

ENHANCING THE HUMAN DIMENSIONS OF CLINICAL CARE FOR YOUNG PEOPLE WITH MUSCULAR DYSTROPHY

RESEARCH SUMMARY

Study Purpose

We wanted to explore and improve the ‘human’ aspects of care for young people with muscular dystrophy (MD) and their families, and how these are addressed in healthcare practices. We aimed to work with the clinic’s team members to plan some changes to their services to help enhance this type of care for young people with MD.

‘Human’ means the emotional, social, and personal dimensions of illness experiences.

Why is this study important?

Most young people with MD regularly attend medical clinics. We want to help make sure this experience has a positive effect on peoples’ lives beyond medical or rehabilitation (what we call ‘biomedical’) benefits.

What were the study methods?

15 families and 12 clinicians took part in the study.

- 1. Clinic Observations:** Over 6 months we observed the clinic visits of 15 families – taking note of interactions between staff and families, clinic processes, and the physical environment.
- 2. Clinician Dialogues:** We also ran 3 ‘dialogues’ with the clinic’s 12 clinicians. We discussed how ‘human’ aspects of care were (or were not) attended to in the clinic.

We discussed what we were finding with a family advisor.

Key findings

Our main finding was that there was a mismatch between the importance clinicians placed on the human aspects of care and what actually happened in clinics. There were times when human concerns were considered, but this was less often, and more ad hoc, than the focus on biomedical aspects of care.

1. Clinic processes

There was a clear focus on biomedical priorities within clinic visits. For example, clinicians routinely used checklists oriented primarily to the biomedical progress of the child (e.g. routine functional tests, breathing tests).

Example (from the observation notes):

Amaan (11year old child) began to ask, with a slight whine, ‘How much longer? And how many more people?’ He stared at the wall above the sink as he spoke to Mom. I looked up and noticed that he had been staring at the clock as the clinicians spoke to him.

The clinic’s timing was set by biomedical goals based on ‘best practice’ standards rather than human-focussed care. This meant clinic visits often had the same timing and frequency for everyone. This standardisation may hinder care: regular and long visits were often difficult for families personally, financially and socially.

2. Clinician-child/family interactions

Involving children and family in care discussions/decisions is integral to providing human-focussed care but was often difficult to put into practice. For example:

- i. *Involving the child:* Clinicians often tried to involve the child using directed questions or eye contact, but this was not always successful. Most interactions were conducted with parents or other caregivers.
- ii. *Different priorities:* Children and families often directed discussions towards human aspects of care, while clinicians often prioritised biomedical care. For example, when discussing play which involved some physical risk, families would highlight that the child needs to be able to have fun and take certain risks. The clinicians would caution against these risks. Here are some examples of what families said:

“I can see where this conversation is going... but they’re just kids playing around”

“I didn’t want to deny him the trampoline because he really loves it”

- iii. *Negative emotions:* ‘Negative’ emotions expressed by children or other family members – e.g. anger, frustration or sadness, were often avoided by clinicians. This sometimes meant that families’ need to express these feelings was not met. Clinicians identified that they avoided these emotions so as not to ‘opening the floodgates’ or get ‘negative reactions’, but also acknowledged that they lacked skills in this area. There was also little private space or sufficient allocation of time to have ‘difficult’ conversations.

3. Staffing allocations

Biomedical emphasis was also seen in clinic staffing allocations – most were from traditionally more biomedical professions (nurses, doctors, physiotherapists, respiratory therapists), some were mixed (occupational therapists, social worker) and there was only part time or occasional involvement of the more ‘human’ focussed professions (recreational therapist, psychologist).

Key recommendations

Establish integrated clinic processes to consider human focussed care, for e.g:

- Increase flexibility of clinic length, frequency and focus
- Create opportunities for the child and family have separate time with clinicians so all can contribute to care decisions
- Allocate physical space and time for discussions of ‘difficult’ or emotional topics
- Shift staffing to have a greater focus on ‘human’ care
- Continue process of reflexively analysing clinic practices and processes

4. Next Steps

- We are currently implementing these recommendations
- The study is expanding to encompass other hospitals

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