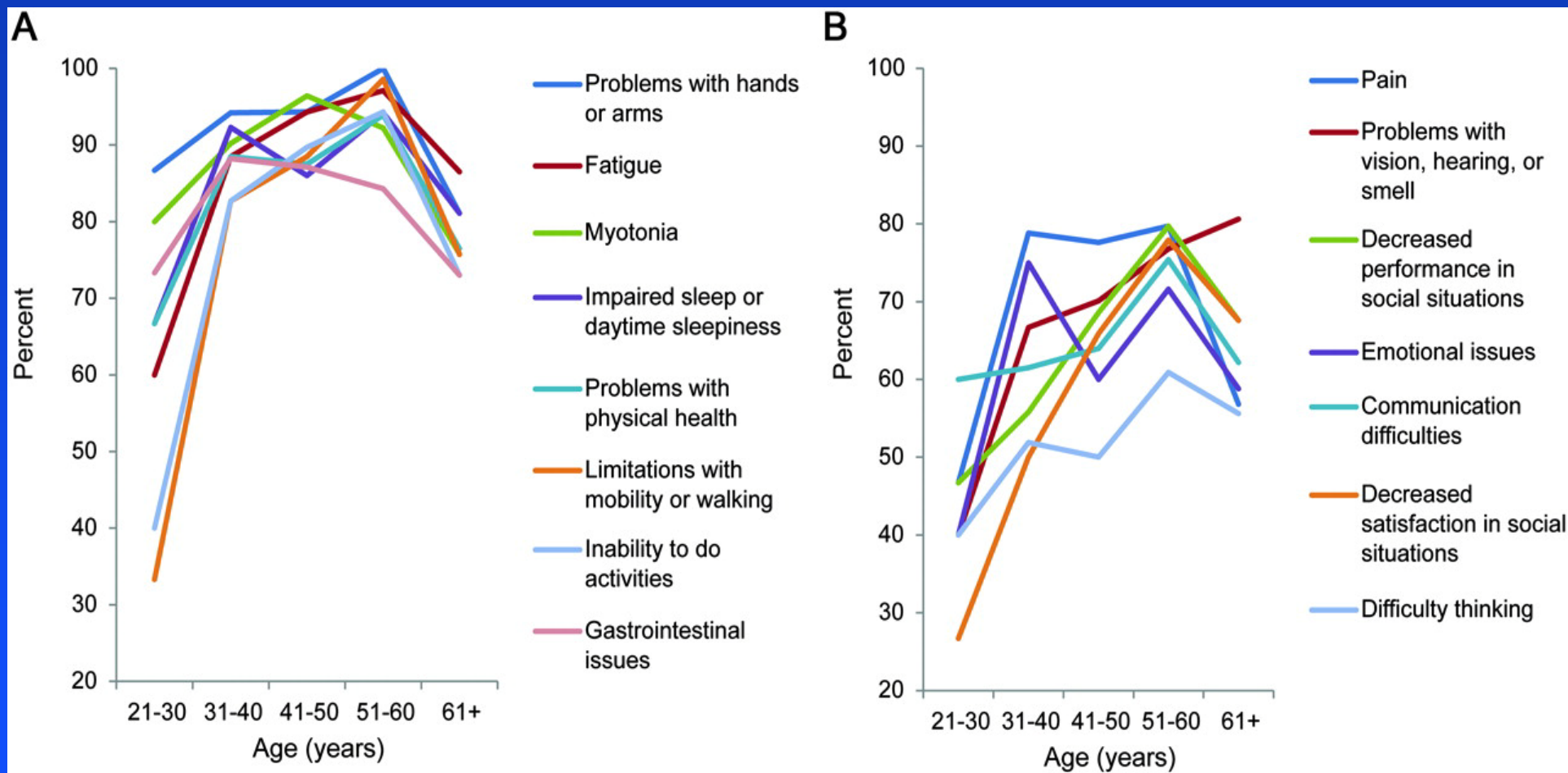


**Fig. 2.** Data summarize percentages of Registry members who reported use of assistive devices for ambulation at baseline. Wheelchair use is shown for either short or long distances. A significantly higher percentage of FSHD members reported use of wheelchairs at baseline compared to DM1 ( $p = 0.02$ ) and similar use compared to DM2 ( $p = 0.55$ ). A significantly lower percentage of DM2 members reported use of leg braces compared to DM1 members ( $p = 0.03$ ) and FSHD members ( $p = 0.008$ ) at baseline. No other significant differences were apparent at baseline. After follow-up, wheelchair use was reported as "always" (for both short and long distances) by 6.3% of DM1, 8.3% of DM2, and 18.1% of FSHD members.



