



Tinkering with responsive caring in disabled children's healthcare: Implications for training and practice

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ABSTRACT

Health professional education has traditionally relied on the acquisition of vertical expertise whereby learners apply top-down principles and methods to develop clinical skills. In this critical qualitative study, we examined horizontal processes of “knotworking” and “tinkering” in the development of expertise amongst clinicians and trainees in a children's rehabilitation outpatient clinic. Using ethnographic methods of observation, interviews and group dialogues, the study explored what constitutes “good” child healthcare, the risks of separating humanistic from biomedical care, and how discursive assumptions and conventions shaped learning and practices. Our analyses identified processes of *responsive caring* that integrated medical and humanistic imperatives into transposable, dynamic repertoires through which clinicians could pivot in response to child and family needs and priorities, resource access, and socio-material contexts. We discuss the challenges for teaching and mentoring medical trainees who have to both learn and unlearn particular practices in their efforts to develop responsive expertise.

1. Introduction

Across the healthcare landscape there have been increasing calls for addressing “wellness” in clinical practice. Wellness however is a rather vague concept with considerable overlap with other concepts and approaches such as quality of life, person centred care, compassionate care, the biopsychosocial model, and holistic care to name a few (Crawford et al., 2014; McCormack et al., 2021; Sturmberg, 2005; Wade & Halligan, 2017). Considerable research and scholarship are oriented to defining these ideas and delineating how to clinically implement and teach related practices to health professional learners. Within this context, we conducted a study with an initial aim of developing processes for addressing “wellness” in the clinical care of children with cerebral palsy and their families. However, as we explore further in the paper, our investigations led to an examination of wellness as an open-ended term that benefited from being suspended or “made strange” to indicate that a final or definitive understanding cannot, and perhaps should not, be achieved (Kumagai & Wear, 2014). Instead, we drew on our investigation to 1) develop insights into what constitutes “good” child healthcare, 2)

consider the risks of separating wellness from other medical aims, and 3) explore the implications for health professional training. As we develop further below, our analyses worked towards developing approaches to education and practice that integrated wellness into medical care through *responsive caring* practices.

1.1. Humanistic healthcare

Traditionally, healthcare for disabled children¹ has been guided by a biomedical model, emphasizing physical health and providing interventions for individual impairments (Setchell et al., 2022). The pervasive and persistent influence of biomedical thinking on practice, research, and education, and more broadly the cultural ethos of healthcare, cannot be overstated. The patient-as-pathology underpins everything from evidence-based medicine, the divisions of medical specialities, how hospitals are organized, research priorities and funding, to how the recipients of care are spoken with and about. Care that addresses patients as persons with unique lives, needs, and capacities who are affected by a range of socio-material mediators that enhance or

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diminish health and life, is acknowledged as important but is not central to clinical work. Moreover, the delivery of health services is extensively and increasingly organized according to managerialist principles of efficiency, cost effectiveness, and measurable quality indicators (Holford, 2020; Webster et al., 2015). Within this context, efforts to incorporate humanist priorities often get boiled down to a narrow set of statistically analyzable data points (e.g., length of stay, measures of functional change) despite well-meaning intentions (Gibson et al., 2021).

Questions regarding how to address the dominance of biomedicine in disabled children's healthcare and professional training initially prompted us to consider the concept of wellness. In the extant literature, "wellness" is conceptualized as extending beyond conventional notions of health as the presence or absence of disease to incorporate multiple overlapping dimensions of life including the physical, social, psychological, emotional, intellectual, and spiritual (Hamdani et al., 2022; Majnemer, 2012). Wellness is not a new concept, and its recent popularity in medicine highlights the considerable overlap with other approaches and concepts that aim to promote what we refer to collectively as "humanistic" care, that is, practices which foreground caring for humans rather than the treatment of pathologies and impairments. Prominent among these is the concept of person-centred care which is one of a group of related "centred" approaches (e.g., patient, family, child, and/or relationship centred care) that attend to needs, preferences, and circumstances of individuals receiving health services (Hughes et al., 2008; Judge & Ceci, 2022).

Humanistic approaches are important for ideological and ethical reasons and have helped reform healthcare thinking and practice (Gibson et al., 2020; Hughes et al., 2008). We recognize that other concepts and phrases convey similar ideas to humanistic care. Rather than attempt parse out each approach, we find it more instructive to delineate what they collectively do. Within each is an attempt to flesh out the dimensions and properties of "good care" that extends beyond the diagnosis and treatment of pathology. While it is unlikely that any clinician, program, or organization would claim to practice only within the parameters of pathology-based medicine, there remains considerable critique of its dominance and the hierarchization of medical over humanistic care. These imperatives persist in disabled children's health care, including rehabilitation settings, where the focus on normalizing pathologies expresses itself in a shift toward treating functional deficits (Gibson, 2016).

Across healthcare settings and disciplines, those committed to providing humanistic care may not know how to do so, especially within systems that do not easily accommodate change, or may not even recognize if and when they are doing it well or poorly (Goodgold, 2005). A second challenge is the pervasive notion that such work is an "add-on" to medical care, that it can be reduced to a set of "soft skills", and that research and education designed to enhance such work is less important and cannot generate "gold standard" evidence.

