


# Enhancing the human dimensions of children's neuromuscular care: piloting a methodology for fostering team reflexivity

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**Abstract** For those with chronic, progressive conditions, high quality clinical care requires attention to the human dimensions of illness—emotional, social, and moral aspects—which co-exist with biophysical dimensions of disease. Reflexivity brings historical, institutional, and socio-cultural influences on clinical activities to the fore, enabling consideration of new possibilities. Continuing education methodologies that encourage reflexivity may improve clinical practice and trainee learning, but are rare. We piloted a dialogical methodology with a children's rehabilitation team to foster reflexivity (patient population: young people with Duchenne's or Becker's muscular dystrophy). The methodology involved three facilitated, interactive dialogues with the clinical team. Each dialogue involved clinicians learning to apply a social theory (Mol's *The Logic of Care*) to ethnographic fieldnotes of clinical appointments, to make routine practice less familiar and thus open to examination. Discourse analyses that preserve group dynamics were completed to evaluate the extent to which the dialogues spurred reflexive dialogue within the team. Overall, imagining impacts of clinical care on people's lives—emphasized in the social theory applied to fieldnotes—showed promise, shifting how clinicians interpreted routine practices and spurring many plans for change. However, this reflexive orientation was not sustained throughout, particularly when examining entrenched assumptions regarding 'best practices'. Clinicians defended institutional practices by co-constructing the metaphor of *balancing logics* in care delivery. When invoked, the balance metaphor deflected attention from emotional, social, and moral impacts of clinical care on patients and their families.

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Emergent findings highlight the value of analysing reflexivity-oriented dialogues using discourse analysis methods.

**Keywords** Reflexivity · Continuing professional development · Chronic disease · Discourse analysis · Qualitative methodology

## Introduction

High quality clinical practice requires attention to the *human dimensions* of health care (Wieringa et al. 2017). By human dimensions, we mean care processes that attend to the emotional, social, and moral dimensions of illness which co-exist with biophysical dimensions of disease. The knowledge foundation that is needed to practice skillfully extends beyond the bioscientific into the humanistic (Kuper et al. 2017). Chronic, progressive conditions shape lives in profound and varying ways, changing experiences of events, opening and closing different possible futures, influencing individual and familial priorities, and shaping interpersonal dynamics in a range of settings. Providing health care requires being attuned to contingency, change, and uncertainty, as well as the illness experiences of patients and their caregivers, on an ongoing basis.

How to develop and sustain the knowledge foundation and clinical skill to attend well to human aspects of clinical care is an active area of study (Kinsella and Pitman 2012; Ng et al. 2015). Much of the related health professions education research focuses on students and trainees (Kinsella et al. 2012; Kinsella and Pitman 2012; Kuper et al. 2017; Naidu and Kumagai 2016). But what trainees learn is influenced by their clinical immersion—sometimes via a hidden curriculum that dehumanises patients (Martimianakis et al. 2015). If the goal is clinical practice that integrates bioscientific and human-focused practices, clinicians also need support to strengthen attention on the human dimensions of health care.

In this paper, we describe and evaluate a participatory educational intervention meant to strengthen attention to the human dimensions of health care within a clinical team. In using the term ‘intervention’, we wish to clarify that we did not enter the clinic with an authoritative stance on what should change, but with axiological commitments to facilitate dialogue about the effects of clinical practices on lives, and to work with clinicians to identify opportunities to better attend to the human dimensions of clinical work. We designed *dialogical processes* that aimed to *make practice strange* to clinicians, to foster individual and team *reflexivity*. Each of these terms have a theoretical foundation and methodological impacts, which we describe in relation to our pilot study with a children’s outpatient neuromuscular care team in an urban community.

We conducted our educational intervention in collaboration with a team who work with children and adolescents with dystrophinopathies—Duchenne and Becker’s muscular dystrophy (MD)—and their families. Physically, MD is characterized by a progressive weakening of skeletal muscle, which leads to loss of physical abilities and increasing reliance on attendants and technologies for most activities of daily living (Bushby et al. 2010). MD is an x-linked genetic condition that affects boys, almost exclusively. Life expectancy is shortened, and persons with MD and their families experience considerable uncertainty about the future. In addition, the prognosis creates emotional and practical challenges for young people and families, including regular home-based management activities, increasing support needs, and planning for adult life (Abbott and Carpenter 2015; Gibson et al. 2014).

With chronic diseases, uncertainty can arise from the disease processes, the effects of treatments, and/or the varied resources available to patients and families (Greenhalgh et al. 2014; Mol 2006, 2008). As Mol (2008) argues, bodies and lives affected by chronic disease are unpredictable. Sometimes, treatments do not work as hoped or predicted. Evidence-based treatments are based on probability and group means, which do not necessarily actualize for individual children and families who seek care. At times, an intervention sometimes produces intended effect(s) at the expense of others. Tradeoffs may only be apparent after starting a treatment or integrating a new technology into one's life, and a new approach must be found. Decision-support texts such as standards, best practice guidelines, and systematic reviews are not prepared to guide the uncertainty and contingency that individual patients and families navigate with clinicians.

Healthcare clinics are a key site where work is done to assist young people with progressive diseases (such as MD) and their families to make sense of their life trajectories in the face of decline and uncertainty (Gibson et al. 2014). The work of the clinic itself creates impacts beyond what is commonly considered, with negative consequences less recognized. For example, the continual testing and home-based body management routines thought of as 'best practice' for childhood chronic disease have significant impacts on children's identities, contributing to their sense that their body is a problem (Bekken 2014; Bjarbaekmo and Engelsrud 2011). Children's own felt sense of being normal is challenged in these ongoing clinical consultations and home-based clinical activities (Bekken 2014). The limited or highly medicalized approaches to speaking about decline and dying create unmet needs in those facing emotional and practical challenges near the end of their lives (Abbott et al. 2017). These and related issues faced by those managing MD resonate with other progressive chronic diseases. It is these kinds of concerns and experiences which the bioscientific aspects of clinical care are unable to address well. What good should clinicians pursue with individuals who have a degenerative condition and uncertain prognosis?

How might we support clinicians to attend to the emotional, social, and moral dimensions of clinical care when working with young people with chronic, progressive conditions, when other institutional imperatives often emphasize different priorities? These questions underpinned our development and analysis of a participatory educational intervention with a clinical team. We aimed to facilitate discussions with and between clinicians of how to align clinical practice with living well with MD.

In the current paper, we evaluate how our intervention methodology succeeded and failed in spurring reflexive dialogue within the team. Our contributions are both methodological and substantive. We first detail the theoretical framework and methodological commitments informing the reflexivity intervention developed for the study. We then describe our methods to spur reflexivity: a series of three facilitated, interactive 'dialogues' with the clinical team that delved into ethnographic observations of practice and introduced Mol's (2008) contrasts of choice and care logics. How to assess the impact of reflexivity-oriented education is an open discussion; we used a discourse analysis approach which attended closely to the intersubjective dynamics which give rise to both particular utterances and dialogical, reflexive perspectives (or not) over time. Finally, we discuss our specific findings and their implications. We found the ethnographic observations and Mol's (2008) description of care-logic to be a rich foundation by which to foster dialogical, reflexive learning, though the reflexive orientation could be challenging to sustain.