# Patient-reported impact of symptoms in myotonic dystrophy type 1 (PRISM-1)

Heatwole C, Bode R, Johnson N, Quinn C, Martens W, McDermott MP, Rothrock N, Thornton CA, Vickrey B, Victorson D, Moxley, RT III.



# Physical Therapy in DM

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## Pain in DM

- 50-85% of patients report pain
- Most common sites include low back and legs
- Pain affects quality of life
- Medications, heat, massage, etc. have all been used
- No controlled trials reported

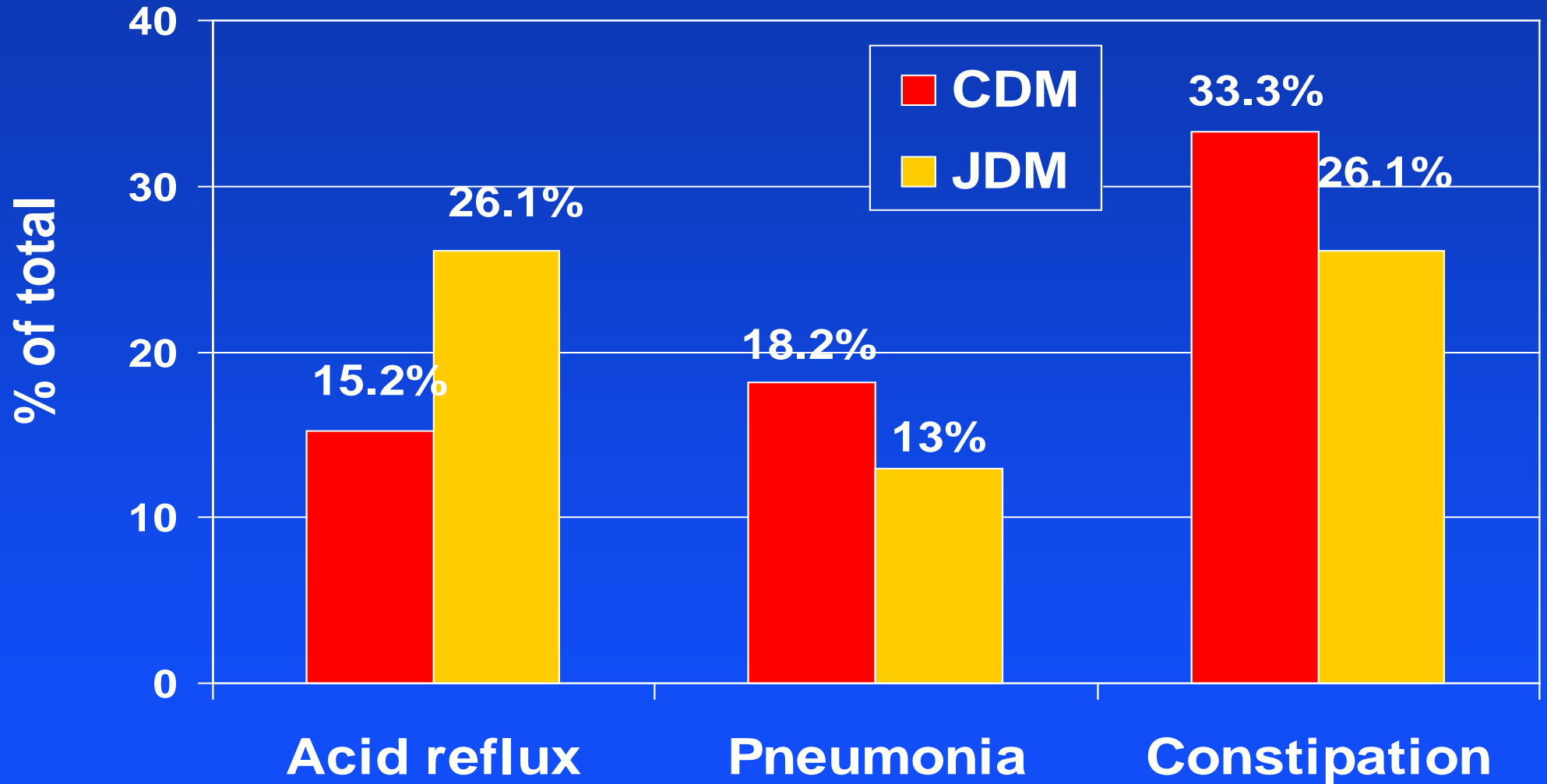
# Physical Therapy in DM

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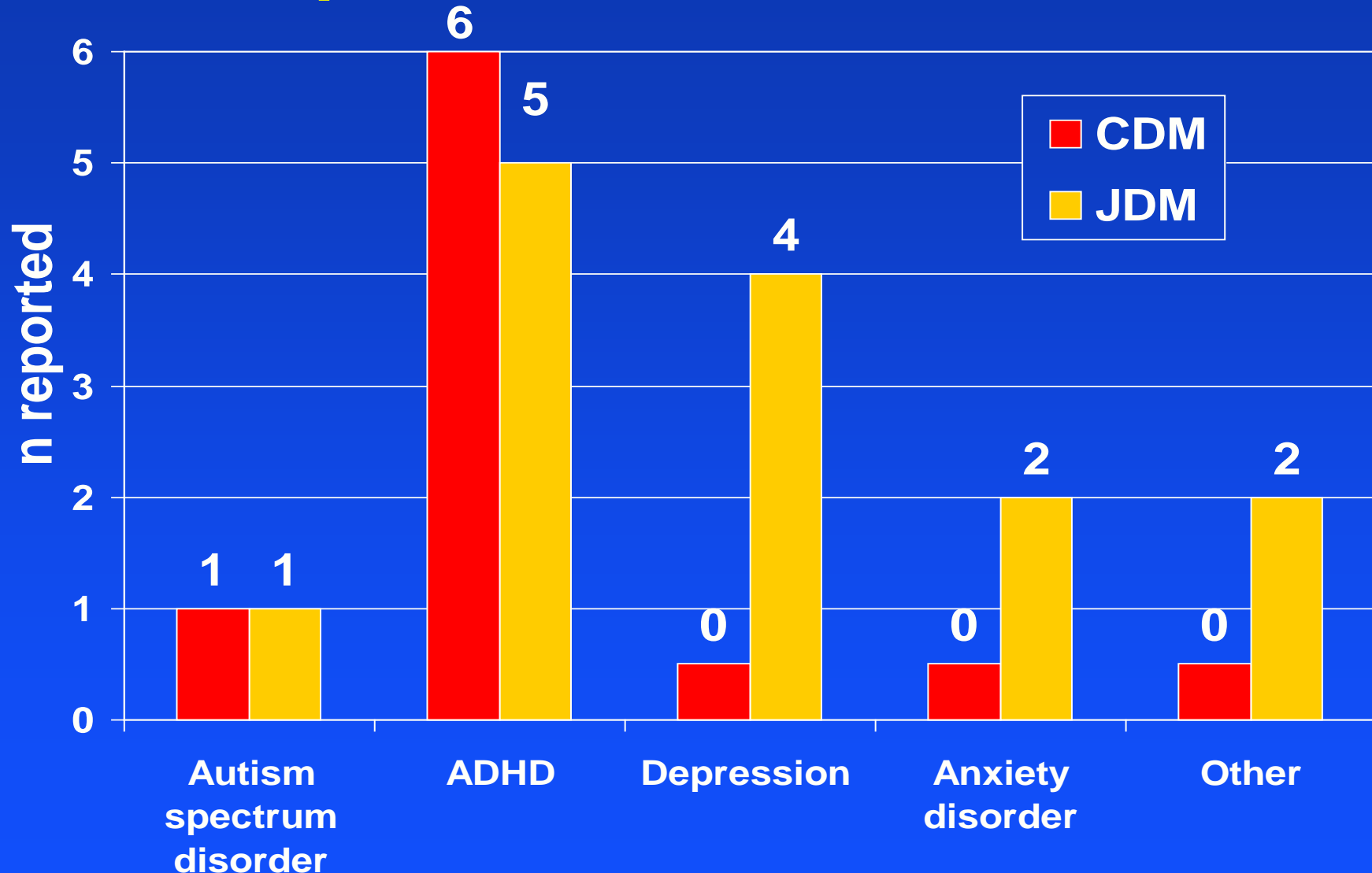
## Fatigue in DM

