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Enhancing human aspects of care with young people with muscular dystrophy: Results from a participatory qualitative study with clinicians

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Abstract

Background: Most research into clinical care of Duchenne or Becker dystrophinopathies (MD) has focused on slowing progressive muscular weakness and extending lifespan. Scarce attention has been paid to the "human" aspects of care such as psychosocial health, living a fulfilling life, or dealing with disability stigma. This study partnered with clinicians to identify and address local and systemic barriers to these human aspects of care.

Methods: We employed a participatory qualitative design at a multidisciplinary MD clinic using 2 methods: (a) ethnographic observations over a 6-month period of clinic visits of children with MD and families, involving 12 clinicians, and (b) 3 "dialogues" (2-way discussions) with these clinicians to collaboratively analyze practices and co-produce recommendations for change.

Results: Our methods produced rich data that, when coanalyzed with clinicians and in consultation with a family advisor, provided deep insights into the practices and underlying assumptions of a neuromuscular clinic. Staff recognized the importance of the human aspects of care but, in reviewing the observational data, identified that it was given insufficient attention in (a) routine clinical processes, (b) clinician-family patterns of interaction, and (c) staffing allocations.

Conclusion: Although the human aspects of care were important to clinicians in the MD clinic, the routines and nature of the clinic meant these were frequently sidelined for biomedical objectives. We present collaboratively produced practical recommendations toward addressing this disjunction between ideals and practice including developing flexibility to tailor appointment frequency, composition, and length; providing time and physical space for psychosocial aspects of care; and clinician skill building to support child/family expression of "negative" emotions; and discussion of sociopolitical aspects of MD such as living with disability stigma. The study offers a set of considerations that, taking into account individual differences, offer insights for similar clinics elsewhere.

KEYWORDS

Annemarie Mol, Becker muscular dystrophy, Duchenne muscular dystrophy, ethnography, psychosocial

1 | INTRODUCTION

Most research into clinical care of dystrophinopathies has focused on physiological outcomes such as slowing muscular weakness and prolonging lifespan. This has arguably come at the expense of attention to the human aspects of care such as psychosocial health, living a rich and fulfilling life, or dealing with disability stigma. We use the term human to include not only psychosocial concerns but also emotional, existential, social, and moral dimensions of illness experiences and care. Our conceptualization of the human aspects of care at times intersects with, but differs from, "patient-centred care" that places emphasis on patient autonomy and decision-making (Mol,

2008). Human aspects of healthcare coexist with biomedical dimensions (we use biomedical to refer to the application of the physical sciences to medicine: encompassing biological, physical, and technical aspects of care). This participatory qualitative study investigated the provision of care in a single neuromuscular clinic over a 6-month period. Our aim was to engage clinicians to critically examine and improve the human aspects of care provision. In partnering with the clinical team, we sought to produce a viable process for analyzing and, where necessary, addressing human aspects of clinical care; and to identify approaches that are transferable to other clinical environments. In this paper, we report on Phase 1 of this project in which we partnered with a neuromuscular clinical team to produce a process for coanalyzing their existing practices and developing recommendations for change that are currently being implemented and evaluated (Phase 2).

This study focuses on the care of children with the two most common types of muscular dystrophy: Duchenne and Becker dystrophinopathies (hereafter MD). These genetic conditions are characterized by increasing loss of function resulting from progressive muscular weakness. People with the most common and severe form (Duchenne) have an average life expectancy of less than 30 years (Bushby et al., 2010a) whereas those with Becker (three times less common than Duchenne; Bushby, Thambyayah, & Gardner-Medwin, 1991) have a more variable but longer life expectancy. There has been some research attending to the human aspects of MD care including, for example, investigations into what "quality of life" might mean for people with MD (Gibson, 2016; Pangalila, 2016); consideration of how to best manage transitions to adulthood (Abbott & Carpenter, 2014; Hamdani, Mistry, & Gibson, 2015); and the social aspects of living with a disability (Skyrme, 2016). Our project adds a novel ethnographic (systematic study of people and culture) exploration into the human aspects of MD healthcare practices to this research. The vast majority of research attention, however, has been directed towards biomedical aspects of MD such as epidemiology, prevention, genetics, (e.g., Goemans et al., 2011) and medication (e.g., Mendell et al., 2013). Clinical rehabilitation of MD usually addresses physical, communication or psychological "deficiencies" (e.g., Bushby et al., 2010a, 2010b), levels of functional independence (Abrams & Gibson, 2016), and/or approximating normal developmental progression (Hamdani et al., 2015). Although undoubtedly important, overemphasizing these medical and rehabilitation goals may divert attention from addressing human aspects of living with a progressive condition with an often shortened and shifting life trajectory.