In medical education, developing skills in humanistic care occurs within contexts of multiple competing priorities and discourses (Hodges et al., 2014; Whitehead, 2013). By discourse we refer to the often taken-for-granted assumptions, practices, and techniques all persons are subject to, and which generate individuals' preferences, options, and choices (Danaher et al., 2000). Embedded in biomedicine and its systems of training and delivery are a dominant set of discourses, assumptions, and conventions that shape the objectives of care and inform practices at all levels (Holmes et al., 2006; Whitehead, 2013). Some are tacit (e.g., disability is equated with problem/deficit), and others explicitly articulated (e.g., evidence-based practice). MacLeod (2011) has demonstrated that medical learners experience tensions between "competence" (biomedical) and "caring" (humanistic) discourses. Others have similarly observed that the dominance of biomedical discourses is reflected in curricular priorities, institutional practices, and modelling by practitioners (Jay et al., 2006; Good & Good, 1993; Gibson et al., 2020). Moreover, conventional medical education practices that focus on staged, "vertical", acquisition of skills risks producing practitioners who

prioritize pathology-based biomedicine over humanistic caring without any explicit intention to do so.

Without a shift in core principles and commitments, meaningful changes in healthcare will be limited and slow. Part of the work of implementing this shift is research aimed at exposing the ways that biomedical discourses and conventions organize care, from the micro to the macro, and within practice, research, and education (Hodges et al., 2014; Jaye et al., 2006; Whitehead, 2013). This study contributed to such work through an investigation of an outpatient service for children with cerebral palsy and their families. In the project we partnered with clinicians and families to investigate what was taken for granted, and what practices "worked" or not and why. Moreover, we considered the challenges for teaching and mentoring medical trainees who had to both learn and unlearn particular practices in their efforts to provide "good" care.

2. Methodology and design

This critical qualitative study integrated theory and methods from the social and medical sciences (Eakin & Gladstone, 2020; Mykhalovskiy et al., 2018). Specifically, the study drew from Annemarie Mol's (2002; 2008) articulation of the "ontological politics" of healthcare; a conceptual lens that can be used to examine "the way in which problems are framed, bodies are shaped, and lives are pushed and pulled into one shape or another" (Mol, 2002, p. vii). In previous work we have developed this framing to examine compassionate care (Setchell et al., 2022) and person-centred approaches (Gibson et al., 2020) and developed a methodological approach for examining how core concepts are understood and organize healthcare practices. In the present study, Engeström's (2008) work on "knotworking" further informed the analysis. As we elaborate below, while not equivalent concepts, tinkering and knotworking provided useful conceptual tools to explicate clinical practices. Our objective was not to evaluate the clinic according to any external standard of care. Rather we sought to explore how wellness was understood and organized and according to what principles and assumptions, i.e., the ontological politics of care, and the implications for care delivery and training. It was through these analyses that we came to reframe the focus of the study from wellness to responsive caring.

2.1. Data generation

The research design combined detailed qualitative *ethnographic observations* of clinic processes, *interviews* with clinicians (nurses, physicians, trainees), children with a diagnosis of cerebral palsy (CP), and their parents; and group *dialogues* with clinic physician leaders. Cerebral palsy is an umbrella term referring to a group of life-long disorders caused by impairments of the developing brain. People with CP experience compromised motor function, and in some cases, visual, hearing, speech, epilepsy, and/or intellectual impairments. All families and children that attended clinic and all clinical staff members were eligible to participate in the study. Children, parents, and clinicians recruited for the observations were invited to participate in an optional interview. The study was approved by the hospital Research Ethics Board where it was conducted, and all participants provided informed consent.

Ethnographic observations: The primary data source for the study was a series of observations conducted by an experienced researcher (BM) who was embedded in an outpatient clinic at a Canadian children's rehabilitation hospital where co-author, (AK), is one of four physician clinic leaders (all were developmental paediatricians). Children/youth with CP (ages 2–18 years) from across the province attend clinic every 6–12 months for follow-up consultations with one of the physicians, a nurse, plus or minus a subspecialty resident or fellow. Each visit is scheduled for 45 min in duration, but they often run more than an hour.

Visits typically begin with a discussion of the family's primary concerns and "best hopes" for the consultation. Nurses and/or trainees see the family first and then do a handover of primary concerns or issues with

the physician leader. Dialogue and assessments focus on the child's general health, a review of body systems, and updates including any outside medical appointments or therapies. Visits typically also include wider discussions about school, social life, financial issues, and emotional health of child and parent. The study occurred during the COVID-19 pandemic which meant that, while most visits remained in person, some were conducted virtually. In all cases, the families had previously established relationships with the clinical team, sometimes for many years.