- 60% of patients report severe fatigue.
- Fatigue related to age and impairment
- Energy conservation strategies as well as aerobic exercises have been found to be helpful

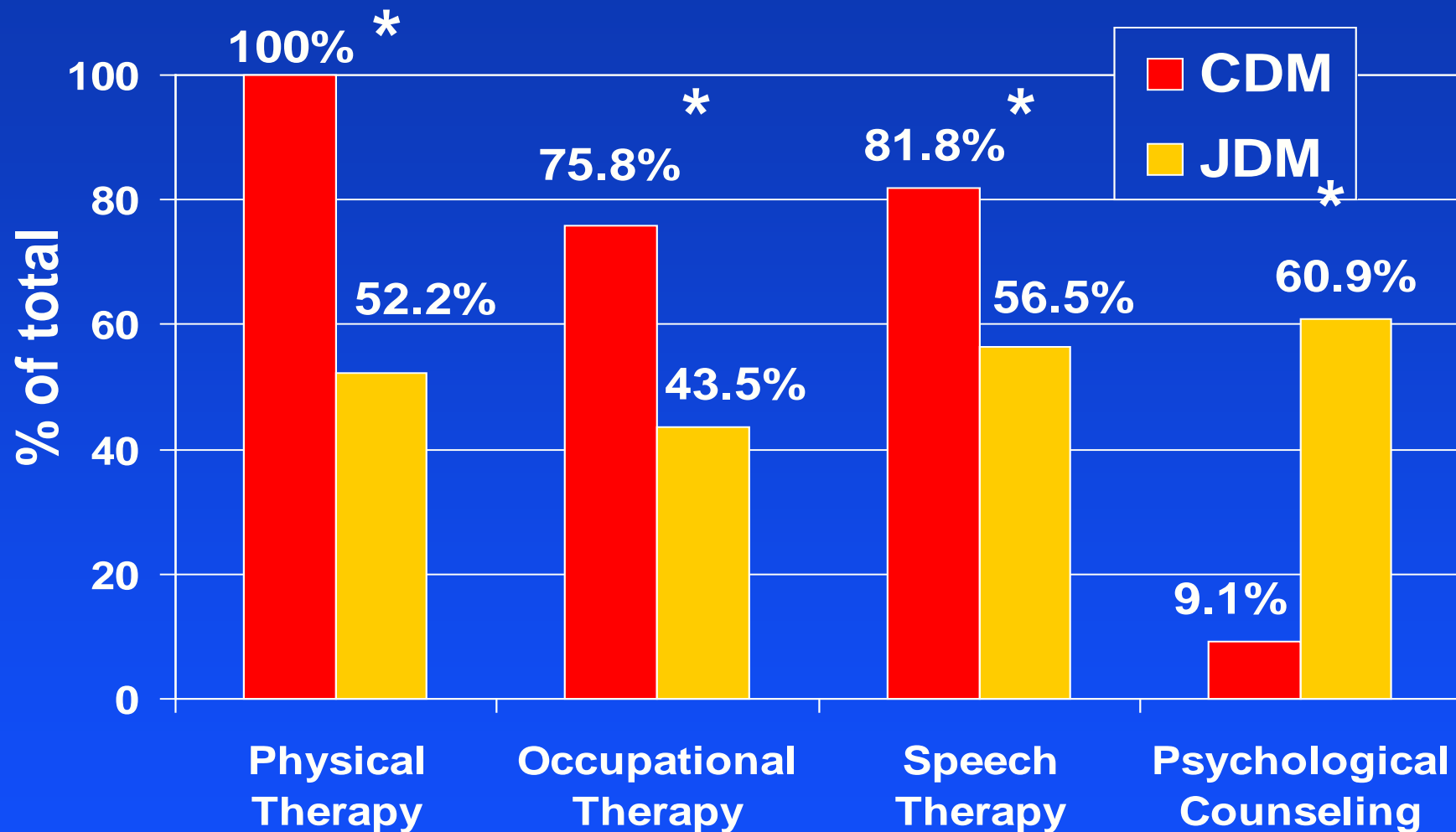
# Medical concerns



# Psychological disorders extracted from patient medical records

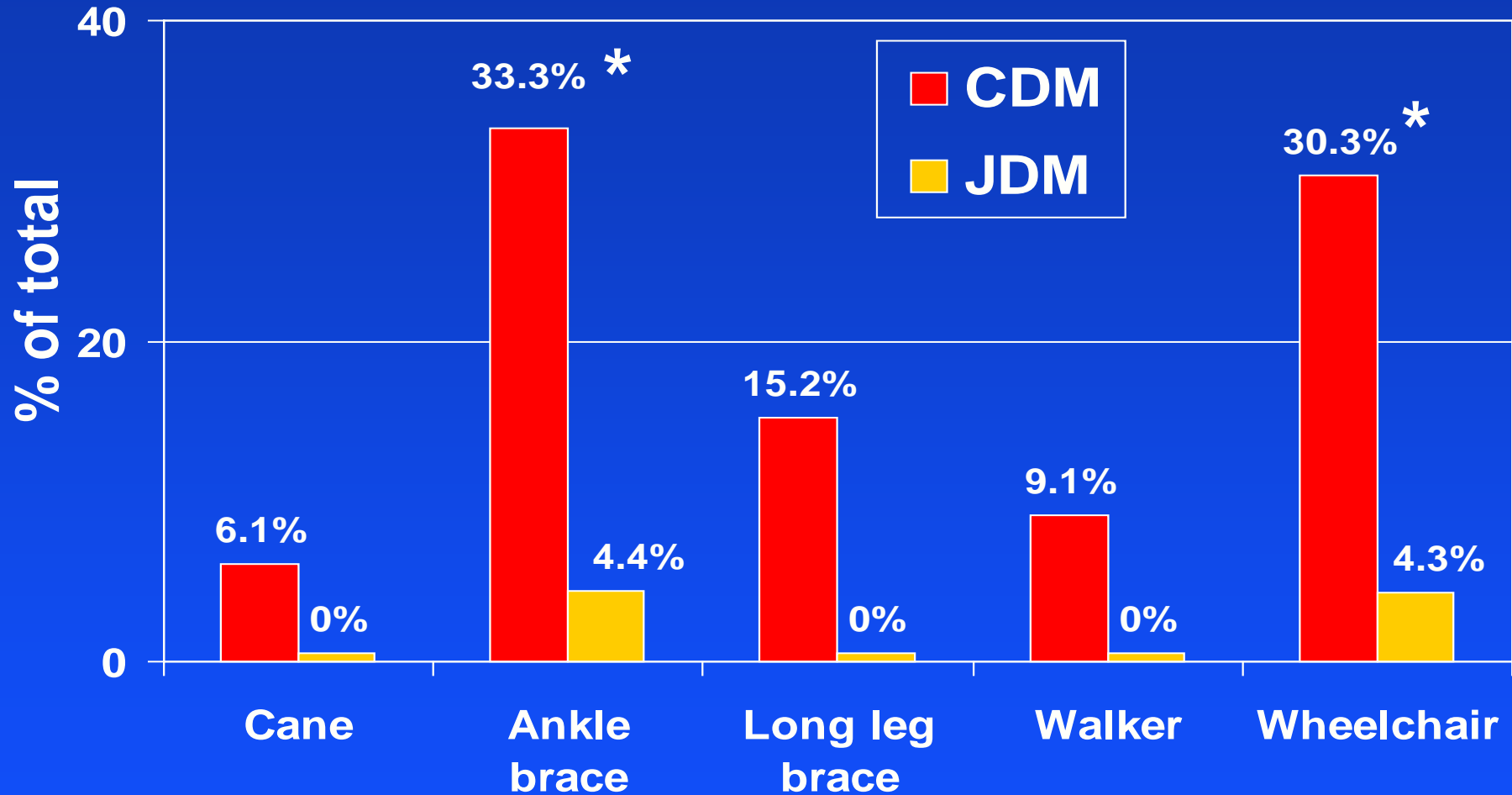