Importantly, an overemphasis on the biomedical aspects of care may cause inadvertent harms (Rosenbaum & Gorter, 2012). For example, medications to slow progression (usually corticosteroids) have frequent side effects including behavioural changes (Sienko et al., 2017), increased fracture risk reducing physical activity (Bushby et al., 2010a), delayed puberty (Dooley, Bobbitt, & Cummings, 2013), and changes to body morphology (e.g. height, BMI: Houde et al., 2008). Each of these has consequences for how life is experienced including family function, peer relationships, and social stigma. Furthermore, continual testing (assessment) is an important aspect of medical care (Bushby et al., 2010a) but may be experienced as an ordeal (Bjorbaekmo & Engelsrud, 2011), and frequent comparison to norms may contribute to negative self-identities (Abrams, 2014; Gibson & Teachman, 2012; Gibson, Young, Upshur, & Mckeever, 2007). A consideration of the human aspects of care takes these effects seriously in the planning and delivery of clinical care.

Key messages

- This study highlighted discord between clinician beliefs and practices of human aspects of care.
- Clinic observation analysis identified frequent prioritization of biomedical goals over human aspects of care.
- Biomedical care took precedence during clinical routines, clinician–child/family interactions, and staffing allocation/roles.
- Human aspects of care, particularly psychological/emotional support, *were* evident but more ad-hoc.
- Co-produced recommendations included appointment time flexibility, clinician emotional/social upskilling, and staff reallocation.

Study aims were to:

1. Illuminate how human aspects of MD care are addressed in a neuromuscular clinic's practices.
2. Pilot methods for building clinical staff's capacity to examine and assess the human aspects of their clinical practices.
3. Collaboratively produce recommendations for enhancing care.

2 | METHODS

Our qualitative design involved ethnographic observations of an outpatient neuromuscular clinic and collaborative dialogues with the clinic's interdisciplinary clinicians.

2.1 | Theoretical underpinnings

We used Annemarie Mol's theory about the "logics" of healthcare to analyze clinical practice (Mol, 2008). Mol suggests *often* a "logic of choice" organizes clinical practice, which emphasizes achieving biomedical targets through evidence-based practice, goal setting, or best practice guidelines. She argues constraining care to such targeted outcomes neglects considerations of the whole person in the broader context of their lives. Mol highlights healthcare is *also* practiced in ways less concerned with targets, and more comfortable with the uncertainty, contingency, and change characterizing bodies and health. She calls this second approach a "logic of care." A consideration of these two logics (choice and care) guided our investigation of human aspects of the clinic's care practices.

2.2 | Participants

All participants were staff or clients/families at a single outpatient neuromuscular clinic in a Canadian children's rehabilitation hospital. The site was chosen for convenience (proximity). Numerous clinics across the region that have similar multidisciplinary teams for young people with MD (McMillan, Campbell, & Mah, 2014). Children/youth with MD (ages 5–20 years) and their parents from across the province attend clinic every 4 months for assessments by various team members. The research coordinator (BM) contacted families with children with Duchenne or Becker MD scheduled to attend clinic during the study period. Families were mailed recruitment information with details of the study design and aims, and consent was obtained via follow-up phone call. Team clinicians were recruited via an information seminar that provided an overview of the study design and aims. Clinician participants included physicians, nurses, physiotherapists, occupational therapists, a social worker, a respiratory therapist, and a recreation therapist. In total, 15 families (Table 1) and 12 clinicians (Table 2) participated. All participants, or their caregivers, gave written informed consent to study participation and publication. No participants refused participation or dropped-out.

