Do our patients really need telerehabilitation?

Digital physical therapy of boys with Duchenne Muscular Dystrophy in the COVID-19 pandemic.

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1. Introduction

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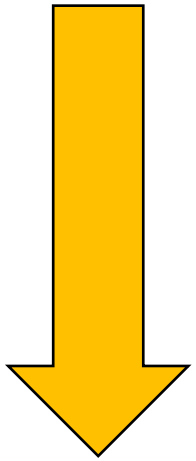
Duchenne muscular dystrophy

One of the most common and severe **neuromuscular disease** affecting approximately **1 in 3500 persons** worldwide. This incurable X-linked disease has the most impact on **MOTOR** and **CARDIOPULMONARY** function.

Progression of disease:



lack of ambulation
loss of ability to use upper limbs
gastrointestinal problems resulting in malnutrition
heart failure
respiratory failure

1. Introduction

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NEW CHALLENGE during **COVID-19** pandemic

TELEREHABILITATION

should be:

- easily available
- free of charge
- adjustable

1. Introduction

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Progression of the disease and muscle weakness lead to progressive **scoliosis**. Massive deformity raises **the risk of cardiopulmonary dysfunction.**

RESPIRATORY SYSTEM
one of the biggest problems

The first signs of respiratory failure:
obstructive sleep apnea.

Adult DMD patients, especially with **FVC < 60%** with week cough and airway clearance are at **high risk of severe respiratory infections**.

1. The aim of the study

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The purpose of the study was to investigate whether it is possible to conduct respiratory physical therapy with the use of telerehabilitation methods in boys with Duchenne muscular dystrophy.




2. Materials and methods

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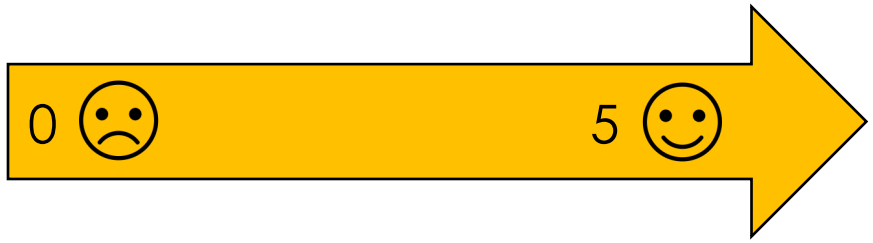
Flowchart showing study interventions:

The study included 152 boys with DMD and it was conducted during on-line conference "DMD-lets be together" for Polish families with DMD. During the physical therapy panel, we showed the video with the instruction of respiratory exercises. After the conference all participants received access to the film on the YTB platform.

After the conference all participants (n=152) were asked to fill in the on-line survey evaluating this home-based programme.

Additionally, caregivers were invited to leave an e-mail contact in case they needed expanded individual consultation or training.

2. Materials and methods



The survey consisted of questions:

- age
- ambulation
- upper limb functional status

assessment in 6-point scale:
- general satisfaction
- appropriateness of the exercises
- intelligibility

- whether the exercises were performed
- difficulty of the exercises
- possibility to implement this treatment to daily routine

3. Results

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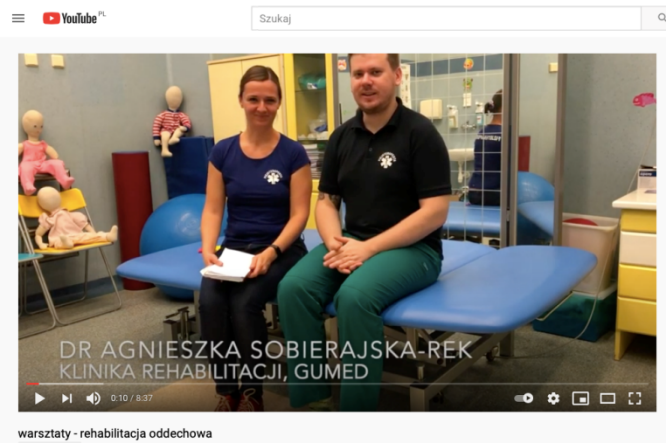
The video with respiratory exercises was displayed **127** times in a first month.



The on-line survey was filled in only by **31 (20,4%)** participants.

Mean age of patients was **13.8** years old.

19 (61,3%) patients were ambulant and **12 (38,7%)** were non-ambulant.

