

The Paediatric Physiotherapist's Role in Teaching Parents and Carers Postural Management for Children with Duchenne Muscular Dystrophy

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Introduction

Duchenne Muscular Dystrophy (DMD) is a Neuromuscular Disorder mainly affecting boys from birth (Effgen, 2005). This disease impacts not only musculoskeletal and respiratory systems, but also emotional well-being, due to its progressive nature, limiting life expectancy (Metules, 2002). The child and their family therefore needs to be at the centre of all plans for effective overall long-term management.

Good posture is essential in DMD to ensure a better quality of life (Emery and Muntoni, 2003). Eagle et al (2007) stated that successful results in DMD are only produced by **daily postural management as early on as possible**. Therefore, the child, parents and school carers need to be **taught how to manage posture daily**.

Aim

- To find the different **teaching approaches** used with parents & school carers.
- To find how the physiotherapist **adapts** these teaching approaches.
- To look at the theories of **motivation**.

Method

- 3 semi-structured telephone interviews, lasting 40 minutes were conducted.
- 3 Paediatric physiotherapists were interviewed from England, Scotland & Wales.
- A Dictaphone was used to transcribe interviews, which were then coded by Thematic Analysis and sent to the participants to verify their answers.

Results

Postural Management

Main differences included;

The Scottish participant encouraged the use of wheelchairs early on.

The English & Welsh participants encouraged the child to walk by using a wheelchair only when struggling.

The Scottish participant also reported using the Symmetrikit Sleep System, whereas the English & Welsh used modified sleep systems of rolls, pillows & brightly coloured cushions.

Teaching Approaches

Dynamic Methods such as DVDs, demonstrations & return demos were shown to be effective, whereas handouts alone were shown to be ineffective.

Parents -

Taught individually through PhysioTools or MDCampaign stretches booklet and DVD's.

School Carers -

The Welsh participant used the same method as with parents. The Scottish & English taught as a group, i.e. informal lecture, group discussions.

Adaptation Skills

The main barriers to learning found:

- Behaviour & non-compliance
- Lack of understanding
- Lack of time

Adaptations to these barriers:

- Make it fun!
- Reinforce basics, keep it simple
- Use a structured daily routine at home & school
- Provide extra support for parents

The Scottish participant - Increased physiotherapy with school carers during family difficulties.

The English & Welsh participants - Stopped physiotherapy for a short while during difficult times in order to increase motivation.

Motivation

External motivation strategies were used by all participants, such as reward charts & goals.

Increased time spent with families, frequented check ups and regular telephone contact, also increased motivation.

It was found that parents need more motivation than school carers, and that mainstream school carers need more motivation than special school carers.

Conclusion

Physiotherapists need to utilise **adaptation skills to the teaching approaches and motivation styles** used with each individual.

Further research is needed to explore these concepts in the larger general physiotherapy population across England, Northern Ireland, Scotland & Wales.

References

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Figure below shows chosen Themes & Sub Themes