2.3 | Procedure and method

Institutional ethics approval was obtained from the centre where the research took place. Data collection occurred between January and September 2016 involving two primary methods:

2.3.1 | Ethnographic observations

During their approximately 3-hr, 4-monthly clinic visits, families typically remained in a consultation room and were seen by each clinical discipline in turn. An experienced qualitative researcher (BM), previously unknown to participants, was situated with each family

TABLE 1 Participant demographics

Pseudonym	Age (years)	Time to drive to clinic	Diagnosis	Mobility devices
Amaan	11	1+hr	Duchenne	Manual wheelchair
Hayden	8	2+hr	Duchenne	Manual wheelchair
Terry	13	1+hr	Duchenne	Manual and power wheelchair
Kyle	10	2 hr	Duchenne	Power wheelchair
Mike	17	12 hr	Duchenne	Manual and power wheelchair—mainly walks
Jake	9	<1 hr	Duchenne	Manual wheelchair
Johnny	14	<1 hr	Duchenne	Manual wheelchair
Kamil	14	<1 hr	Duchenne	Power wheelchair
Enzo	12	<1 hr	Duchenne	Power wheelchair
Jacob	8	~2 hr	Duchenne	Manual wheelchair
Simon	9	~2 hr	Duchenne	Manual wheelchair
Cameron	8	2+ hr	Becker[a]	None
Ron	15	2+ hr	Duchenne	Manual and power wheelchair
Nasim	17	1 hr	Duchenne	Power wheelchair
Jamie	17	2+ hr	Becker[a]	Manual wheelchair—mainly walks

[a]Parents noted that the diagnosis was uncertain but the child was being treated as if they had Duchenne.

TABLE 2 Clinician demographics

	Number of years of clinical practice		
Position[a]	Total	Working in paediatrics	Working in this neuromuscular clinic
Social worker	16	14	2
Registered nurse	41	15	15
Registered nurse	8	8	6
Physiotherapist	6	6	3
Physiotherapist	10	9	4
Occupational therapist	8	8	8
Occupational therapist	b	b	b
Recreational therapist	5	1	1
Respiratory therapist	3	1	<1
Respiratory therapist	b	b	b
Medical doctor (paediatrician)	10	10	8
Medical doctor (respirologist)	7	2	1

[a]All participating clinicians were female.

[b]Missing data due to clinicians leaving facility prior to questionnaire.

where she observed clinical interactions throughout the visit. In addition, BM observed formal and informal within-team case discussions. The main data source was BM's field notes (Emerson, Fretz, & Shaw, 2011) generated from these observations detailing: interactions among/between staff, young people, and families; clinical processes; and the physical environment. In total, 107 consultations with clinicians were observed over 17 visits.

2.3.2 | Reflexive dialogues

Team clinicians participated in three, 2-hr interactive dialogues across the study course. Dialogues included shared analyses of emerging study findings from the observations, and critical interrogation of underlying assumptions (Halman, Baker, & Ng, 2017) organizing the clinic's practices. We employed critical reflexivity to engage clinicians in evaluating their clinical practices, processes, and measures, including both intended and unanticipated effects (Halman et al., 2017). Sometimes referred to as critical reflection, or simply reflexivity (Kinsella & Whiteford, 2009), we use the term "critical reflexivity" to describe the process of examining the underlying principles behind, and potential hidden effects of, practices (Bourdieu & Wacquant, 1992; Gibson, 2016). Specific techniques included introducing elements of Mol's logics of care and choice (Mol, 2008); coanalyzing exemplars from observational data; and reflective exercises. In Dialogue 3, we co-produced of a list of feasible recommendations to strengthen clinical attention to the human aspects of care.

