

ENHANCING THE HUMAN DIMENSIONS OF LIVING WITH MUSCULAR DYSTROPHY

RESEARCH SUMMARY 2

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 worked with two hospital's clinical teams to plan, implement and evaluate 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 people's lives beyond medical or rehabilitation (what we call 'biomedical') benefits.

What were the study methods?

The study was situated across two Ontario hospitals.

- 1. Clinic Observations:** Over 3 years we observed 44 clinic visits of 30 families – taking note of interactions between staff and families, clinic processes, and the physical environment.
- 2. Clinician Dialogues:** We ran 15 'dialogues' with the clinicians. Together we discussed how 'human' aspects of living with MD were (or were not) attended to in the clinics, and how this might be improved.

- 3. Interviews:** We interviewed 17 clinicians; and 5 young people with MD and 9 of their family members.

We discussed what we were finding with a family advisor.

Key findings and changes to clinics

Our main finding demonstrated 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 biomedical aspects of care. The clinics noted key areas of concern and are in the process of making changes to address them. Changes were different between the clinics and amongst different clinicians. Some key examples are:

1. Changing routines

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 function tests, breathing tests) with few routines oriented to psychosocial wellness. Because of the study, there is a shift to addressing human-focused care. This helps to address client and family concerns about the length of the clinic visits.

Example: Timing for clinic visits is more flexible to reduce personal, social and financial pressure some families face attending clinic. **Caregivers of 11yr old 'Kyle' said they:** "like it much better this way... less repetition and [some things are now] done by phone"

2. Changing priorities

Considering human aspects of living with MD was important in clinical interactions with children and families in numerous ways.

For example, there were different priorities. Children and families often directed discussions towards quality of life, while clinicians were more likely to prioritise biomedical concerns. E.g., when discussing play which involved some physical risk, families would highlight the need for fun and to take certain risks. The clinicians would caution against these risks.

Clinicians are working to better partner with child and families to better incorporate family priorities in their advice and care plans.

Example quote from a clinician: “It comes back to that quality of life question: What is quality of life for this child and this family? Is walking as long as possible and fitting in with your peers more important than the risk that they might fall?”

3. Prioritising emotions

Another shift in the way clinicians conceptualise their work is a greater attention to the clinics’ emotional environments. This is something clinicians said they had not previously considered much. Clinicians increasingly spoke of greater attention to supporting clients and families through a *range* of emotions.

Clinicians at study site 1 discussed that they tended to focus on positive emotions, at times to the neglect of other emotions such as grief or anger. They began to question whether being overly positive was always beneficial.

Clinicians created an atmosphere of positivity/cheerfulness which sometimes had unintended unhelpful effects such as:

- Families’ needs to express ‘negative’ emotions e.g. anger, frustration or sadness, was not always met.
- Some abilities that were praised were likely to be lost in the near future—

clinicians worried they were setting children up to later feel bad about this loss.

As a result, clinicians are being more thoughtful about when and why they are cheerful or what they cheer for. If clients bring up grief or loss, rather than trying to put a positive spin on it, clinicians now try to acknowledge and address the emotion.

At study site 2, participating clinicians suggested that they already attended to a full range of emotions prior to the study, though not in a coordinated way. A benefit of our two-site design was the sharing of issues, solutions, and examples across the teams.

Example ‘challenging’ discussions clinicians are working to include:

- Bullying and disability stigma
- Feelings of anger, sadness, grief
- Puberty, sex and sexuality
- Disease progression, the future

Resources from the project

Cards for Humanity: These award-winning cards are a clinician education tool – a small deck of conversation/reflection-stimulating cards which shares key recommendations for clinicians. The cards are freely available: <https://bit.ly/31INdYy>

Scientific Paper: Setchell et al 2018: Enhancing human aspects of care with young people with muscular dystrophy: Results from a participatory qualitative study with clinicians. *Child: Care, Health and Development*. <https://bit.ly/3fn5M2M>

Scientific Paper: Thille et al 2018: Enhancing the human dimensions of children’s neuromuscular care: Piloting a methodology for fostering team reflexivity. *Advances in Health Sciences Education*. <https://bit.ly/2DEWjh7>

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