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The micro-politics of caring: tinkering with person-centered rehabilitation

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ABSTRACT

Purpose: In this paper, we critically investigate the implementation of person-centered care with the purpose of advancing philosophical debates regarding the overarching aims and delivery of rehabilitation. While general agreement exists regarding person centered care's core principles, how practitioners reconcile the implementation of these principles with competing practice demands remains an open question.

Materials and methods: For the paper, we drew on post-qualitative methods to engage in a process of “diffractive” analysis wherein we analyzed the micro-doings of person-centered care in everyday rehabilitation work. Working from our team members’ diverse experiences, traditions, and epistemological commitments, we engaged with data from nine “care events” generated in previous research to interrogate the multiple forces that co-produce care practices.

Results: We map our analyses under three categories: scripts mediate practice, securing compliance through “benevolent manipulations”, and care(ful) tinkering. In the latter, we explore the notion of tinkering as a useful concept for approaching person centered care. Uncertainty, humility, and doubt in one’s expertise are inherent to tinkering, which involves a continual questioning of what to do, what is best, and what is person centered care within each moment of care. The paper concludes with a discussion of the implications for rehabilitation and person-centered care.

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► IMPLICATIONS FOR REHABILITATION



- Determinations of what constitutes good, better, or best rehabilitation practices are inevitably questions of ethics.
- Person-centered care is promoted as good practice in rehabilitation because it provides a framework for attending to the personhood of all engaged in clinical encounters.
- Post-critical analyses suggest that multiple interacting forces, conditions, assumptions, and actions intersect in shaping each rehabilitation encounter such that what constitutes good care or person-centered care cannot be determined in advance.
- “Tinkering” is a potentially useful approach that involves a continual questioning of what to do, what is best, and what is person-centered care within each moment of care.

Introduction

In this paper, we critically investigate the implementation of person-centered care (PCC) with the purpose of advancing philosophical debates regarding the overarching aims and delivery of rehabilitation. While general agreement exists regarding PCC’s core principles [1–4], how practitioners understand and address the demands of PCC and how these demands are reconciled with competing demands of, for example, “evidenced-based practice”, clinical reasoning, resource and time constraints, regulatory requirements, and unique patient circumstances, remains an open question. Our interest was to look at how practitioners understand and practice PCC in their everyday work. In so doing, we hoped not only to describe practices, but also to engage in a process of “diffractive” analyses to interrogate PCC and its

interrelationship with contemporary understandings what counts as “good”, better, or best rehabilitation practices. To do so, we used a post-critical lens to examine the “micro-doings” of care practices to aid in the development of new insights into PCC and its effects. With this analysis, we hope to contribute to ongoing efforts to improve rehabilitation through reflexively asking: “What are we doing when we are doing what we are doing?” in the everyday “doings” of practice [5, p.137].

Person centered care is one of a group of closely related “centred” approaches to care (e.g., patient/client, family, woman, child) which appeal to theories of interaction as psychosocial and ethical goods [6]. While there are important and contested differences between each of these approaches, they have in common an appeal to attend to the needs, preferences, and circumstances of individuals receiving health care or other services. Since its

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inception, proponents of PCC, including members of our team [4,7], have worked to inform healthcare practices with the purpose of considering the personhood of all engaged in clinical encounters. PCC has thus worked to move care from a limited biomedical, disease-focused approach to a broader humanistic one. Moreover, as Hughes et al. [6] argue, health professionals make sense of their work and attribute moral meaning and value to it through the espousal of care principles and models. As such, PCC has become important for ideological reasons as well as for ethical ones.

The proliferation of models of centredness in the literature can be viewed as both a problem and a resource. A problem in that they create challenges of operational specification, and potential conceptual confusion for those tasked with their implementation. A burgeoning literature now exists exploring the nuances and applications of PCC and includes two dedicated journals, the *International Journal of Person Centered Medicine* and the *European Journal for Person Centered Healthcare*. In a recent editorial, Dewing and McCormack [8] warn that PCC is increasingly reduced to one or two key attributes (compassion and/or enabling patient preferences) without recognition of the complex institutional and cultural transformations there are necessary for PCC. Such critiques have also been aimed at measures that attempt to pin down and operationalize concepts so they can be “ticked off” an assessment checklist often by oversimplifying PCC [5,8,9]. Both Dewing and McCormack [8] and Pluut [10] have recently argued that the impetus to create a single standard definition of PCC has resulted in a proliferation of PCC models with little value added. Despite these problems, the multiplicity of available models also provides a richness for fleshing out the complexities of PCC and its applications. Pluut’s discourse analysis of the patient centered care literature is particularly interesting in its focus on analyzing the multiple overlapping, and sometimes competing, discourses surrounding conceptualizations of centredness. She explains that her intention with the analysis was not to promote one discourse as superior, but rather to demonstrate that differences can be a source of productive care practices when understood and specified for local needs, conditions, and preferences. This open-ended approach is perhaps a welcomed response to the proliferation of calls to standardize PCC. Nevertheless, it sustains the challenges for practitioners who are tasked with interpreting the demands of PCC in their daily work where the meanings of PCC are “at once obvious and obscure” [11, p.273].