2.4 | Analysis

The diverse 6-member research team was composed of researchers/clinicians with expertise in qualitative methods, medical ethics, the sociology of health, disability studies, and medical education; and the clinical disciplines of medicine and physiotherapy. The team includes investigators and clinicians with a long history of working with young people with MD, including a researcher with lived experience of the condition (diagnosed with Becker MD). The team conducted formal analyses utilizing techniques described by Miles and Huberman (1984) as follows. Data collection and analysis were conducted iteratively and concurrently to allow investigation of new information as the study proceeded. The team reviewed observation notes monthly (×5) to identify data patterns in relation to Mol's theories and areas of further inquiry. Initial deductive codes related to identifying instances of Mol's choice and care logics within the care of family and children's emotional, psychological or social challenges, clinic caring practices, points of tension, and/or collaboration. Inductive coding, where codes emerge from the data, was used to identify new areas of inquiry (Braun & Clarke, 2013). Initially, these through analytic notes made by individual investigators as they read through the observations. Notes were then discussed and refined in team investigator meetings in further analytical cycles and were used to facilitate identification of patterns and conceptual congruence (Halkier, 2011). These cycles involved refinement of findings and resulted in a written combined analysis. Two sources beyond the core research team gave input into analysis by reviewing data excerpts, emerging findings, and recommendations: the clinicians (during dialogues), and a parent advisor (in separate meetings). This increased depth, rigour, and ensured the recommendations were clinically relevant and feasible.

3 | RESULTS

Our collaborative analyses identified the prioritization of biomedical goals over human aspects of care. Although staff discussed that they believed human aspects of care were central to the clinic's role, the observation data revealed to them how these aspects were marginalized in their clinical practices. Attention to human aspects of care, particularly psychological/emotional support, *was* evident in the observations but these were more ad hoc, with few formal structures, or flexibility in existing routines, to ensure human needs were addressed. Biomedical care consistently took precedence in a number of ways, which we have clustered under three headings: (a) routine clinical processes, (b) clinician–child/family interactions, and (c) staffing allocation/roles. Under a fourth heading, we discuss the less formalized "human aspects of care provision" evident in the clinic. In the following sections, we refer to data examples from the ethnographic field notes. Pseudonyms are used to distinguish participants.

3.1 | Routine clinical processes

Clinic visits were typically approximately 3 hr long (range: 2.5–4.5 hr). Both child and caregivers attended appointments, and most families were seen by six clinicians in turn (range: 5–8). Clinics routinely included the nurse's checklist of disease progression markers; respiratory function tests; checks of adherence to stretching exercises, splinting, diet, hydration, toileting, transfers, medications and breathing exercises; measurements of weight, height, muscle length, contractures and strength; physical function tests; and review of medications. A focus on biomedical care was evident in clinic processes ranging from broader structural factors to finer details of practice.

During dialogues, clinicians discussed that timing and frequency of clinic visits were based around routine biomedical assessments of medication, physical, and respiratory function—derived from "best practice" guidelines such as TREAT-NMD (2010). As per these guidelines, timing and frequency were the same for everyone at all ages. The clinicians identified that this standardization may hinder aspects of human care, and shared that regular, long visits were often difficult for families personally, financially, and socially. The clinicians noted significant frustrations families experienced during clinics, particularly when families travelled long distances to attend: Children often appeared restless and caregivers, fatigued. This was also evident in the observations. For example, Amaan (age 11) signalled he wanted to leave 40 min into his 2.5-hr clinic visit. He continually watched the clock during this visit as is evident in the following field note excerpt:

> *Amaan 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. He and mom spoke about when they could leave, Amaan suggesting they leave soon so*

> *he could be back at school for 12:30. Mom said they could not leave without seeing Dr. Lane. Amaan asked, "Why?"*

The study parent advisor also reported experiences of disquiet related to clinic visits. She said although her son never complained verbally, she could always tell when a visit to the clinic was coming: He was emotionally affected and slept poorly for days before and after. The patient advisor and clinicians alike questioned whether this routine scheduling could be changed to make at least some clinic visits shorter and/or less frequent.