A total of 14 observations were conducted virtually by BM in real time. For in person visits ($n = 10$), BM observed remotely via Zoom and a laptop that was moved as needed by the clinician. For virtual appointments ($n = 4$) she participated via Zoom. In addition, BM observed post clinic debrief and training discussions amongst the team. BM had met all study participants (families and clinicians) prior to the visits to discuss the study and obtain informed consent. The main data source was BM's field notes generated from the observations (Emerson et al., 2011) which detailed: interactions among/between staff, fellows/residents, young people, and families; clinical processes; the clinical space; and initial impressions of care processes. The observations were conducted over 13 months, seven of which included medical trainees (4 residents, 3 fellows).

Interviews and Dialogues: In-depth (1–2 h) virtual interviews were conducted with five children, eight parents, two nurses, three developmental paediatricians and one fellow ($n = 21$). Interviews were conducted after clinic observations and focused on exploring participants' views of what wellness and "good care" meant to them, as well as eliciting their perspectives on observed clinical conversations and processes. We held three virtual group "dialogues" (focus groups) led by first author [BEG] and attended by three of the developmental paediatricians (one left their position at the hospital during the study) at midpoint and end of data generation. Nurses and fellows were invited to these dialogues but declined to participate or were unavailable.

The dialogues differed from traditional group interviews/focus groups in that they were working sessions wherein members of the research and clinical teams partnered to co-identify "what worked" or not in clinical care and training and explore changes. For each dialogue, observational data excerpts were shared with participants along with some guiding questions to inform group reflections. For the second and third dialogues, draft analytical summaries were shared to further inform these conversations and stimulate group analyses. AK's dual role as both study investigator and participant uniquely informed these conversations and facilitated implementation (trying out) of ideas emerging from early analyses.

2.2. Analysis

In addition to the co-analyses in the dialogues, data were formally analyzed by the research team using flexible coding and memoing techniques consistent with the research objectives and the study's conceptual framework (Eakin & Gladstone, 2020). The four-member team included researchers with collective expertise in clinical practice/children's rehabilitation, qualitative inquiry, education scholarship, and critical disability studies. Data generation and analysis were conducted simultaneously to allow for new information to be investigated as the study proceeded. The research team reviewed all observation notes together in the first months of the project to identify patterns and areas of further inquiry. We began by identifying instances of family/children's emotional, psychological, or social challenges; clinic wellness practices; education/modelling practices; patterns of interaction; and points of tension and/or collaboration. In addition, we inductively identified new concepts, topics, and patterns to develop further areas of inquiry, and spur engagement with new literatures and concepts. The investigator team held regular meetings to discuss impressions, develop explanations, and discuss alternate interpretations. Consistent with the study's conceptual framing, our analytical aim was not to evaluate practices per se,

but to examine the contingencies, forces, ideas, and behaviours that mediate and shape how "good" care was understood and addressed.

Before presenting the results, some further comments on how the analysis proceeded are needed to ground our interpretations. Early on in analysis we identified that our efforts at exploring wellness were not working. Labelling some processes as "wellness" or "biomedical" care was challenging, and through the dialogues we collectively recognized that such parsing risked further dichotomizing practices, i.e., with wellness as a "nice to have" add-on to medical care rather than essential to good practice. Moreover, our analyses were not capturing the integrated doings of care that we were observing. As we discuss in the Results section, we labelled these processes as *responsive caring*. Responsive caring integrated medical and humanistic principles into transposable, dynamic repertoires through which clinicians could pivot in response to child and family needs and priorities, resource access, and socio-material contexts.

Elsewhere in the literature these dynamic skills have been theorized in terms of "tinkering" (Gibson et al., 2020; Mol et al., 2015; Schwertl, 2016) and/or "knotworking" (Engeström & Pyörälä, 2021; Engeström, 2008) and we drew on each as the analysis proceeded. While not equivalent concepts, the two terms have a number of features in common. Both are gr in relational approaches concerned with understanding practices as locally produced by heterogenous elements of humans, tools, motivations, expectations, discourses, and rules; and both focus methodologically on the "doings" of activity. Knotworking is rooted in Cultural Historical Activity Theory (CHAT) and focuses on interacting activity systems and the tying and untying of threads of activity in systems such as healthcare provision. Engeström (2008, p. 194) elegantly refers to knotworking in terms of a "rapidly pulsating, distributed, and partially improvised orchestration of collaborative performance." While our study was not grounded in CHAT, the notion of knotworking provided a useful conceptual tool for explicating practices. Tinkering comes from AnneMarie Mol's work in ontological politics as applied to health care (Mol, 2002, 2008) and is concerned with how empirical realities are enacted within the improvisational doings of local material practices. Mol (2002, p. 38) suggests that doing good in health care "is a matter of indeed doing. Of trying, tinkering, struggling, failing and trying again". Approaching our analysis as "bricoleurs" (Kincheloe et al., 2011), we drew on the commonalities between knotworking and tinkering to interpret the data.

3. Results of the analysis

We present the results of our analyses as follows. We first flesh out our primary finding of *responsive caring* where we explore what constitutes "good" care in clinical practice. We then expand on the ideas through an elaboration of the discursive and material forces at play in producing practices and specifically in relation to the risks of separating medical and wellness care. We conclude with a discussion of the observed differences between fellows and physicians and the implications for health profession education.