3. Results

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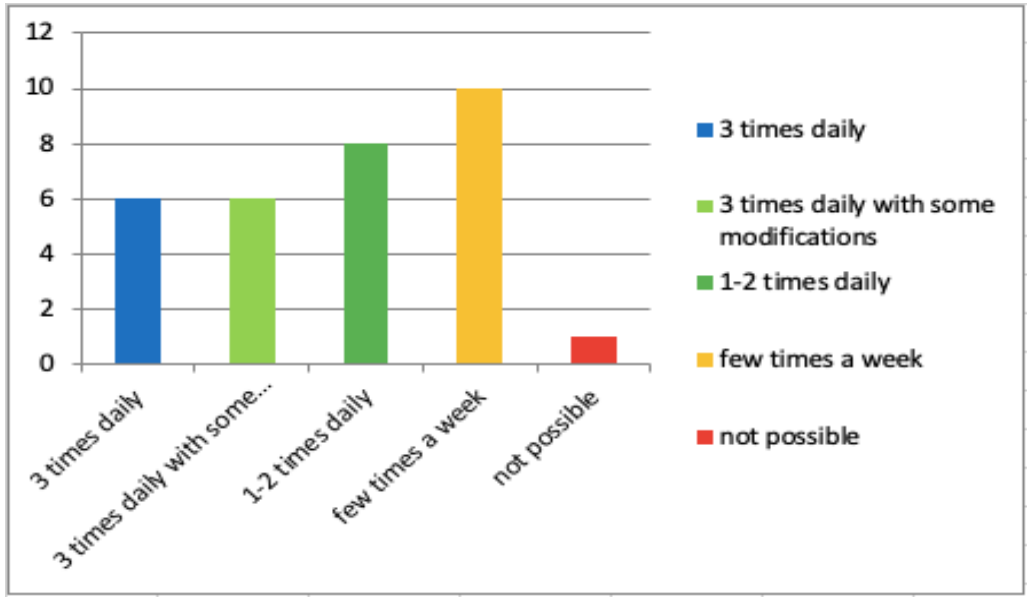
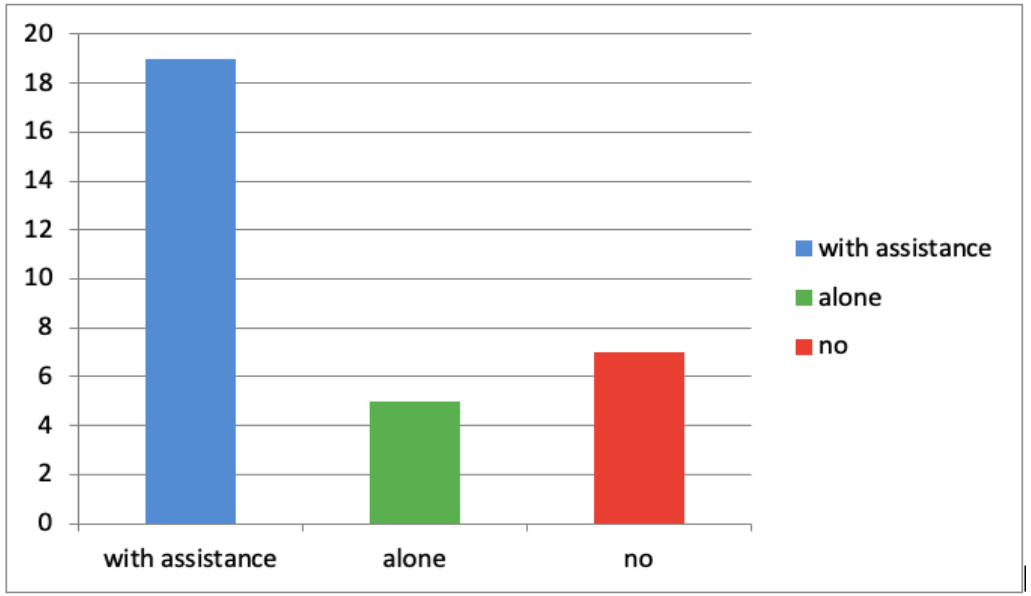
Respondents declared that **it is possible to implement** respiratory exercise to home-based rehabilitation routine.





5 (16,1%) performed the exercises by themselves, **19 (61,2%)** with assistance, **7 (22,6%)** did not perform the exercises.

3. Results

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The general satisfaction was **4,77/5**, appropriateness **4,74/5**, intelligibility **4,74/5**.

Only **one** respondent declared that the patient was able to perform properly all exercises, **16** would be able to perform all exercises after practicing, **14** declared that some exercises were too difficult.

Only two caregivers responded for the invitation for further individual consultation or assistance with exercise performance.

4. Conclusion

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Findings from the study show that respiratory telerehabilitation may be implemented in DMD patients, however it should include caregiver's assistance. **The interest of digital rehabilitation among caregivers of DMD boys in Poland is low.** The reason of this situation requires further research. Moreover, there is a need for well designed randomized clinical trial assessing effectiveness of proposed interventions.

Thank you for your attention.