There was also a clear focus on biomedical priorities *within* most clinicians' sessions. Observations showed clinicians routinely used checklists oriented primarily to biomedical progress of the child (e.g., nurse's set questions, physiotherapists' routine functional tests and respiratory therapists' pulmonary questions), and routine measurements (e.g., blood pressure, range of movement, pulmonary function tests, and weight). Tests done fitted best practice guidelines—but were arguably never strictly necessary. Clinicians also identified in the dialogues how biomedical thinking more subtly influenced their routines. For example, they stated they made decisions about risk based on biomedical rather than human priorities—promoting biomedical goals such as functional independence and physical safety over human goals such as psychosocial well-being. Clinicians also identified that they often "entered the room with an agenda" that prioritized clinician-driven biomedical goals and reduced possibilities for flexibility.

Finally, how best to involve children and families in care discussions/decisions was identified as integral to providing the human aspects of care, but challenging to navigate. Generally, clinicians attempted to involve the child, using eye contact or directed questions; however, this did not always achieve the desired endpoint of child engagement. For example, Amaan (discussed above) engaged little in clinic discussions, and, according to his mother, preferred "not to be directly involved." Further, clinicians suggested that they avoided bringing up potentially sensitive issues in front of children, and thus, may omit discussions of particular issues altogether. This raised a tension between a commitment to supporting children's developing autonomy and providing children and caregivers with time and space to be able to contribute to care. The team observed that speaking with the child and/or parent separately at times may help facilitate certain aspects of care—and they may need to develop formal policy to implement this.

3.2 | Clinician–child/family interactions

A focus on biomedical care was also evident in the interpersonal interactions between clinicians and young people with MD and their caregivers. Clinicians tended to direct discussions towards biomedical aspects of care and away from human aspects. For example, Quinn (physiotherapist), 17-year-old Jamie, and his mother discussed Quinn's concerns about Jamie being carried by a friend when encountering stairs. Jamie generally walks but uses a manual wheelchair occasionally. During this conversation, Quinn continually redirected discussion towards biomedical risks of physical injury and rehabilitation goals of functional independence (autonomous mobility). In the excerpt from the field note below, we use bolded font to highlight where in the discussion Quinn continually returns to these biomedical notions. For example, she repeatedly returns to the option to use a wheelchair, something Jamie was not interested in doing, rather than considering that Jamie and his friend were fine with their current approach.

> *Quinn (physiotherapist) spoke with concern, leaning in towards the family. She asked about the possibility of using the wheelchair for* ***safety reasons*** *and maybe even a power wheelchair if they're going longer distances* ***so that he doesn't have to self-propel or have someone push him****. Neither mom nor Jamie said anything. Mom looked at Jamie and then at the floor as they spoke. Quinn then asked Jamie about his thoughts about his friends carrying him versus* ***using a wheelchair for safety****. Jamie said, "Not really. I don't typically have my wheelchair with me." Mom looked at the floor. She said, in a slightly exasperated voice, that the friend who was carrying Jamie is a really good friend and is always asking Jamie if he is okay and if his legs got tired. Mom said, "I can see where the conversation is going but this was just a one off." She said that they're just kids playing around but that the friend is always concerned about Jamie. Quinn nodded and said that she was speaking from "a clinician hat" and she was on her "soap box". She added that the* ***wheelchair would give Jamie more independence*** *for going longer distances.*

Quinn's focus on safety, orthodox mobilities, and independence are consistent with biomedical assumptions and priorities, and can be contrasted to the logics employed by Jamie and his mother. Jamie's mother resisted the imposition of these biomedical logics, emphasizing her son's needs and desires as a young person who wants to have fun and connect with his friends. Jamie may also have been reticent to use a wheelchair, a powerful marker of disability and potential focus of stigmatization. Note the clinician did not raise this possibility: When discussing disability stigma in the dialogues, the team said such sociopolitical issues related to disability rarely featured in clinic visits. The clinicians identified that such aspects of care were usually minimal in interpersonal interactions and were outweighed by their professional responsibilities regarding biomedical safety, goals, and disease management.

There were many other instances where we observed a focus on the biomedical aspects of care by clinicians, such as in discussions about a child who wanted to play on a trampoline (the clinician highlighted the risk of fractures whereas the family emphasized that it was important for the child to play); in a discussion about weighing a child (the child was uncomfortable and frightened when he was being weighed in a suspension sling, but the clinicians pushed for the weight measurement as they deemed it necessary for charting/medication titration); and in a discussion wherein a child and his father were arguing for riding on an off-road vehicle (it was good bonding experience, fun), the clinician returned to the biomedical risks involved.