3.1. Responsive caring

As noted, "responsive caring" is our conceptualization of what worked well in clinical contexts. Responsive caring was produced within local contexts, was improvisational, and did not separate wellness from biomedical care but moved between and integrated the two in response to the situation at hand. We begin by considering how responsive caring unfolded in real time using the example of a virtual visit with six-year-old Maddy's mother, Jean (all names are pseudonyms). At the outset, Jean was asked by the clinic nurse to describe her goals for the appointment. Jean identified that she wanted to obtain a referral for a sleep study to diagnose and address Maddy's issues with interrupted sleep and anxiety. From the observation notes: *Jean explained that because of the lack of sleep, everyone would be irritated the next day. After a few minutes she said with*

absolute exhaustion, “We need help. We really need help.” The nurse met with Jean first and then shared this information with the physician, Ellen. When Ellen signed on, she began by engaging Jean in conversation about recent life events. The visit then proceeded as follows:

Ellen reminded Jean that she spoke to the nurse who went over everything they had discussed. Ellen then asked, “What are your best hopes for the sleep study? What do you want with that?” Jean said it wasn’t she that wanted it but that the psychiatrist had recommended it. She noted they’ve been experimenting with melatonin, but that Maddy would still wake up in the middle of the night. Jean talked about how she was “not sure how she feels about other medications”. She noted that the sleep issues were affecting the whole family. When Jean finished, Ellen said in gentle, supportive tone, “Not a problem. Absolutely I can do that for you”. Ellen said she would issue the requisition and that in the interim they needed a plan [given long wait times for sleep studies]. She acknowledged all of the work the family had done to that point, stressing that they had taken on a lot. Jean nodded and her eyes welled up. Ellen added, “We need to think about how to support YOU going forward.” Jean thanked Ellen and, sounding distraught, added “We need help!” Ellen nodded and again acknowledged the work the family had done to date. She then said that some medication could be helpful right now as they waited for the sleep study. Jean nodded. Ellen said, “I want to be honest with you, it’s not 100%” and added that she would also like to suggest other strategies that could be helpful. Jean nodded. Ellen then began to explain the medication, noting they would start at a low dose and gradually increase. Ellen smiled and said, “If we can get Maddy to sleep, we can get everyone to sleep!” A smile appeared on Jean’s face as she nodded, still teary eyed. She said “Maddy HAS to sleep!” She’s a really happy girl and fun!” Ellen smiled and said, “We want to see the real Maddy.” Jean said, “This isn’t her. We need something in the interim to deal with all of the stuff.” Ellen smiled sympathetically. Jean then said, “Thank you for hearing me.”

Several features of responsive caring are evident in this exchange and the longer conversation that followed. From the outset, the clinical team demonstrated a flexible approach that varied according to the family’s stated needs. This does not mean that the mother dictated the visit, rather it meant that the clinicians oriented the visit to addressing her primary concerns. This was addressed through integrating a focus on the medical issue (sleep disturbance) and its treatment (medication, diagnostic test), while also attending to the child and family’s distress and providing in-the-moment emotional support for Jean. Tinkering is a useful metaphor here. What to do draws from clinical repertoires but only in relation to what is pressing for the family, how they are affected, and what they are willing and not willing to do. Moreover, it is informed by the realities of the social and medical contexts: what options are available, what can the family afford (e.g., they discussed that a private sleep study has a shorter wait time), what are the possibilities and limitations of medications, what are the family’s concerns and hesitations, and what other non-pharmacological strategies are available to help the child and the parents in the interim and the long term. The aims of care are negotiated and specified, and the solutions offered are multi-pronged and open to revision. Importantly, responsive caring is oriented to emotional “caring about” and supportive “caring for”. Ellen creates space for discussion, reinforces an atmosphere of trust and partnership, and offers needed emotional support and assurances to Jean. Jean affirms the value of this approach in thanking Ellen for “hearing me”.

Similar examples were pervasive in the data wherein, as visits unfolded, clinicians and families would engage in a back-and-forth rhythm of moving amongst the medical aspects of CP and the effects on daily life to co-identify the possible paths forward. Delivering this nimble, responsive caring was far from easy or straightforward and could not be achieved by adherence to algorithms or checklists, even though these tools pervaded clinical spaces. In the example above, and in all clinic visits, the nurse had a list of questions organized by body systems (e.g., respiratory, musculoskeletal etc.) that she reviewed with the

mother, but the focus of the visit was not dictated by these. As we further demonstrate below, responsive caring went off script which required clinicians to let go of assumed priorities and/or to address these priorities through a commitment to “really listen” to families and assess the situation in the moment and over time. There may be tacit agreement about the goals of care, e.g., to maximize child and family health and wellness, but in the doings of care there were multiple competing interpretations, approaches, and scripts (professional, institutional, cultural) at play in how such open-ended outcomes were framed and achieved (Bleakley, 2013).

3.2. Resisting discursive binaries: the risks of separating wellness from other medical aims

In the study, responsive caring manifested at the micro level of interpersonal engagement with children and families but was shaped by institutional priorities and the *structural, systemic, and discursive forces* or “threads” that knotted care processes. These forces affected not only clinicians but also patients and their families who were immersed in discursive understandings of the purpose of healthcare in general and in the clinic specifically.