## Theory and methodology

### Reflexivity

Reflexive processes aligned well with our goal of increasing attention to the human dimensions of living with a chronic, progressive disease. The health professions education literature contains overlapping concepts and/or variants of reflexivity, including critical reflection (Ng et al. 2015), critical reflexivity (Kinsella and Pitman 2012; Rowland and Kuper 2017) and epistemic reflexivity (Kinsella and Whiteford 2009). All refer to processes that foreground and examine social and structural influences that organize thought within fields of practice. We opt to orient to the concept of reflexivity.

Reflexivity, in Kinsella's (2012) conceptualization, helps individuals recognize that their everyday actions—in this case, clinical activities—are shaped by historical, social, institutional, and discursive influences that are often left unexamined. Relatedly, practicing reflexivity helps mitigate against assumptions that professionally-trained interpretations of social situations are objective or unbiased (Charon and Marcus 2017; Kinsella 2012). Practicing reflexivity, as per Kinsella (2012), enables “practitioners to begin to ‘crack the codes’, to consider together the invisible cloud that pervades everyday life and everyday practice, and from this location to envision new possibilities together” with patients (pp. 45–6, citing Kinsella and Whiteford 2009). Practicing reflexivity strengthens recognition of how clinician behaviours are shaped by taken-for-granted norms and discourses that organize fields of practice (Charon and Marcus 2017; Kinsella 2012). In a more pedagogically-focused description, reflexivity involves “introspection, intersubjective reflection and collaboration” (Kumagai and Naidu 2015, p. 283). Thus, working to foster reflexivity amongst healthcare professionals requires that education spurs appreciation of the assumptions underpinning clinical work in a collaborative (rather than solitary) way.

### Dialogical approaches and situated knowledges

Dialogical approaches promote reflexivity by enhancing resistance to the assumption that a clinical (or research) perspective is the singular or right view (Kumagai and Naidu 2015). We rely on theorist Mikhail Bakhtin's (1984) description of dialogical as that which resists closure or finalization—that is, not monological. There is no authoritative voice that knows all, in a dialogical approach. This resonates with Haraway's (1988) argument that no one sees the whole—no one has a “gaze from nowhere” that sees all (p. 581), which she calls a ‘God-trick’. Haraway argues for the concept of ‘situated knowledges’, which develop within our limited locations. It is by recognizing how what we know is situated (and thus partial) that we can avoid treating our knowledge as total and complete.

Exchanges of ideas that allow varied ways of experiencing the same moment to surface are dialogical (Kumagai and Naidu 2015). Speaking specifically about medical education, dialogical explorations of health care require (a) participant safety to talk openly, (b) a purposeful removal from everyday demands, and (c) an active awareness of the transition, of change and becoming (Kumagai and Naidu 2015). Dialogues work well when learning activities make the familiar unfamiliar, and encourage the denaturalization of habitual ways of thinking and working (Kumagai and Wear 2014).

## Making the familiar strange

In order to foster reflexivity, we worked to make familiar practices strange. *Making strange* involves making the ordinary appear less familiar, less natural, and thus more open to interrogation. This theoretical and pedagogical premise has been adopted elsewhere in medical education by discourse analysts (Kuper et al. 2013) and in the medical humanities (see Kumagai and Wear 2014). Making strange allows for consideration of actions in new ways, and without (or with less) defensiveness. Making strange “troubles one’s assumptions, perspectives, and ways of being in order to view anew the self, others, and the world” (Kumagai and Wear 2014, p. 973). It provokes the discomfort of facing the unfamiliar, prompting reflection, and ideally influencing future action. Working with practicing clinicians, we made current practice strange through two different strategies: introducing a social theory frame through which to interrogate current practices, and co-analysing ethnographic observations of their clinical work.

### *Incorporating social theory: a lens and vocabulary through which to interrogate practice*

Clinicians often lack a human-centered vocabulary to support purposeful periods of reflection and reflexivity about clinical practice (Kumagai and Naidu 2015). We found Mol’s (2008) delineation of the *logic of care* a relatively accessible and rich vocabulary from which to approach human dimensions of care practices, and to help make current practices less familiar. Mol (2008) argues that multiple logics operate in health care. By logics, she speaks to practices that have affinities, commonalities, and coherence within specific cultural, historical locales. She aims to show how logics envision “a specific mode of organising action and interaction; of understanding bodies, people and daily lives; of dealing with knowledge and technologies; of distinguishing between good and bad; and so on” (Mol 2008, p. 7). Logics that developed elsewhere, such as efficiency or (consumer) choice, have come to reconfigure clinical practices in health care institutions, with multiple intended and unintended consequences (Mol 2008). We used this logics-heuristic to examine practices which may seem natural or best, raising questions about the impacts of different logics on the lives of those with chronic conditions.

Mol (2008) develops her argument by contrasting practices associated with two different logics: the logic of choice and the logic of care. In Mol’s logic of choice, practice is organized around striving for pre-determined outcomes, where patients are not forced to comply, but given a choice. This merging of biomedical priorities with autonomy embeds a moment where patients can accept or reject pre-selected clinical treatments. In contrast, the logic of care is not organized around meeting pre-determined targets, but rather ‘looking after’ the whole person in the broader context of their lives. The clinical priority is ‘doing good’, by which Mol (2008) means doing that which leads to a better life for the given person, in the face of an ongoing and unpredictable disease course. In care-logic, clinical care involves tinkering on an ongoing basis with all that may affect a life, recognizing that changes will be needed over time and living well does not necessarily align with biomedically-prioritized treatments. Tinkering alludes to careful, attentive adjustments to produce good effects, aiming to be attuned to what makes a difference, learning from past attempts and trying again (Mol 2008). She argues

that care-logic aligns better with the management of chronic diseases than does choice-logic, due to the continually changing and complex entanglements of people's lives.

In practice, a combination of choice-logic and care-logic may produce good effects. Mol draws our attention to the impacts of clinical practices on individual lives; we can only begin to answer the question of which clinical practices comprise 'good care' if we appreciate what they *do*, broadly considered. What is 'good' is not able to be determined in advance by a single authority, as is often the case with guidelines, outcome measures, or systematic reviews. These types of scientific knowledge and medical technologies are not to be excluded but put in service of the open question of what helps craft a better life for the individual alongside other forms of knowledge. Mol's framing helps contrast practices and emphasizes the need to recognize and make visible different 'bads' and 'goods' enacted through practice.