This special issue questions if and how recovery principles embedded in rehabilitation support human flourishing through an exploration of “ultrabilitation”. Ultrabilitation is a concept developed by Buetow, Martinez-Martin and McCormack [12] that rejects the normalizing tendencies of rehabilitation, and particularly its embedded notions of recovery towards a previous state. In proposing this new conceptualization, the authors ask health providers to “question and debate the continuing sufficiency of rehabilitation as optimal care” [p.4]. Moreover, they suggest that rehabilitation might be better oriented to “human flourishing”, that is, a life of “meaning and purpose” in “developing and using one’s capabilities” (p.2). In this paper, we take up this challenge in relation to PCC and the broader issue of what constitutes good, better, or best rehabilitation care. Rather than commencing with assumptions of PCC (or flourishing) as a moral goods, we put on our critical hats to examine how practitioners act and talk about what they do. We wanted to investigate what they saw as good practice,

how this aligns or diverges from prevailing notions of PCC, and how such knowledge might inform debates about the goals and purposes of rehabilitation.

Methodological approach

As noted, we took a *post-critical* approach to analysis. Specifically, we drew on emerging post-qualitative approaches to inquiry [13] to examine the micro-politics of care and the multiple forces (care logics, professional expectations, internalized responsibilities, institutional imperatives, conventions, policies, etc.) that co-produce particular practices. We wanted to know what was “made to matter” [14–17] in both senses of the word: what practices materialized in the clinical encounter, and what meanings and significance were attached to them, both by practitioners but also by our team in our readings of the data. Within this analytical frame we were interested not only in practices, but also how subjectivities were shaped. Consistent with our post-critical approach, we considered “persons” not as preexisting entities but as realized through intra-action. “Patient” and “practitioner”, for example, represent different subject positions that are shaped and materialized within particular social and material spaces.

Because PCC is promoted as the right and proper way to provide care, we argue that it demands a normative assessment. As such, our analysis was informed by scholarship in critical ethics [18,19] which, like all ethical inquiry, is concerned with questions of “the right thing to do”, but differs in that it recognizes contingencies [20]. Said differently, a critical approach espouses that what constitutes good care cannot be known in advance or determined through the application of decontextualized top-down principles. Rather, in critical ethics what to do is always provisional, open to reassessment, and needs to be specified in the doings of practice.

We approached the analysis recognizing that we as researchers were not separate from the data but were immanent to the “research assemblage” [21]. Like all research, through our collective practices we produced knowledge in particular ways with the aim of generating useful insights. We are a team with extensive experience researching care processes and, for some of us, particularly PCC. Indeed, most of us are part of a research unit dedicated to understanding and advancing PCC¹. We however come from different countries (New Zealand, Canada, and Australia), disciplinary backgrounds (sociology, physiotherapy, speech–language therapy, psychology, and bioethics), include both clinicians and non-clinicians, and work from different theoretical traditions including interpretive, critical, and new materialist approaches. Our goal in coming together was, borrowing a useful metaphor from Karen Barad [15], to offer a “diffractive” reading of the data. That is, working from our diverse experiences, traditions and epistemological commitments, we wanted to eschew consensus in favor of opening up new ways of understanding and doing “good” rehabilitation practices. Our point of departure was PCC, but our discussion inevitably considered the multiple and intersecting logics and assumptions underpinning contemporary health and rehabilitation, and how these shape care practices.

Diffractive analysis

Our approach, inspired by Zabrodzka et al. [22], involved an iterative process of drawing on texts to instigate our writing and thinking, sharing these to produce and/or identify existing additional texts, and together sharing and co-analyzing again. Diffraction in this approach is not a top down analysis of

empirically produced data to which we applied a set of predetermined principles such as those commonly articulated in PCC. Rather it is an “intra-action” of materials, forces, affects, and acts – including texts, concepts, the context of the analysis (including the aims of this special issue), and each of our specific professional and personal histories, commitments, and positions.

The texts we drew on included previously generated research data from across our individual research programs supplemented by related literature. We approached the analysis through entangled processes of re/reading data with three “trigger” questions in mind:

- What assumptions, principles, and/or goals of rehabilitation care recur in the doings of practice and its representations?
- What is produced and promoted as “good” or “best” practices or PCC?
- How/do the normative categories of good practices and PCC overlap and diverge?