An example of how discursive forces intersected to produce preferences arose in relation to parents’ expectations of the clinic, particularly how “wellness” was understood in relation to biomedical care. When asked, families said they wanted wellness addressed, including parent psychological health, but did not see it as the clinic’s priority and did not expect it to be. In the interviews, parents reproduced shared discursive understandings of the roles and goals of medical care within a dominant biomedical framing and their experiences of care provision. Charlene, for example, suggested that her focus was on helping her child “live a good life” and when asked how the clinic addressed this focus she noted:

I think when we say it in an appointment, it’s kind of an abstract concept. I don’t think it falls on the hospital or the medical team to support that. (Int: Why do you say that?). I don’t know - they’ve got to deal with, sort of, the acute, here and now, and for us to say, ‘Oh, we want (our child) to be happy and resilient.’ That means different things to different people. And I guess if a medical team wanted to help with that, they’d have to understand what we meant. It would take time ... I think it’s asking too much.

The parent’s last words are telling here. It is not that she would not welcome support but draws on her experience of the health system in which she is embedded, the clinic, and wider discourses of medicine to delineate what is and is not the role of clinical care, what would be reasonable to ask for, and what clinicians have time for: the “acute, here and now” biomedical needs of her child. Asking clinicians to understand and respond to the broader and more abstract goals of happiness and resiliency, is seen as outside of scope and rejected based on the required time commitments. In other words, any overhaul of the current organization and delivery of healthcare was not easily or readily envisioned and was (more or less) unthinkable. These comments were repeated across the parent interviews wherein their talk revealed how families learn to understand healthcare and what it could offer. However, our broader analysis revealed layers of complexity in the doings of the clinic.

Our observations suggested that children and parents, including those interviewed, did indeed receive psycho-emotional and material supports (e.g., liaising with community programs) within even the most routine clinical visits. The excerpt with Jean in the previous section provides an example. These forms of support however may not have been easily recognized by families because they were integrated into conversations rather than experienced as formal assessments and interventions. Said differently, within interpersonal exchanges about “how are you doing?” or conversations that were primarily oriented to medical issues, clinicians provided micro level forms of validation and encouragement, and referrals/advice for substantive material supports. These micro-supports may not be recognized by parents as “wellness care” because they did not

involve formal assessments or “counselling” and may not, to be fair, have met all of a family’s needs. But they nevertheless do work towards supporting children and families in ways that the interviewed clinicians confirmed are very deliberate and part of their work to provide flexible responsive caring. Another example of this work is seen in the following observation:

Nicole [physician] asked, “As a family, a year into the pandemic, how are you coping? With work, school -with everything?” Her tone was very gentle. Dan [parent] smiled slightly and said, “It comes in waves. Right now, it’s okay.” He added that the “times were stressful.” ... He said they had extra time with the kids which was great but that he worried, “we’re not doing enough to push them forward ... you feel like a disaster parent.” ... Nicole gave Dan a supportive smile and began to speak, slowly and carefully. She explained how some of the behaviours they spoke about were normal behaviours at that age. Dan looked relieved. She added, again slowly, that some of what he described was also concerning and it was worth checking into to see what was going on. Dan nodded. She said it was hard not to compare the boys to each other and other kids, she understood that and said, “it’s normal” to do that. She added with sympathy, “But you guys are doing a great job!” Dan thanked Nicole twice, “I really needed to hear that.”

This passage exemplifies both a flexible approach - wherein the physician asks an open-ended question and then pivots to address the parent’s needs - and provides another example of the micro levels of “informal” supports that are seamlessly integrated into responsive caring. The clinician employs particular tactics to provide emotional supports including active listening, and validating statements which are delivered using a calm manner, speaking slowly, and allowing space for silence. Importantly, these tactics are part of her toolbox of skills that were developed over time and could be drawn upon as needed. Recognizing what tactics to use when, to pivot according to the situation at hand, is also an important skill. In the scenario, the clinician addresses the biomedical needs of the child (i.e., potentially “concerning behaviours”) and the “wellness” needs of the parent by tinkering within the clinical encounter (i.e., “As a family, how are you coping?”). One is not separated from the other according to a predetermined hierarchy of needs or outcomes. Rather the object of caring is a highly specified event or knot, produced in this instance and context, that is worked through. Its threads connect it to other knots, other issues with this family and others, but not necessarily or even usually in a straight causal chain. Each event has its own configuration of discursive forces, expectations, emotions, limitations, and capacities that call for and produce different responses.

The examples demonstrate how successful or “good” caring emerges in particular times and places when and if clinicians have the tools and capacities to be nimble within environments that may or may not, explicitly or tacitly, support such work. Our data suggests that the experienced clinicians developed these capacities over time, often by learning to reformulate discursive binaries of care versus cure or wellness versus medicine, into sophisticated integrated care repertoires. Moreover, expert clinicians develop workarounds to the conventions and patterns of managerialist care, such as time constraints or best practice standards. In the above examples, both Ellen and Nicole were highly experienced, and this was reflected in how they worked with families. In contrast, knowing when and how to make these adjustments was most apparent in situations where clinicians struggled with what to do, and which were especially prevalent within the observations of less experienced trainees.

