

Sitting clinic for children with neuromuscular diseases

L Christensen, OT, R Iversen, OT

The National Rehabilitation Centre for Neuromuscular Diseases, Denmark (RCFM)



Runa Iversen
Occupational therapist
ruiv@rcfm.dk
www.rcfm.dk



Lone Bech Christensen
Occupational therapist, MR
loch@rcfm.dk
www.rcfm.dk

Results

Seven out of ten parents say the clinic has given them tools to assess their child's sitting posture and a better understanding of when adaptations are needed. The parents give priority to the annual evaluation as they still find it difficult to estimate when a sitting posture is inadequate.

Half of the parents say they have changed routines after having participated in the sitting clinic.

Eight out of ten parents say that their child felt the examination took place in a safe environment and that they felt included in the examination and subsequent decisions.

They find the booklet good for small children up to 8 years of age, but too childish for older children.

Eight out of ten parents say they think the report is useful in their collaboration with assistive technology professionals.

"Our OT uses the description and the photos when she communicates with the supplier ..."

Assistive technology professionals read and use the report and find that it supports their work with the families. The included photos support the descriptions. The professionals act on the recommendations.

"The report supports my casework and strengthens my work with the child and its family."



Aim

To evaluate the effect of a sitting clinic which aims to:

- instruct child and parents in the interplay between sitting posture and functional capacity.
- suggest seating adjustments that enhance functional capacity/sitting posture and minimize complications from inadequate postures.
- provide timely information for collaborators to act on (assistive technology professionals in the local communities, orthopedic surgeons, orthotics manufacturers).



Background

Clinical observations

- Sitting postures developed during childhood are difficult to change in adulthood.
- Preventive measures early on are key to maintaining the child's activity and participation throughout life.
- Promoting good sitting posture and making children and adults understand its importance can be difficult, especially when inadequate habits have already been formed.

In 2020, the National Rehabilitation Center for Neuromuscular Diseases (RCFM) established a sitting clinic for non-ambulant children ≤ 10 at start-up. Each child has one consultation per year.

The sitting clinic

During the period 2020-2023, 49 families were invited to participate; 38 accepted the invitation. 34 children have attended the clinic two or more times.

A visit to the clinic includes:

- Posture analysis: Assessment tools are the EK scale and Observation form for sitting posture in persons with NMD/modified.
- Consultation with parents/child based on the booklet *Maintaining good posture throughout life*, a conversation booklet made by RCFM.
- A short report aimed at assistive technology professionals in the local communities and other collaborators.

Conclusion

- The sitting clinic helps parents understand the importance of good sitting postures and teaches them how to change habits.
- The short report strengthens the dialogue between the family and assistive technology professionals and supports the professionals' in their follow-up.
- Corective and preventive interventions are most successful in younger children. Children older than 10 will often resist interventions because they are limiting for their activity.

Method

A questionnaire was developed using the online survey tool SurveyXact and sent to 40 assistive technology professionals and 48 parents.

14 professionals and 10 parents responded to the questionnaire.



The National Rehabilitation Center for Neuromuscular Diseases (RCFM)

- is a national, highly specialized private outpatient hospital for people with neuromuscular diseases in Denmark
- has approximately 3500 patients with over 40 different neuromuscular diagnoses
- supports the Danish health and social system with expert knowledge on rehabilitation of people with rare neuromuscular diseases.