In the pilot study, we worked with Mol's arguments in three ways to help make clinical practice strange and support reflexive dialogue. First, we emphasised exploring the impacts of practice on people's lives—impacts which may be multiple. This required ethnographic attention to detail and considering more than the most immediate or biomedical aspects of people's lives. Second, we anticipated Mol's logics of choice and care were unfamiliar to clinicians, which would unsettle existing ways to talk about clinical activities. Finally, with clinician participants, we applied Mol's arguments to attend to the core assumptions that influence practices—such as the logics underpinning best practice guidelines or clinic funding models—that are central to being reflexive.

### *Ethnographic observations: a contrasting way to see practice*

We opted to study existing clinical processes via *ethnographic observation*. An experienced qualitative researcher (BM) observed individual appointments at the participating children's neuromuscular clinic. BM is not a clinician, which aided her writing fieldnotes with an unfamiliar perspective on clinical practice. Methodological aspects of the ethnographic fieldnotes are detailed in the next section.

## **Methods**

### **Design**

The study design was a pilot of a novel, participatory educational methodology with a clinical team, which aimed to generate dialogical exchanges with and between clinicians of how to align clinical practice with living well with MD. The study was conducted over an eight-month period in 2016. We observed care using ethnographic methods, and facilitated a series of three meetings (which we called critical dialogues), applying the pedagogical practice of *making strange*. Observation and dialogues were conducted concurrently to allow the former to inform the latter. Dialogues were audio-recorded and examined using discourse analysis methods designed to examine interactions. The participating centre's Research Ethics Board approved the study.

## Participants

We completed the study with a children's neuromuscular clinical team located in a large urban community in Canada. The clinical team observed and participating in the dialogues included: two registered nurses, occupational therapists, physical therapists, respiratory therapists, physicians (one pediatrician, one respirologist), one social worker, and one recreation therapist. The fifteen participating patients were boys aged eight to seventeen. We recruited patients through purposive sampling for a wide age range, continually from the bi-weekly schedule. All attended the clinic with at least one adult member of their family.

## Observation and fieldnotes

Over a five and half month period, BM observed the care of fourteen different families, over seventeen observations. Two brothers, both with MD, were seen in one family appointment. Three were observed twice during the pilot study (and continue to be observed in a follow-up longitudinal study). For more details about participants, see Setchell et al. (2018).

Typically, BM stayed in the appointment room with the families, while clinicians came in and out to see the young people and their family members. Families saw between four and eight clinicians per appointment. Appointments lasted between two and a half to four hours and 40 min. She also observed pre-clinic rounds (one morning per week), and occasionally left the room to observe a 'handover' to another clinician. Overall, BM observed 107 clinician-patient/family interactions.

BM prepared fieldnotes following Emerson et al's. (2011) guiding principles for description. She wrote fieldnotes in episode-style, written as a continuous flow of action, embedding occasional 'still life' sketches to develop the setting for other readers. She included: concrete, sensory detail, avoiding evaluative language; as much as she could recall, rather than being selective; her physical location in settings, and how that influenced what she could see and hear; people's actions, as well as details about the setting and appearance of participants; and the back-and-forth nature of conversations, reserving quotations for verbatim comments she jotted down at the time of observation. She differentiated her analytic asides from the rest of the fieldnote, commenting on her own emotions and tentative interpretations of what was happening at the time. The researchers selected excerpts of fieldnotes to introduce in the dialogues, to ground conversations about clinical practices.

## Dialogues with clinicians

We developed and facilitated a series of three critical dialogues with the clinical team. Informed by the reflexivity and dialogical concepts discussed above, we worked to: approach this work with humility and the desire to learn with the clinicians rather than assuming we knew what is to be done; use facilitation methods to help highlight external influences on clinical practice, such as funding or legal requirements; foster deep engagement with contrasting perspectives on clinical practice. JS held prime responsibility for dialogue design, and refined the learning activities with BG, BM, and PT.

Their work built on that of the complete research team, who met approximately every 2 months to analyse new observation data, identifying patterns of practice, assumptions underpinning them, and flagging potential topics for discussion with the clinicians.

Each dialogue lasted 2 hours. JS and BG facilitated the dialogues; both are physical therapists with transdisciplinary training in critical health psychology and bioethics respectively. Each had prior experience fostering reflexivity with groups of students and clinicians. To ground conversations about clinical practices, we shared excerpts of observations with the clinician participants in the dialogues, and in the final dialogue, emerging findings from our analysis of these observations (Setchell et al. 2018). The sessions were approached as co-analysis of practice.

"Appendix 1" outlines the content of the three dialogues. Each dialogue was audio-recorded and selectively-transcribed by the first author (PT) for analysis. Summarization was used for sections where the arguments were more straightforward and/or periods where the content was less likely to show participants' working with the ideas. For example, we summarized the facilitator's presentation of Mol's logics. Each dialogue transcript was developed over repeated reviews of the audiorecordings, ensuring that the sequences that spoke best to analytic interests were captured verbatim. All quotes in this article are verbatim.

## Data analysis

We aimed to evaluate the extent to which the methodology succeeded in spurring and deepening reflexive interpretations by clinicians over time. We used techniques of discourse analysis to do so. In the dialogue transcriptions, we looked for evidence of reflexivity in clinicians' talk, including: tentative, exploratory versus monological, authoritative statements; active consideration of the perspective of the patient or family members when discussing clinical care; talk about possible impacts of clinical experiences on the lives of those with MD and their family members; critical examination of clinical or institutional perspectives; raising and examining influences on clinical practice that block the practice of care-logic; change in sophistication of analyses within the group over the three dialogues; and possible clinical changes identified, and the justifications clinicians offered for such changes.

Attention to the conversational dynamics is an analytic principle that Kitzinger (1994) argues is central to working with focus group data. Though the data source here is not focus groups per se, we treat the analytic principle as transferable. Moments of reflexive dialogue were treated as emergent, situated expressions where clinicians were responding to each other and also to the ethnographic examples and facilitator questions. We started from the theoretical premise that the language is indexical; i.e., the meaning of an utterance is not just in the words, but in how it fits within a sequence (Wilkinson and Kitzinger 2000)—a premise that starts in Saussure's work and has been developed by multiple theorists (see Cameron (2001) and Silverman (2007) for a review). This required use of analysis methods that preserve dynamics of conversation rather than isolating quotations of reflexive utterances (Silverman 2007). Our approach preserved the intersubjective production of meaning that is central to dialogue (Kumagai and Naidu 2015).

To analyse the content of the conversation, we looked for what Wetherell and Potter (1988) call 'interpretative repertoires'. These are bounded, consistent phrases such as metaphors, figures of speech, and tropes that are shared within a particular culture (Wetherell and Potter 1988). When a speaker introduces a particular interpretative repertoire, they



propose a way to understand the situation and disqualify others. For example, in the dialogues, we introduced and asked clinicians to apply interpretative repertoires—choice-logic and care-logic—to examine their practices. Over the course of the conversation, clinicians could associate these with other interpretative repertoires (e.g. clinical practice as art and science). Studying interpretative repertoires over the course of a conversation is a way to study the co-construction of meaning over time, and also gives analytic clues as to whether the new ideas were treated as 'strange' or made familiar by the clinicians (which could limit the impact of the methodology).