# Use of rehabilitation therapies



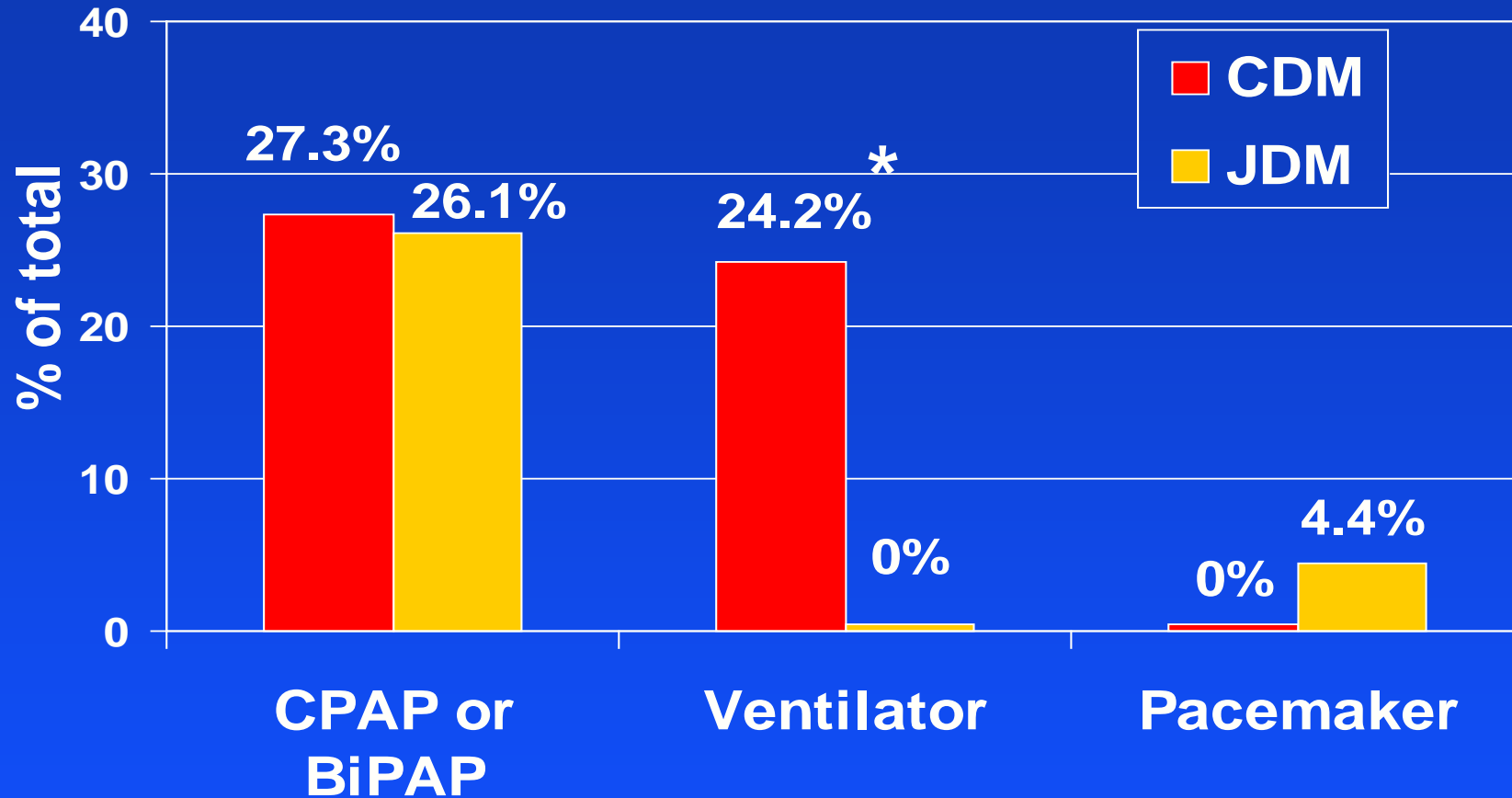
\* significant difference between JDM and CDM ( $p < 0.05$ ).

# Use of assistive devices



\* significant difference between JDM and CDM ( $p < 0.05$ ).

# Use of assistive devices



\* significant difference between JDM and CDM ( $p < 0.05$ ).



# Physical Therapy in DM

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## WHO Definition of Health

Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.

Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June, 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948.