3.3. Learning responsive caring

To further illustrate the skills and challenges of responsive caring, and the implications for training health professionals, we present an example with a medical trainee. The example includes two extended excerpts from the observational notes generated in a single in-person 2-h clinical visit

with Amita age 10 years, her mother (Tapti) and father (Sanjay). Tapti spoke very little English. Amita was nonverbal and had significant cognitive and physical impairments. Prior to the clinic visit, a major hip surgery (reconstruction osteotomy) had been recommended by a surgeon and is the main point of discussion in the excerpts. The family was first seen by a developmental paediatrics fellow (Maryam). The supervising physician (Ellen) joined later. The first excerpt begins about 30 min into the visit when Maryam was alone with the family.

Maryam asked, with a kind of matter-of-fact tone, if they were thinking of having the surgery now or in the summertime. Sanjay said, “Not right now for hip, maybe later.” He stressed the surgery would only happen if it was necessary, such as if Amita was experiencing pain or something else was occurring. He also noted that if it sounded as though the surgery would be beneficial to Amita, they would consider it. However, he said, if it was just to keep her hip straight so that she “looked okay” then there was “no point.” He added that they know Amita would always be in a chair and would not walk, so they weren’t sure why she needed the surgery. Maryam then described what the surgery would do to the hip joint. Sanjay nodded along as she spoke. Maryam went on to say that the surgery might be helpful when providing Amita’s care because of how her body would be able to move, that the hip would heal “correctly” and thus not cause her pain if it (developed) incorrectly like the other hip [which had dislocated]. She noted that she could not explain all of the details and that the best thing would be to meet with the surgeon who could answer their questions and take them through the process. She ended with, “I can’t make this decision for you.” Sanjay said that they were on a waitlist to meet with the surgeon. Maryam nodded and said with enthusiasm, “Good, then you can contact them and talk to them about the surgery.” Sanjay asked again, “What is the point of the surgery?” After further anatomical explanation that focused on correcting the misaligned hip joint, Sanjay said that if the surgery would help to keep the bone in place long term, then okay, but he did not want to put Amita through the surgery and the recovery if it was a short term solution. [Later in the exchange Sanjay explained how the recovery period would require him to take time off work and he would not get paid for this time off.]

In the exchange, which was much longer than this excerpt, the clinician and parent seem to be working at somewhat crossed purposes. Sanjay wants to know, and asks repeatedly, if the surgery will have long-term effects. He wants to know if the pain, the risk, the loss of income for the family is worth it in the long term. Maryam draws on biomedical and anatomical explanations to “educate” the family regarding the benefits of the surgery without ever directly answering Sanjay’s questions or acknowledging his main concerns. She may not have been able to answer these questions, could not predict the long-term outcome, or felt that it was not her role but the surgeon’s to address his concerns. Nevertheless, she never directly acknowledges the family’s priorities or circumstances. So, they go in circles. Moreover, in both overt and subtle ways, Maryam works to persuade Sanjay to move forward with the surgery without ever directly recommending it. She does this, for example, by starting the conversation with a “when” (not if) question, by “educating” him about the pathology and the surgery, and by praising his appointment with the surgeon as the presumptively correct next step. In what is likely a nod to respecting the family’s “autonomous choice”, she directly says to Sanjay “I can’t make this decision for you” while making it clear what she believes is the only reasonable option.

Importantly, our aim is not to suggest that Maryam’s approach was necessarily in error but rather to demonstrate her work in attempting to deliver good care and the threads that she pulls together in doing so. She is clearly trying to offer support and draws on her available repertoires, knowledge, and understandings to engage the family. Her approach has been produced through and is reflective of her medical training and experience to date and her efforts to translate principles into practice. We contrast this work with that of Ellen, the supervising physician who accompanied Maryam to talk with the family after the two of them had

debriefed:

Sanjay said he would rather have Amita on medication to help the situation not get “worse and worse.” Ellen said, cautiously, that there might not be a medication that would help and reminded him of a bad reaction that Amita had to a previous anti-spasticity drug, Baclofen. Sanjay then said, a little abruptly, “For right now, we are not ready.” He noted that Amita needed G-tube surgery first and that, “maybe in 1 or 2 years we can help her another way (with the hip).” Ellen suggested they could try Baclofen again but at the lowest dose possible. Sanjay immediately liked this idea, sounding very happy that there was another option. Sanjay and Tapti began to speak in their language for a few moments. Sanjay then said that the medication had made Amita very sleepy, and she also vomited. Ellen said they would begin with a much lower dose and then slowly go back up to the regular dose if she tolerates it. She said she felt this would be a “good first start to help with the tone” and they would also link the family to an occupational therapist and physical therapist. Ellen reassured the family that they did not have to do everything right now. She suggested they start with a couple of the options, see how that goes. Ellen suggested they start slowly and then change depending on what they family needed. Sanjay sounded happy with this plan ... Ellen then suggested the family contact [home care] to reinstate services that had been suspended because of COVID. She added, “There’s lots to be done, but a little bit, by a little bit.”