Through repeated readings, PT considered utterances and interpretative repertoires in terms of what was said, how it responds to what came before, and the function of the comment (Cameron 2001) in the broader discussions across the dialogues. The term 'function' refers to the actions that speakers do when speaking, such as rejecting, reinforcing, or clarifying an suggestion that has already been offered. Studying the function and content of comments within sequences allowed close consideration of interpretation happening among dialogue participants, and the emergence of co-constructed meaning over time. Attending to the function of different utterances within a sequence of talk also helped examine the extent to which the methodology created a safe and dialogical space (Kumagai and Naidu 2015). In a series of analysis meetings, PT worked with the other authors to review emerging findings and refine the analyses.

## Findings

We evaluated the extent to which facilitators established a dialogical environment conducive to fostering reflexivity. We assessed the three critical dialogues with the clinical team to consider: signs of safety and trust; the extent to which the methodology made clinical practices strange; and how well the methodology produced dialogue consistent with reflexivity, and if that changed over time. Of note, some of the examples developed have relevance to more than one topic.

## Creating an environment conducive to reflexivity

### *Establishing safety and trust*

Safety and trust are necessary for dialogue that promotes the practice of reflexivity (Kumagai and Naidu 2015). Throughout the dialogues, we used Mol's logics and findings from ethnographic observations to destabilize assumptions that best practices should pursue biomedically-defined targets. This produced the possibility of conflict within the team, conflict between the team and the researcher-facilitators, as well as defensiveness among team members, especially those more biomedically-oriented professionals that may have had stronger associations with choice-logic. We analysed the transcripts of the critical dialogues for signs of these factors.

In the first critical dialogue, in order to establish a safe environment, we intentionally introduced fieldnote excerpts of clinicians not present at the dialogue to reduce the caution clinicians might have displayed if the colleague was in the room. We selected two stark examples of the different logics for the team to review and discuss. The care-logic example involved a physician with the family. For the example of choice-logic, we selected an example external to the clinic—a moment when a parent described the school-based clinical team. The examples worked well; clinicians spoke without hesitation when discussing

them, and easily identified the scenario as choice-logic in action, noted why it can be a problem, and spoke about the institutional imperatives that result in such a scenario.

For the second dialogue, we introduced elements of risk while working to preserve safety and trust. Clinicians worked through a full fieldnote in advance of the dialogue. While not every clinician on the team was included in the fieldnote, most were. The note included a range of practices, which varied with respect to degree of choice-logic and care-logic. Each clinician was prompted to identify moments they interpreted as examples of care-logic and choice-logic in the material. The facilitators opted to not delve into specific examples in detail. Instead, they opened a conversation about insights that clinicians had from reading about the whole appointment. This facilitation technique limited the extent to which any particular clinician was scrutinized.

Trust was further evident in the second dialogue during clinicians' responses to the facilitators' provocative questions and clarifications. In the absence of trust, we would anticipate such ideas would be worked against or rejected. This was not the case. For example, JS asked a series of probing questions on the topic of 'what is the purpose of clinic?'. All participants participated, actively questioning their own assumptions. We heard at the third dialogue that that line of questioning had been important in ongoing discussions within the team outside of these meetings.

In another example, BG offered a somewhat challenging clarification in a conversation about professional duty when discussing risks with patients. The discussion arose from examples of children with MD who wished to pursue physically risky activities, such as riding on an all-terrain vehicle with a parent, or jumping on a trampoline. Such activities were framed by clinicians as pitting enjoyment of life against risk prevention. Clinicians suggested that their regulatory bodies required them to always promote the safest choice. BG drew on her prior expertise as a regulator to clarify the regulations and expectations:

Your interpretation is—is very correct, in terms of you have to tell people the risks and benefits as well. But there's nothing in the college guidelines that says you have to make a recommendation about these things. If patients ask you for one, of course you're gonna give one [right] but it doesn't say you have to choose a side [right] or say, 'well I think my job is to recommend the safest option', that's not a legal requirement.

BG drew on her prior expertise as a regulator to clarify the regulations and expectations (which are not as firm as clinicians presented them). BG also discussed research indicating that clinicians often felt a strong sense of moral obligation to protect patients from possible physical harms, seeing this a core responsibility of a health professional, and assuming this responsibility is embedded in regulation. Clinicians did not challenge that interpretation, and the conversation moved on. Whether through questions or the occasional clarification (of Mol's logics, of legal requirements), clinicians engaged with the ideas directly, a sign that they felt sufficiently safe to interact. Of note, each facilitator often added a comment such as 'I'm being intentionally provocative' prior to passing the floor—an attempt to promote safety and trust by making explicit the potentially controversial nature of their approach to the topics, and highlighting that it was acceptable to agree or disagree with issues raised.

The third dialogue had a different emphasis; most of the time was used to present and discuss the research team's emerging analytic insights and working with the clinicians to develop possible changes to practice. We anticipated one statement of findings could threaten the team's sense of their work: that biomedical care (assessment and treatment of disease sequelae) was usually prioritized and more systematically addressed than

psychological and social care. The facilitator introduced the statement about less systematic psychosocial care, connecting it with prior discussions. The team responses included active listening and contextualizing the issue to examine possibilities for change, without signs of defensiveness.

For example, after one clinician clarified that the psychologist's role is limited to educational assessments or occasionally addressing "some complications around behaviour", she acknowledged that the brunt of psychosocial care comes down to the social worker. A respondent noted:

I think, we talk about that, the rest of the team talks about that when you're not around. "How do you have a clinic that has (.) this many psychosocial implications and have a social worker that's only here 3 days a week. You know? It just seems so:0 (.) crazy.

As the conversation continued, several team members agreed and spoke about the grief families faced. They considered ways they could work to improve psychological and social care.

The facilitators introduced related issues that have the same type of risk, such as the lack of opportunity for expression and processing of difficult or 'negative' emotions such as anger or sadness. Clinicians responded to each of these research findings with thoughtful discussion of the issues—including speaking about their own emotional coping challenges—and possible changes. At the end of the session, many expressed a commitment to working in the near future to address the limited opportunities in the clinic for patients and family members to process difficult emotions.

Clinicians actively managed their own safety as well. This was evident, for example, in how the clinician argued for a 'balance' of care-logic and choice-logic. The metaphor of *balancing logics* came up in the first session, and was repeated by clinicians throughout. It was at times used as a device to deflect deeper interrogation of some clinical practices, particularly entrenched assumptions regarding 'best practices'. We develop this concern in the next section; *balancing logics* rhetorically reduced dialogical talk about certain topics, and deflected from active consideration of the impacts of clinical care on young people.