The clinicians identified another common method by which human aspects of care were sidelined: Negative emotions expressed by children or parents, such as anger, frustration, or sadness, were generally ignored or discouraged. The observer noted the overall

positive, "smiley" style of the clinicians often contrasted with the impassive faces of the families. In the dialogues, clinicians identified multiple reasons for their approach. They said they avoided discussing topics that might generate "negative reactions" or "open a floodgate," including the: uncertain but shortened life expectancy associated with MD; loss experienced by children and parents associated with declining function; and stigma/marginalization associated with disability. The team questioned their capacity to cope with the sadness these discussions might evoke, were concerned about their lack of communication skills in this area, and noted the constraints of the physical space and time allocated to have "difficult" conversations.

3.3 | Staffing allocations

A biomedical emphasis was further reflected in the clinic staffing allocations. Staffing was weighted towards professions that are traditionally predominantly biomedical (nurses ×2, doctor ×2, respiratory therapist ×1, and physiotherapist ×2). The clinicians identified that the professionals in mixed roles (social worker ×1 and occupational therapist ×2), although trained in providing psychological aspects of care, predominantly used clinic time for equipment fittings and funding applications—attending mainly to biomedical rather than human aspects of care. The team and patients had only occasional access to the professionals who predominantly focused on the human aspects of living with MD. The recreational therapist attended clients on only one of the two weekly clinic days, and there were only infrequent visits by a psychologist (if specifically requested and largely for educational or behavioural concerns rather than psychological support).

3.4 | Human aspects of care provision

At times, human aspects of care *were* attended to in the clinic—and did take precedence over biomedical care. For example, a discussion between 8-year-old Hayden's father and the paediatrician revealed how the two foci could be intertwined effectively. They discussed whether Hayden should stay on a corticosteroid medication (used to slow progression of muscular weakness).

> *Dad indicated that he and his wife wanted to talk about altering Hayden's medication as it was affecting his behaviour. They began to discuss the medication Hayden was currently taking and why he was taking each one. … [it was] a frank conversation about the impacts of changing medication and the reasons dad would like them to change, even knowing that there might not be a change…[Hayden was moving around a lot. Dad once had to tell him to stop throwing something (Hayden didn't stop)]…. Dad raised in hands to his chest and said, a little exhausted, "In my wife's words, 'I want my son back'. He's just not himself." Dad looked over at Hayden, who smiled. Dad added that his wife had noticed that before they started the medication, Hayden would often climb up on the sofa and cuddle with his mom and be affectionate at other times. Since he had started the medication, this affection had stopped and it really bothered his wife. Dr. Lane looked sympathetically at dad and said, "Yes", "mmmm". She nodded and agreed with him.*
>
> *Dr. Lane suggested a plan for how to proceed with stopping Hayden's medication to see if Hayden's behavior might change. Dad said that sounded like a good plan for him. She showed dad what she had written down and why this change would be safe for Hayden's system – a gradual decrease in the medication to a point where he would no longer be taking it, rather than stopping it cold turkey…. Dr. Lane then paused and said that she wanted dad to understand that if they stop the medication now, that when they begin again Hayden will be at a different strength level than he is at now. Dad looked a bit confused so Dr. Lane pulled her chair closer to dad, leaned down and began to draw a graph that illustrated what she was trying to explain to dad. Dad nodded and asked questions to clarify what Dr. Lane was trying to say… [in the background Hayden was wetting paper towels and placing them on the walls and bed]… Dr. Lane then sat up said, "I understand the need to make this change," and added that one other family had made a similar change. Dad leaned back and looked relieved. He then asked what had happened after the change in medication. Dr. Lane looked a little apologetic and indicated that there was no change. Dad nodded. Dr. Lane then added that she felt good about making the change in medication now versus later and explained why. She went back to the graph that she drew and asked, "Does this make more sense?" Dad sounded confident, "Yep, yep." Dad sounded a tiny bit exhausted when he said that he and his wife just want to see a change. Dr. Lane nodded and smiled, "I fully support her and you in this decision."*