There are a number of differences in the two exchanges that illustrate our notion of responsive caring. Both Maryam and Ellen are working to support the family but draw on different repertoires to do so. Ellen’s approach, we could say is rooted in the standpoint of the family and the immediate circumstances as they present themselves i.e., *this* knot. Maryam is focused on another knot, one that sees the obviousness of the need for biomedical interventions and where her role is to convince the family to make the “right” choice. Maryam is not necessarily wrong in this assumption. She knew before the visit that the primary medical goal was to discuss the surgery with the family and ensure they knew their options. Offering medication was not something she and Ellen had discussed beforehand as a possible option, as both were aware that medication would not address the hip dislocation itself (but could potentially help with ease of caregiving and Amita’s comfort). In their debrief between the excerpts we have presented, Ellen asked Maryam for her suggestions on how to proceed and support the family. Maryam responded, “meet in the middle” and went on to describe finding a compromise between “what the family want to do and what we want to do”.

Arguably both Ellen and Maryam wanted to “meet in the middle” but went about it in very different ways. Ellen unties, ties, and reties multiple threads - the family’s material circumstances, Amita’s biomedical needs, the father’s stated choices, the emotions in the room, the fellow’s training needs, the fatigue of the actors etc. - and tinkers with a way forward. The offer of low dose medication is unlikely to be effective in addressing the hip pathology, but importantly Ellen’s responsive caring approach does not consider this the only goal. It is a goal, and it is addressed (e.g., through referrals to therapy), but there are other processes and endpoints at play: maintain trust, provide material help (e.g., home care relief), provide emotional support, respect choices. Ellen engages directly with what Sanjay says to come up with solution that fits with his sense-making of the problem and the family’s socio-material realities. In discussing this encounter in a study dialogue, Ellen noted how she understood that Sanjay was not going to change his mind on that day and in doing so considered: “What else can I offer? How can I help this family given what we are working with right now?” Said differently, she formulated the problem differently, not as what “we want vs what they want” as Maryam had said, but something akin to “what can I offer to make life better as we move forward?” This approach engenders the full richness of the forces, circumstances, and available options to produce responsive caring. It is not ruled by the discursive imperatives of pathology-based medicine, but rather tinkers with them to care-fully care (Fullagar et al., 2019).

Importantly, Maryam is in the room during these exchanges to see not only what is said, but how it is delivered, how Ellen responds, pivots, and tinkers in the moments of the exchange and how these skills map onto other exchanges with this and other families.

4. Discussion

In this study we analyzed clinical encounters to formulate an understanding of integrated humanistic care that we have labelled as responsive caring. Our conceptualizations align with other recent work that challenges linear and instrumental approaches to understanding and addressing care delivery (Struhkamp et al., 2009; MacLeod, 2011; Bleakley, 2013; Kerosuo, 2007; Gibson et al., 2020; Engeström & Pyörälä, 2021). By attending to the full range of forces and circumstances and how they interact within and across care events, we have suggested that responsive caring is produced through careful knotworking and tinkering. The verb forms of these concepts are important (Bleakley, 2013). A focus on the doings of care moves away from static concepts to an understanding of what is “done” in a double sense of actual performance and its effects. Tinkering and knotworking in practice expect and embrace uncertainty, instability, and humility. Although our study focused on micro-level clinician practices, we reiterate that these practices are produced through and by structured health systems and institutions. They are formed within systems, and respond to institutional imperatives and the wider discourses of biomedicine and managerialism within which they are embedded.

For clinicians to be able to learn and provide responsive caring, we argue that healthcare systems and the conventions, practices, and discursive imperatives of contemporary healthcare need to be exposed and reconfigured so that all the actors concerned share a common understanding of its possibilities. Our inclusion of parents’ expectations in our results is an example of how ingrained conventions limit what is thinkable and thus possible for everyone in the care event. Quotidian practices of responsive caring work over time to challenge larger structural imperatives of biomedicine toward instigating lasting change. As Kerosuo (2007, p. 138) notes, healthcare institutions are “still trapped inside organizational models and practices that derive from conventional management thinking” that attempt to optimize care by breaking activity down into composite parts as if care were a jigsaw rather than a series of dynamic and localized events. Viewing responsive caring in terms of tinkering and knotworking decentres the care event and makes working the knot itself the focus of activities (Engeström, 2008). This shift in thinking from content to process creates a space for dynamic responsive caring.