### *Dialogical exchange*

Being dialogical involves lacking an authoritative voice that is treated as The Truth. Dialogical processes resist closure or finalization, and involve recognizing the varied ways situations can be experienced. We interpreted several dynamics as evidence of dialogical processes: the capacity for disagreement, avoidance of early closure or imposition of a monological frame on a topic, and consideration of new situated perspectives.

In each session, the clinicians disagreed with each other and with the facilitators. For example, in the first session, a participant hesitated to describe the excerpt exemplifying care-logic as 'good' care. She disagreed with the family's decision to discontinue deflazacort due to what the family viewed as untenable side effects in the form of behaviour changes. She spoke of how the child was 'doing well' and was asked to clarify, to which she replied "He was doing quite well, physically". Her colleagues responded by re-framing the situation. A second participant drew on choice-logic to suggest that, while discontinuing medications might not be what the team would choose, they had to respect what the family wanted. Another then added a dialogical turn that brought care-logic into the foreground, commenting that successful treatment may be about quality of life, being happy, and functioning well as a family rather than (or in addition to) slowing physical decline.

After reviewing the logics heuristic, several clinicians spoke of why it is families may make this decision, and the possibility that not taking the medication (which slows the progression of the disease, but also have numerous deleterious side effects including weakening of bone, delayed puberty, and can exacerbate attention deficit hyperactivity disorder) crafts a more bearable way living for the family.

The medication topic appeared repeatedly during the dialogues. Each time it surfaced, we witnessed a comfort among the clinicians with challenging one another and avoiding a monological closure. Clinicians discussed the medication scenario as a recurrent situation and spoke about how it could be handled with care—that is, how clinicians can continue to support parents and young people even when they opt out of the ‘gold standard’ treatment. Conversations across the dialogues shifted to treating this type of situation as more of an ethical and emotional challenge for clinicians to navigate rather than an issue that can be closed in any definitive way. Medication conversations are but one example of the dual nature of dialogical thinking outlined earlier: resisting an authoritative clinician-knows-best way of thinking, and an opening up to other possible perspectives as important.

However, one form of monological closure happened. By the end of the first session, several team members developed the metaphor of ‘balance’ outlined above; they argued that a balance of Mol’s two logics indicates good practice. A clinician first introduced this metaphor in the first dialogue, when discussing Mol’s logics:

Gosh, now I’m choosing my words carefully, but like evidence-based practice or we have to make sure they have informed decisions or they have access to all of the care, but then we also make them feel supported and comfortable and uh, help them lead the best life whatever that, may look like to them. So I think it is, I think it is always a balance between the two. [facilitator: Yeah] I mean, ideally, you would like, you know this one, feels better when you’re reading it [laughter] but sometimes, there are times when this one has to come into play.

Over the course of successive comments, three other participants linked scientific knowledge to choice-logic, which then spurred this response from another participant:

I think it’s nice cuz this, there’s no right or wrong. Like I think that, like in this, I don’t- I don’t think that she’s saying um like logic of care is the ‘gold standard’, everyone should be doing that, no questions asked. I think it’s a, ‘you use a combo, and that’s okay’. That there’s times when it’s more appropriate and times when it’s less appropriate. So it’s, I think using the combo is, the best thing you can do. I don’t-like when you look at it, you’re like ‘oh my god! This is what we’re supposed to be doing’ and stuff. But then you’re like ‘no. You’re supposed to be flip-flopping and—and doing like a combination-

The facilitator interrupted her at this point to correct her on Mol’s argument about chronic disease and care-logic. But the rhetoric of balancing logics continued, and some invocations blocked dialogical responses. For example, in the second dialogue, one clinician found reading the whole fieldnote striking for how clinicians acted:

I also thought, you know reading it, people were really strength, based focused you know like, I think everyone went in, like clinician-wise, trying to be very positive, um (pause) that wasn’t, I think that’s what we try and do, and it just was nice that it did seem to come across that, we try to focus on strengths. We try to focus on things that were, going well. Um, and seeing both the care and choice approaches, like integrated both.

Of note, the observed appointment that participants read had an example of choice-logic informed actions, actions that in the excerpt exacerbated a child's fear of being suspended in the air in a sling for weighing. In the excerpt, it was another clinician's intervention offered in a care-logic vein that de-escalated the child's distress. What was lost in the specific utterance quoted above was the dialogical implication of Mol's argument, of the importance of centering the impacts of a practice on the patient's life lived. 'Good care' was, in this moment for this clinician, about how clinicians acted rather than what happened as a result. Being monological in this way blocked the reflexive practice of exploring effects, broadly considered, of intervening in the lives of patients and families.

An exchange in the third dialogue exemplified openness to differently situated perspectives. In a discussion about creating space for the expression of more difficult emotions, we learned that the above example, of being 'very strength focused' and 'very positive' was something this particular clinic had worked to develop. Team members explained that this type of talk emerged from prior feedback that the clinic was too deficit-focused—and that deficit-focus had troubling effects on the person with MD as well as their family members. Being strength-focused and positive had, for several team members, come to signify 'good care'. It was also described as a coping strategy for clinicians, working with young people who face decline. The possibility that current ways of doing this may create other problems, such as lack of space for the expression of negative emotions by patients and family members, was a new conversation for the clinic. The question of how to be strength-focused, how to not focus continually on deficits and loss, while also creating the space for a range of emotional expression is one of the topics the team agreed they will work to improve.

### *Making practice strange*

As discussed, reviewing the fieldnotes and applying Mol's logics were the primary methods by which we sought to make practice strange. Inviting the clinicians to review and discuss the fieldnotes helped to de-familiarize practice. In particular, the reading of a whole fieldnote—that is, of a whole appointment—prompted new understanding of clinic processes. For example, many agreed with a clinician when she said:

I was like (pause) I think as individuals, everything was as I would have predicted. Everything. But I was absolutely overwhelmed with um, the feeling of, how awful it must be for these families to set out for this day, go next door, do a bone density, have blood work drawn for a research project, be handed some papers to complete, have a-have a young person who really doesn't want to be here and, like constantly the pushback from the child, you know? Each clinician gets a snippet of that, but the mother's going through it the whole time. [skipped text] You sitting there, and relaying it back to us, I feel so anxious for the mother. [skipped text] We're constantly asking them 'can you do this?', 'now can you do this?' and 'now can you do that?' [skipped text] Is that fair for us to expect that much to happen? [skipped text] If I were the mum, I'd say 'no, I can't do it. I just can't do it'.

Clinicians continued discussing the topic, flagging their tendency to try to use every minute and the impact that might have on the parent, the child, and the accuracy of physical tests done late in the day. Similarly, in response to the full fieldnote, clinicians raised concerns about the continual interruptions during client visits. The clinicians mentioned the rationale that produces interruptions—keeping the clinic moving efficiently—and noted interruptions disrupted the possibility of a safe space for expression of emotions:

I've also tried to have some pretty involved conversations, and it's not worked out well because they're fully into it emotionally, and then knock-knock-knock, "your time is up" or there's people coming into observe. (yeah, residents, students) And I understand, we have to keep it going.