In this conversation, many aspects of Hayden's life were considered: various medications Hayden was taking, Hayden's changes in behaviour on the corticosteroid, mom's feelings, dad's feelings, likely decline in Hayden's muscular function, importance of affection in the family, likely reduction in Hayden's weight, and Hayden's self-esteem. A decision was made to stop the corticosteriod, despite likely acceleration of Hayden's rate of functional loss. The paediatrician said "I fully support you and your wife in this decision," explicitly expressing support for the family's prioritization to "have their son back" and the importance of the social and emotional aspects of the child and family's life at that time. Considerations of human aspects of care often required movement off the usual roadmap for care.

4 | DISCUSSION

The primary finding of this study was the discordance between the importance clinicians placed on human aspects of care and their marginalization in the reality of clinical practice. The interrelationship between human and biomedical care involved a range of practice

dimensions including clinic routines, interpersonal interactions, and staffing decisions.

Our findings highlight that aligning biomedical care with human-focused care is possible, but not automatic. The impetus to create efficient and accountable healthcare leaves little room for attending to human challenges of living with MD. Yet standardized best practice guidelines, procedures, and evidence are often insufficient in the complexities of healthcare practice—and do not always fit individual situations (Wieringa, Engebretsen, Heggen, & Greenhalgh, 2017). Guidelines may not take into account particular psychosocial, emotional, existential, and moral (human) aspects of a person's life. As the clinicians in our study highlighted, attending reflexively to their own practices of human care makes these issues explicit and opens possibilities for different ways of practicing.

Explicitly considering human aspects raises questions of how to do MD care well (Mol, 2008) and extends a growing conversation within children's rehabilitation regarding care priorities (Rosenbaum & Gorter, 2012). To better address whole-person/family needs (Rosenbaum & Gorter, 2012), clinical approaches need to balance biomedical concerns (e.g., physical risk, and functional independence) with human concerns (e.g., living well with progressive disease). Clinical care that attends to both concerns would incorporate the particular needs, desires, worries, and challenges faced by children and families (and clinicians), rather than treating them as "interfering context" or "social problems" (Authors unpubl.). Issues such as risk-taking, behavioural changes, the importance of play and pleasure, considerations of grief and loss, how to negotiate the complex issues of autonomy in child health, and the social stigma associated with disability would need to be considered alongside biomedical indications; each contribute to a better life for young people with MD. The question is not so much "should we attend to biomedical OR human elements of care?"—that is, we are not suggesting that biomedical concerns should not be attended to. Rather, a more fruitful question might be "what is missing from routine ways of caring for people with MD?" Given limited time and finite resources, some activities have to make way for others (Mol, 2002; Setchell, Nicholls, & Gibson, 2017). Are there times when routine biomedical practices might be put aside to allow attention to human aspects of care, or when biomedical decisions such as medication management can be undertaken with stronger attention to human aspects of life (e.g., the discussion about Hayden's corticosteroids described earlier)? Observing what occurs in practice highlights it is possible, and at times preferable, to apply human logics that suggest a need for a nuanced negotiation between child, family, and clinician needs amongst other factors.

Developing the intellectual resources of clinicians and decision-makers to discuss and evaluate services through filters such as Mol's logics could contribute to answering calls for more individualized care (Pritchard et al., 2017; Wieringa et al., 2017), and improve the lives of people with MD. In our study, clinicians developed a list of possible changes towards more human care in their clinic (see Appendix A). For example, changes included flexibility to tailor appointment frequency, composition, and length; time and physical space for psychosocial aspects of care; clinician skill building to support child/family expression of negative emotions and discussion of sociopolitical aspects of MD (e.g., living with disability stigma); and increasing hours of staff trained in the human aspects of care.

Our methods produced rich data that, when coanalyzed with clinicians and in consultation with a family advisor, provided deep insights into the practices and underlying assumptions of a neuromuscular clinic. The study produced innovative and practical recommendations for changing MD care at one site—which offer a set of preliminary considerations for similar clinics elsewhere (taking into account individual differences). The in-progress next phases of this research are testing the effects and relevance of implementing recommendations, and broaden the project to other sites. Study findings also highlight areas for possible further research, such as the impact of gender on clinical care (e.g., all clinicians were women, whereas all patients were boys).