We draw further on Engeström’s articulations of knotworking (2001; 2008; Engeström & Pyörälä, 2021) to discuss the implications for health professions training. We have emphasized that in responsive caring each care encounter is approached as a specific event, but this is not to diminish the transposability of the skills and repertoires. Engeström (2008, p. 229) uses the metaphor of the rhizome that pervades the work of Gilles Deleuze to suggest that “knotworking eventually requires a mycorrhiza-like formation as its medium or base ... turning it from an unpredictable, often spontaneous, process of multiple and compact interactions, to an acquired expertise guided by tacit knowing.” Rhizomes (or mycorrhiza) are underground stems that form connections between plant structures. A “mycorrhiza-like formation” is thus not something that can be reduced to hierarchies or algorithms but instead over time creates a dynamic, growing, and transposable “horizontal” expertise in responsive caring. We argue that development of this expertise can be aided through explicitly revealing its underlying structure and unpacking how it works in practice. Making the familiar strange (Kumagai & Wear, 2014) works to disrupt the taken for granted, exposing the ontological politics of practice, and mitigating cognitive leaps to preconceived conclusions. This is something we have attempted to do in this paper, but to be effective such work must be applied and integrated into clinical training.

Current models of health professions education focus on acquisition

of competencies through stages of development, propelling learners upwards towards higher levels of competence, what might be called “vertical” expertise. The metaphor of mycorrhiza-like development of skills suggests that these approaches do not reflect the complexity of learning in healthcare spaces, what Engestrom (2001) refers to as “horizontal” or “sideways” learning. In learning to knotwork within micro level interactions with care recipients and clinician-mentors, trainees learn skills that lay the groundwork for future expansive learning involving complex healthcare teams and systems that ultimately inform how care is practiced over time and across spaces. Consideration of how educators can facilitate horizontal learning in relation to current vertical competency-based approaches may be critical in ensuring that clinical trainees develop responsive caring capabilities for future practice (Engestrom 2001; Engeström & Pyörälä, 2021).

Developing knowledge and skills in responsive caring may, at least in the short term, require unlearning as much as learning. As we have noted, discourses of pathology-based biomedicine and managerialism continue to organize the health sciences including clinical training. Trainees and instructors develop habits of thought and patterns of behaviour which are oriented to these modes of thinking and reproduce them in their teaching and learning (Kumagai & Wear, 2014). These habits (or “habitus” in the Bourdieusian sense) need to be unlearned and/or modified with other repertoires and dispositions for action (Bourdieu, 1990). Bleakley (2013, p. 25), in discussing team processes, refers to this as the “collective honing of necessary practices, where knotworking insistently seeks improvisation and renewal in “hot” work contexts.” Instead of assuming that trainees develop repertoires through absorption of modelled skills, there is an opportunity to teach different ways of understanding healthcare, health systems, and responsive caring practices. We suggest such efforts are most effective when unpacked in the moment of care, but we also recognize that individual instruction cannot be effective without wider system changes. Ultimately each will inform the other as micro processes lead to system changes and vice versa.

In relation to children's health care, supporting children and families requires the hard work of confronting biomedical framings and assumptions regarding the object of medical intervention that are embedded in healthcare practices, medical pedagogies, and the broader social imaginary (Fullagar et al., 2019). Importantly, the dominance of biomedical thinking in everyday life, affects how everyone – health professionals, families/children, administrators, policy makers, the public etc. – understands the goals and roles of healthcare, the problems to be addressed, and the range of possible interventions. Responsive caring within these contexts is no easy feat especially because *what constitutes good care is not obvious* (Mol, 2008). Responsive caring considers the particular needs and desires of families and children in relation to their contexts, and stimulates questions about what a good life looks like for *this* child and family, now and in the future. The answers to these questions will always require shared exploration with children and families and will change over time. For particular families or within specific clinical events, caring might be primarily oriented to addressing pathology, but this does not mean that patient-as-pathology discourses should be driving practices. The goal is thus broader than adding “wellness” care onto other practices, but to work through which aspects of health, wellness, or other forms of care are/should be central to clinical work and how to do this in practice and education. If making life better is the aim of healthcare, then we argue that pathology-based biomedicine cannot be the driver or even core business of care and must be continually scrutinized.

As with all research this study had limitations that suggest directions for further inquiry. Ours was a localized study that drew on the example of a single clinical service in a Canadian children's rehabilitation hospital to interrogate notions of good care. Additional research with more diverse populations of children and families and in other jurisdictions/systems would help to extend this work and further develop its applications to education and practice. We are particularly aware that we have not directly engaged with issues of equity and diversity, and the related

implications for conceptualizing and delivering responsive caring. To this end, additional research and scholarship is needed and welcomed.

5. Conclusions

In this paper we presented the results of a study in which we ethnographically investigated what constitutes “good” care in the context of an outpatient clinic for children with CP and their families. Our analyses suggested that caring was an achievement that was best understood as an open-ended process that required responsive and nimble “tinkering” and “knotworking” to address the specificities of each care event and over time. We described these approaches in terms of “responsive caring” and suggested that transferring these skills to health professional trainees required an explicit engagement with the dominant forces, conventions, and discourses of contemporary biomedicine. Such engagement includes system wide changes and individual learning that rely on efforts to “make the familiar strange”.

Notes

¹ We use the terms *disabled children or disabled people* rather than *people with disabilities* in keeping with current usage in critical disability studies of identity-first language. Disability is not considered a condition of individuals as is implied by the phrase *with disabilities*, but rather something experienced as a result of ableist discrimination and social exclusion.

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Declaration of competing interest

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