These insights led to active discussions of possible changes. For example, in the third session, one co-developed recommendation was to establish a process to lessen interruptions, the "knock-knock-knock" at the door. This was deemed especially important in light of a consensus in dialogue three that the biomedical aspects of MD were attended to more consistently and thoroughly than other topics—clinicians told us that the risk of being interrupted is part of what limits them from delving into harder topics with patients and families.

Making strange through review of a whole transcript also led to troubling of routine actions taken by some individual clinicians. Some questioned their habit of greeting families with an upbeat, cheerful disposition. Through the observations, clinicians detected moments when their cheerfulness may have unintended impacts on patients and families. For example, one clinician noted how that new knowledge might shift her practice:

Today, just hearing everyone, being more aware of the families and how they're feeling. When I was reading through those 15 pages, that was just so striking. I don't tend to be involved in those heavier conversations, I just kind of hear it in little bits and pieces. Just being aware when I'm going in and asking 'what do you do for fun?' and 'what are you doing this summer?'. Like they just talked about a lot of heavy stuff, that just kept coming into my head.

Other individuals discussed the value of the observations in highlighting habits of which they were not very aware. For example, one participant noted the number of times she responded enthusiastically (in particular, "Great!") to descriptions young people offered of their functional independence. She raised concerns about the effects of saying 'Great!', given the progressive physical decline of the young people, and the sense of failure they may experience when they cannot do what is "Great!". She committed to changing how she responds to patient descriptions on this topic.

Introducing Mol's logics frame was more mixed in terms of making practice strange. As clinicians employed the interpretative repertoires of care-logic and choice-logic, they identified institutional practices that enact different logics, such as an organizational shift to using standardised outcome measures and 'goal attainment scores' by which the clinic is evaluated. But clinicians also associated Mol with a more familiar metaphor to talk about clinical practice: that of practice as art and science. For example, in the second dialogue, one participant introduced the metaphor of 'art' and 'science' to differentiate the logics. Others then took that up that language. Mol (2008) argued explicitly against the idea that technologies (or science) are somehow opposed to care. Instead, technologies (and science) can be integral in care-logic; it is a question of how practice is organized, how scientific knowledge is mobilized, and to what effect on people's lives. A facilitator used the notion of art of practice to interrogate another set of issues—specifically, that art is a learned skill—but this translation may have had the effect of reinforcing that inaccurate representation of choice-logic as science and care-logic as art. Through these discursive associations with the art and science of care, Mol's logics were 'made familiar', at least in part.

## Reflexivity in practice: bringing external, institutional influences into view

Reflexivity involves a 'cracking of the codes' that are often invisible but pervade everyday practice, and interrogating the taken-for-granted norms and assumptions that organize fields of practice (Kinsella 2012; Kinsella and Whiteford 2009). Our study methodology brought to the fore many of the institutional influences on the team. Institutional influences tended to organize services in a choice-logic register.

Local organizational imperatives highlighted by participating clinicians during the three dialogues included the use of 'goal attainment scores' and measuring pre-determined outcomes, and the organizational pressure to complete checklists that set up an clinician-led agenda. Various clinicians noted limited funding and thus less coverage for psychosocial practitioners. Moreover, the primary role of the social worker was to help families secure funding rather than provide psychological or social care. Despite recognition of the grieving these families revisit with each sign of decline—which they described metaphorically as the "cascade of sorrow"—clinicians said that organizational funding and priorities limited their capacity to address grief and other human dimensions of living with MD.

Clinicians also discussed regulatory obligations as an important influence on care practices, as noted earlier. Multiple clinicians articulated the need to 'push safety', even if potential effects of talking about risk (or "spoiling the fun", as one participant phrased it) included damaging rapport and provoking guilt. Around the room, there was general agreement that regulatory requirement that clinicians outline benefits and risks is one that reflects choice-logic.

In response, in the third dialogue, the facilitators opened the potentially contrasting 'goals' of enjoyment in life and avoiding risk by introducing examples from the fieldnotes where clinicians met their regulatory obligations but approached this issue with different logics. Each example was of how a clinician closed the discussion and framed the patient's decision. "It's not an activity I'd recommend, but it's up to you" was first presented as an example of choice-logic. Next a care-logic oriented comment was presented: "I understand the need to make this change. I fully support you in this decision." While both meet regulatory requirements, these two responses differ in framing responsibility and the clinical relationship. While emphasizing autonomy ("it's up to you") does challenge paternalism, several clinicians did not delve deeper (at the time of the dialogues) to see that the way they framed their comments mattered in terms of producing different effects in the lives of patients and families.

## Discussion

This study started from an understanding that clinical practices can have deep impacts on the lives of patients and their families. What happens in clinics can shape identity, emotions, and how people make sense of their lives in the face of decline and uncertainty (Gibson et al. 2014; Mol 2008). We sought to support clinicians to attend to these emotional, social, and moral dimensions of illness which co-exist with biophysical dimensions of disease. Our pilot study aimed to foster reflexivity to strengthen the human dimensions of care in a children's outpatient neuromuscular setting.

We found many promising indications that the intervention fostered reflexivity within the team. That is, we saw many signs of recognition of historical, social, institutional, and

discursive influences on practice that were previously unexamined. We witnessed clinicians interrogate their own individual and team practices, and appreciate that their interpretations are situated and influenced by values, training, and institutional pressures rather than an singular, authoritative truth. For example, the dialogues spurred reconsideration of efficiency goals in light of the effects of the frequent interruptions on patients' and family members' opportunities to express grief. Through the combination of Mol's theory, the facilitation processes, and the review of ethnographic notes, clinicians were able to de-center and de-naturalize certain types of clinical actions. However, not all clinicians sustained a reflexive, dialogical stance throughout, which we explore below.

### **Mol and dialogical thinking**

Dialogical exchanges bring varied ways of experiencing the same moment to the surface (Kumagai and Naidu 2015). We found that Mol's (2008) emphasis on the impacts of clinical actions on the lives of patients and families a powerful way to facilitate dialogical thinking, as well as assess when clinicians took a more monological stance. In our data, imagining impacts of clinical practices on others was a powerful way to shift perspective, to unsettle what Greene called "the cloud of givenness" (cited by Kinsella 2012) that clinicians may have about clinical routines. Imagining the effects of particular clinical actions on the lives of patients and family members was effective at focusing clinicians' attention away from professional or organizational obligations, at least for a moment. The ability to imagine, however tentative and uncertain, the position of another person within the wider context of their lives helped clinicians appreciate the historical, institutional, and discursive situatedness of their own interpretations of what comprises good care.