This study demonstrated that operationalizing best practice standards, clinical guidelines, and imperatives of evidence-based practice leave little room for attending to human challenges of living with MD. Our findings also highlighted that other ways of practicing are possible but will likely require sustained effort and training to improve care directed towards the human aspects of life in both individual practice and broader systems. We reiterate that this does not mean that we should discard evidence based practice or best practice guidelines, nor that biomedical aspects of care should not be attended to. Rather, that clinicians should strive for a different balance that considers some of the unintended harms of an overemphasis on such aspects of care and how these might be avoided or minimized. In this collaborative study, clinicians found the process of examining human aspects of care illuminating and identified a discord between beliefs about, and practice of, this type of care. They proposed a way to work differently—which can be built upon in future research applying findings to other sites and patient populations. We see care that attends to the human aspects of living as possible, but there is a need to carve space for it in healthcare by addressing deeply ingrained biomedical patterns of thinking.

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CONFLICT OF INTERESTS

The authors have stated that they had no interests that might be perceived as posing a conflict or bias.

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APPENDIX A

CLINICAL SUGGESTIONS

1. **Routine clinical processes**
    - Consider flexibility in frequency, length, and focus of clinic visits
    - Flexibly prioritize which clinician sees families each visit (family input?)

- Some shorter focused visits with 1 to 3 key clinicians
- Some visits focused primarily on psychosocial care
- Ensure adequate time for preclinic rounds to prioritize integrated, streamlined care
- Develop "safe spaces" for sociocultural aspects of care
  - Create physical therapeutic space (separate from other clinic spaces)
  - Options for separate appointments (outside of clinic)
- Create mechanisms to convey psychosocial priority to families
  - Modify standard assessment forms and procedures to address human needs
- Develop processes for determining if/when child or caregiver(s) is or is not present
  - Consider processes for when child is taken out of room (e.g., predetermine time)
  - Child/parent time out of clinic as standard part of visit (e.g., with social worker).
  - Identify when caregiver/child needs a break during clinic
- Create mechanisms for peer to peer support (create community)
  - Promote advocacy/support groups
  - Create opportunities for families to meet

- MD only clinic day
- Central space in waiting area for families to connect
- Speakers on MD including sociopolitical aspect of living with MD
- Team camp
- "Meet ups" based on young people's interests—not just "therapy" (anime group, remote videogame tournaments, etc.)

2. **Interpersonal interactions**
   - Create culture for expressing and supporting negative emotions (e.g., grief and anger)
     - Skill building and reflective practice to enhance clinician ability to recognize and respond to parent/child's needs to express/discuss a variety of emotions/issues.
   - Create mechanisms to convey psychosocial priority to families
     - Develop related "mission statement" for clinic brochure & online
   - Strategies for addressing psychosocial needs of staff
   - Spiritual aspects of MD journeys
     - Incorporate queries re spirituality into supportive conversations
   - Upskill clinicians on sociopolitical aspects of living with MD:
     - upskilling clinicians on disability stigma, marginalization
     - referral to resources (e.g., blogs, films, and TV)
     - cultural appropriateness
3. **Staffing allocations**
   - Shift staffing focus to human aspects of care:
     - Reframe social worker role
   - Reallocate funding discussions to other personnel
   - Present role to families as focused on psychosocial care
     - Increase FTE of social worker, rec therapist, and psychologist
     - Incorporate psychosocial strategies into all clinician practices
     - Upskill clinicians on psychosocial, existential, and spiritual aspects of MD
     - Hospital multifaith chaplain or pastoral care
4. **Ongoing dialogues/critical reflexivity**
   - Regular critical reflexivity in team meetings
   - Check in with families outside of clinic regarding recent clinic visit experiences
   - Develop knowledge of language effects and alternate approaches to conveying partnership
   - Identify external facilitation opportunities
   - Identify uses for theory/frameworks