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## Goals of physical therapy:

- Maintain optimum health
- Prevent/delay secondary complications
- Maximize functional abilities
- Improve/maintain quality of life

# Physical Therapy in DM

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Requires individualized plans based on individual needs

Plan may include recommendations regarding:

- Appropriate activities and exercises
- Management of pain and/or fatigue
- Orthotics and mobility devices

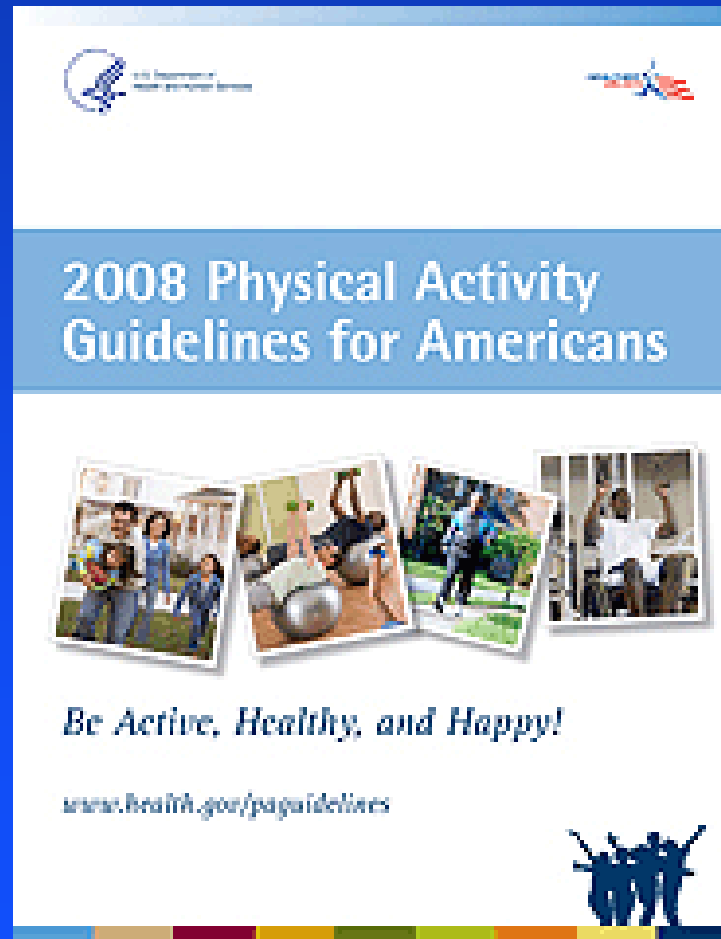
# Physical Therapy in DM

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## The Benefits of Physical Activity

- Control your weight
- Reduce your risk of cardiovascular disease
- Reduce your risk for type 2 diabetes
- Reduce your risk of some cancers
- Strengthen your bones and muscles
- Improve your mental health and mood
- Improve your ability to do daily activities
- Increase your chance of living longer

# Physical Therapy in DM



<http://www.health.gov/paguidelines/guidelines/default.aspx>

# Physical Therapy in DM

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## Aerobic activity recommendations

- 2 hrs and 30 minutes (150 minutes) of moderate intensity aerobic activity every week
- Spread your activity out during the week  
30 minutes x 5 days = 150 minutes
- Break it up into smaller chunks of time during the day. 10 minutes at a time is fine
- Moderate intensity activities are activities where you can still carry on a conversation such as brisk walking, raking, mowing, cycling, line dancing

# Physical Therapy in DM

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## Recommendations for strengthening activities

- 2 or more days a week of muscle strengthening activities that work all major muscle groups (legs, hips, abdomen, back, shoulders and arms).
- You can use body weight, free weights, elastic bands, aquatherapy or equipment for resistance.

# Physical Therapy in DM

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## Current Recommendations in DM

### Exercise/Activities

- Aerobic/cardiovascular
- Strengthening
- Flexibility/range of motion
- Hydrotherapy/pool
- Recreational activities



# Physical Therapy in DM

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Factors affecting individual recommendations include

- Age (pediatric/adult)
- Clinical profile (current status)
- Personal profile (work, family role, interests, financial/environmental/social barriers & facilitators)

# Physical Therapy in DM

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## Implementation

- Evaluation by healthcare provider(s)
- Recommendations from health care provider(s)
- Regular monitoring and adjustments as necessary by provider(s)
- Self monitoring

(Providers may include primary care provider, neuromuscular specialist or rehabilitation specialist)

# Physical Therapy in DM

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## AFO's



# Physical Therapy in DM

## Assistive Devices



# Physical Therapy in DM



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# Physical Therapy in DM

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Factors to consider when recommending orthotic and assistive devices:

- Strength and functional abilities
- Caregiver assistance
- Environment
- Cost (home modification, transportation)

# References

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# References

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- <http://www.health.gov/paguidelines/guidelines/default.aspx>

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