However, the dialogical quality was not sustained throughout. Moments such as when clinicians emphasized what another clinician did as good care (e.g. "went in being very positive") were glimpses of monological, authoritative assessments of clinical activities. The persistent metaphor of a balance of logics—the proposal that an integration of choice-logic and care-logic was ideal—deflected attention to the possible effects of observed actions. When invoked, the balancing logics argument was monological and tautological: balanced logics are good, and care was good because it was balanced. Attending to the human elements of care—the moral, emotional, and social aspects of living with a chronic, progressive illness—involves a more dialogical and emergent focus for clinical care, on what most improves a life in all its specificity.

Invoking balancing logics rather than Mol's arguments about what characterises good care might have been a protective manoeuvre, one that defines current practice as good. It may (also or instead) reflect a misunderstanding of the role of biomedical knowledge in Mol's logics. Technologies or science do not guarantee 'good care' nor are they necessarily associated with poor care (Cussins 1998; Mol 2003, 2008; Winance 2010). Instead, we are to attend to what they make real and possible in a person's life. Technologies, such as pharmaceutical medications, can have both anticipated and unanticipated effects. For example, one of the "gold-standard" treatments for MD, the corticosteroid medication deflazacort, may slow disease processes but also intensify difficult behaviours. What matters most to a person's and family's life has to be determined in each individual case. We will look to unsettle this association of scientific knowledge with choice-logic in future iterations.



## (Non)Resonant methodologies

Working with practicing clinicians to improve clinical services situates our work in conversation with knowledge translation, continuing education, and quality improvement practices, all of which seek to reduce the gap between best available positivistic evidence and everyday practice (Kitto et al. 2013). In addition, our methodology can be situated in relation to others working to enact care-logic. Our methodology resonates with each tradition in different ways.

Our concern is situated at a different gap than that which Kitto et al. (2013) argued is the common core of knowledge translation, continuing education, and quality improvement. Our work is located at the gap between care values and everyday practice. However, our methodology has some similarities with those of audit and feedback, and educational outreach visits. Audit and feedback involves auditing clinical performance via chart reviews and surveys, then providing feedback to clinicians on their own performance, compared with that of peers or targets (Ivers et al. 2012). Educational outreach visits involve trained facilitators visiting clinical settings and working with clinicians in situ to improve clinical performance (O'Brien et al. 2007). To frame our study in the language of these methodologies, we could consider our ethnographic observations as 'audit', and the critical dialogues as 'feedback' and 'outreach facilitation'. Two critical differences: we added social theory and a dialogical approach.

Audit and feedback initiatives decide *a priori* what clinical practices matter most. This is reflected in their choice of quantitative indicators as the method to assess current practice. *A priori* outcomes are typically pre-selected for outreach facilitation as well (O'Brien et al. 2007). Both build upon an assumption that meeting guidelines or population health targets constitutes good care of individuals. 'Good care', made visible in indicator form, is treated as a straightforward concept, one based on positivistic, probability-based logic. This is a monological, authoritative view of what comprises good care.

The present study is predicated on the argument that an indicator-driven understanding of 'good care' is ill-suited to improving attention to the lived effects of clinical practices (Charon and Marcus 2017; Greenhalgh et al. 2014; Mol 2008; Moser 2010; Wieringa et al. 2017). When it comes to chronic, progressive diseases such as MD, clinical services need to be attuned to what treatments and assistive technologies enact in the lives of individual people (Mol 2003, 2008; Setchell et al. 2017; Winance 2010). A better life is not guaranteed by following a guide or checklist, or adhering to 'gold standard' treatments. Thus, we did not enter clinics with an authoritative stance on what should change. Instead, we entered with an axiological commitment to open up dialogue about the effects of clinical practices on lives, and work together to identify opportunities for improved care.

Our work resonates with other qualitative observation-and-facilitation methods to support learning and practice improvement. For example, the Marte Mao nursing method highlights how clinicians can learn about what already works well, and build on these actions to produce good results for individuals (Moser 2010). In that method, clinicians watch and discuss video-recordings of clinical practices as a group with a trained facilitator to identify what works well for a specific resident with dementia in a long-term care home. Moser (2010) notes the video-recordings bring relational, embodied activities into the foreground for discussion. The potential improvements in clinical practices that follow are not about the pathology, but about crafting a better life for residents. Like our methodology, such an approach reflects care-logic in the continual tinkering and adjustment to the specific context of each resident. Similarly, Moser notes that the process helps carers recognize that their work creates good results in the lives of residents. Carroll et al. (2008)

also found merit in an intervention-oriented ethnography, where facilitated discussions of video-recordings of team rounds in an intensive care unit helped a team identify multiple methods to improve team communication. The knowledge produced in our and these other ethnographic-intervention studies is local and specific—and that is their strength in spurring improvement.

### **Strengths, limitations, and future directions**

Our research contributes needed methodological developments for evaluation of dialogical, reflexivity-oriented learning. The question of how to assess reflexivity is an open one, often related to questions of trainee assessment. Fostering reflexivity with practicing clinicians who work as a team raises different evaluative questions. Our work is situated at this gap.

Reflexivity is, as conceptualized, a practice that is aided by group dynamics; it is easier to appreciate one's own assumptions when talking with others. The discourse analysis methodologies used here are theoretically grounded by communicative dynamics and emergent meaning, which are well-suited to detecting when clinicians spoke in reflexive or non-reflexive ways (and what spurred a switch between, including facilitator's actions). The evaluation methodologies used help make visible the dynamics that participatory, group-based reflexivity interventions are intended to achieve, and what to look for as signs of a safe, dialogical communicative dynamic.

Consistent with participatory research methodologies, this study involved a deep co-engagement of researchers and clinicians. The pedagogical methods used here depend on the co-creation of a safe communicative space. While we have offered outlines of our dialogue activities, it is worth emphasizing that following these closely does not guarantee similar success. Part of what made the present study possible was variation of knowledge and skills within the research team (which includes physical therapy, medicine, sociology, psychology, disability studies, and geography—and people with no experience with this type of clinic, or who have participated as either a patient or clinician). This diversity of theoretical and experiential backgrounds, and varying degrees of familiarity with rehabilitation work with children and muscular dystrophy, supported the research team's own reflexivity during design, facilitation, and analysis. Our personal, intellectual, and professional diversity enabled subtle analytic discussions about the observations, which supported the design of the dialogues. While a strength of the present study, this may present challenges for transferability.

We conducted this evaluation in service of a larger aim: improving clinical attention to the human dimensions of practice. While developing skills in reflexive analysis of clinical care help, different methods will be needed to explore effects on clinical practice. It is possible, for example, that clinicians encounter unanticipated challenges when trying to shift clinical service into a more care-logic 'tinkering' approach. We are continuing a longitudinal study with the clinic, using critical realist evaluation methods. We are conducting ongoing observations of practice as well as interviews with children, parents, and clinicians, to explore the extent to which planned changes occur, how clinical routines changed as a result, and effects of the changes on patients, family members, and clinicians. We are also further testing the methodology in a new MD clinic site; cross-site analyses will help identify crucial influences on success and sustainability. For example, pre-existing team cohesion may have enhanced participant safety in the dialogues, a question we will explore. But any new, innovative methodology leaves much to be examined. The study lends itself to number of other avenues of

further exploration. Questions of transferability, duration, and methodological improvements or adaptations for new clinical environments and/or other patient groups are worth exploring.

We see merit in future work considering the particular strengths and limitations of this educational methodology to others that already exist to strengthen clinical attention to the human-dimensions of clinical care. We think here of narrative medicine and arts-based methodologies (Charon and Marcus 2017; Kidd et al. 2016). There are also variations that could be considered within the existing approach, such as giving individual clinicians all the excerpts of their care and conducting individual dialogues with a facilitator. Relatedly, we acknowledge there may be limits to the pedagogical principle of 'making the familiar strange' to address the range of relevant topics. For example, Abbott et al. (2017) found men with Duchenne muscular dystrophy thought the end-of-life conversations in clinics were limited and overly medicalised, and in need of a personable approach that integrated clinical knowledge. We suspect that it is not only implicit assumptions but also deep emotions that foster clinician avoidance of the topics of decline, dying, and death in the clinic. The pedagogical principle of 'making the familiar strange' is likely better suited to bringing out assumptions, and other approaches are needed to create a space to address clinicians' emotions. Finally, other theoretical frames may be useful to consider as ways to make practice strange. Mol's logics, presented in simplified, ideal types, helped as a vocabulary to analyse practice, but could only go so far in analysing the complexity of the clinic with multiple clinicians, children, and family members all involved in deciding what treatments to pursue in terms of life priorities. The question of what is to be done, what outcomes are valued to the person or family, is not simple but involves navigating many possible and varied sources of friction. Used as a heuristic to make practice strange, we found it very helpful, but we also learned to appreciate its limitations. A deeper appreciation of the strengths and limitations of different pedagogical and theoretical approaches will help support more nuanced interventions.

In our ongoing work with the new and existing sites, we are increasing the number of dialogues, based on the participants' feedback and our own impression that three was insufficient. Three dialogues sufficed to develop trust with the clinicians and foster reflexive explorations of assumptions about what constitutes 'good care' and a 'good life'. We did so because we see these are central topics organizing clinical services, ones which are open-ended enough to invite clinicians into the analysis. The research team identified additional, important topics but did not have time to explore these as thoroughly as we believe indicated. For example, reflexivity interventions are well suited to explore how assumptions about social identities, such as those associated with gender, influence clinical care. Assumptions about gender may shape how a patient, family, and/or clinician communicate, such as a clinician making assumptions about what kind of play boys like to engage in, or parents overriding their child's choice of wheelchair color (Gibson et al. 2014). Gender is only one social construct relevant to the human aspects of health care. Many others—such as sexual and gender orientation, or disability-related stigma—are highly relevant to this group, to similar patient groups, and to the human aspects of health care (Kuper et al. 2017). These are among other topics we are preparing to address in future iterations that have longer duration interventions.

## Conclusion

The present study aims to enhance clinical attention to the human elements of illness—the moral, the social, the emotional aspects of illness. We sought to design a methodology that could support team learning specific to this aim and focused on fostering reflexivity within

the team. The pilot of the methodology helped clinicians recognize both individual and team practices may be having unintended impacts on the patient and family members—to a point.

The impacts of this work may be many and varied, due to local variations in clinics and clinicians. Two general benefits we anticipate are improved clinical relationships and better attention to unmet psychological and social care needs. In the clinic studied here, for example, the reduction of repetition in the clinic has opened up time for clinicians to better assess and address psychological and social aspects of muscular dystrophy care. For clinicians and trainees, the intervention may shift clinicians' experiences of their work, and shape the learning environment for trainees to better align with desired values (Martimianakis and Hafferty 2016; Martimianakis et al. 2015). Consistent with a logic of care, we anticipate clinicians will better attend to muscular dystrophy as it is lived in a life, rather than primarily locating the disease in the body [e.g. by focusing on deteriorating physical functioning (Bekken 2014; BJORBAEKMO and ENGELSRUD 2011)].

Our study is both timely and crucial, as the limitations of evidence-based medicine—which has strong affinities for choice-logic—become more widely recognized (Greenhalgh et al. 2014; Wieringa et al. 2017). If taking seriously the argument that the starting point for clinical practice is the unique, individual person, continuing professional development opportunities need to support clinicians to (re-)orient clinical practices in the face of institutional pressures to standardize care. This calls for both pedagogical and assessment methodologies to support clinicians in this work, to which the present study contributes.

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## Appendix 1: outlines of the three dialogues

### Dialogue 1

1. Introduction to the project and explanation of first exercise (5 min).
2. Exercise: record thoughts about 'good care' in relation to two provided examples. (10 min) Prompts:
  - a. How is good care practiced? (i.e., identify what you think of as incidents of good practice in the examples).
  - b. What does client-centered and family-centered care mean?
  - c. What is a successful treatment when a condition is not aggressive/acute?
3. Group review (10 min).
4. Short lecture: Mol's logics of care and choice (15 min).
5. Writing exercise: revisit two examples (5 min).
6. Group discussion with facilitator probing questions (55 min).

7. Group feedback to facilitator about session (10 min).

## Dialogue 2

Preparation: participating clinicians read a full fieldnote (15 single-spaced pages) with instruction to identify choice-logic and care-logic examples.

1. Feedback/responses to first dialogue (8 min).
2. Mini-lecture: Review of Mol's logics (7 min).
3. Clinicians identify and discuss examples of logics in the fieldnotes (7 min).
4. Writing exercise: impact of reading whole field note (6 min).
5. Group review/discussion (18 min).
6. Facilitator poses provocative questions: (70 min).
  - a. Why does clinic exist?
  - b. What's the difference between function and safety (often clinical goals), and an enjoyable life? Are these things mutually exclusive? How do we decide?
  - c. With the family, how to approach the topic that this child will die young?
  - d. What does the term 'safe emotional space' mean in relation to the clinic?
  - e. What about introducing a critical disability perspective, that difference is something to be proud of rather than hidden?
  - f. You're dealing with a person dying quite young while at same time growing a life—that's something that different from palliative care in old life. How do you deal with those two things at once?
  - g. How to make grief okay?
  - h. (Not discussed, but raised): How is child-centered care practiced? Ie, compared to family-centered care? And how do you balance those two?
7. Writing exercise: what clinical practices do you think should be revisited or changed? (4 min).
8. Group discussion (10 min).

## Dialogue 3

1. Review of session to come (2 min).
2. Participants' thoughts about the process (4 min).
3. Facilitator presentation of main thematic findings and draft recommendations, with discussion of each that refine or challenge the findings, explore implications, or planning how to act on recommendations (70 min).
4. Discussion of extension of study—purpose and processes (4 min).
5. Clinician-initiated conversation, returning to recommendations (20 min).
6. Next steps writing exercise: what are the two most important things you would like to change (2 min).
7. Review of answers (5 min).
8. Participant feedback on study (8 min).

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