Our discussions were oriented to examining the micro-politics of “care events” that included local practices, assumptions, material contexts and demands. Each care event consisted of an exemplar extracted from data generated in the course of our team members’ previous qualitative research. The care events included interviews with practitioners and observations of clinical interactions (See Table 1). Our choices of event-texts developed over the meetings as we interrogated the relations and generated new questions. To begin, we each chose one example from our previous research that we viewed as demonstrating aspects of compromised PCC practices. We did this to stimulate discussion regarding what was, to each of us and collectively, NOT person-centered care, and how care relations were produced. Next we each shared examples that we considered exemplary care, which we individually viewed as demonstrating at least some aspect of PCC. We first conducted separate analyses of the care events, and then met on four occasions to share, question, and discuss our impressions. These analyses generated broader debates regarding the function of PCC within rehabilitation.

As noted, our analyses were focused on the “micro-politics” of care, that is, how power circulated in the quotidian practices of rehabilitation – its “micro-doings”. Power in this context does not

refer to the conscious exercise of oppressive power by one group over another, rather power is seen as a pervasive force acting at the micro-level of everyday actions and events [13]. Our post-qualitative analysis examined the effects of power as it circulated within and across care relations and social/material contexts. In other words, our focus was on how everyday interactions enact forms of power that are often unrecognized as such, and their effects in producing, sustaining or resisting what counts as “good” or “person-centred” care.

We included nine care event texts in the final analysis (Table 1). Across all discussions, we were not looking for agreement but rather to raise questions regarding how PCC operated in clinical practices, and also within the “research assemblages” that produced the data. Said differently, we did not view the data as existing separately from the researchers or research contexts, rather the texts were active and activated, produced and interpreted as part of assembled and shifting relations [21]. The assemblages included persons with proscribed roles (patient, practitioner, parent, student, researcher/observer/interviewer), rehabilitation tools (equipment, plinths, measures), spaces (clinic, home, hospital), as well as research and clinical aims, expectations, goals, demands and requirements. Thus our “secondary analysis” was an/other knowledge co-production, materialized through intra-acting materials, forces, ideas, intentions and contexts.

Analysis: co-producing PCC

We identified instances of what we saw as both “good” and “bad” care moments and/or PCC across the data. We did not always agree. Moreover, we noted that the same practices had different effects in different contexts, or had multiple effects within the same care event. In what follows, we map these relations under the following headings: *scripts mediate practice*, *securing compliance through “benevolent manipulations”*, and *care(ful) tinkering*. Rather than presenting any notion of finalized “findings”, we ground the mapping in our shared deliberations with the intent of contributing new insights regarding PCC and rehabilitation.

Table 1. Care event summaries and sources.

Care event	Research context ^a	Description
1	Observational study investigating humanistic care practices in an outpatient multidisciplinary “neuromuscular clinic” in a children’s rehabilitation center – Canada [23]	Observation of a 13-year-old boy, his mother, a nurse and an OT. The event is centered on attempts to convince the boy to agree to be weighed with a mechanical lift
2	Interview and observational study of engagement practices of health professionals in stroke rehabilitation – New Zealand [24]	Observation of a clinician on a home visit with a stroke survivor
3	See Care Event #2	Interview with community-based occupational therapist conducted by a clinician-researcher
4	Intervention study aimed at supporting PCC/new ways of working in physiotherapy – New Zealand [25]	Pre-intervention audio recording of physiotherapy session in a musculoskeletal clinic
5	Interview study focused on exploring patients’ and practitioners’ perspectives of their roles in “self-management” for people living with osteoarthritis – New Zealand [26]	Interview with a physiotherapist participant conducted by a physiotherapy student researcher
6	See Care Event #1	Observation of a physician discussing with a father his choice to remove his 8-year-old son from a medication designed to slow progression of muscular dystrophy. The child is present
7	See Care Event #4	Post-intervention audio recording of a physiotherapy session in a musculoskeletal clinic. The event occurred after a knowledge translation intervention aiming to embed PCC and behavioral strategies into practice
8	Observational study investigating men’s embodiment within rehabilitation - New Zealand	Observation of a treatment session where a man with a spinal cord injury is getting up to stand with the aid of a physiotherapist and a student
9	See Care Event #5	Interview with a physiotherapist conducted by a physiotherapy student. This is a different participant than for Care Event # 5

^aAll studies received research ethics approval from the centers where they were conducted.

Scripts mediate practice

Each of us noted across the care events how scripts organized day-to-day practice and in so doing, produced practice priorities, realities, and taken-for-granted truths. By “scripts”, we refer to written and unwritten rehabilitation texts and conventions such as outcome measures, forms, charting, standards, funding policies, practice patterns, and best practice principles. These scripts reflect and reproduce particular dominant logics, discourses, and understandings embedded in rehabilitation. We noted how scripts interwove with bodies, shaping gestures and behaviors and operating to curtail possibilities for spontaneity, risk taking, creativity and flexibility. Scripts acted as more than guides, they were embodied in the everyday work of both practitioners and patients, and tended to reinforce rather than reimagine particular subject positions and approaches to care. Moreover, we discussed that while (some) scripts are necessary to organize care processes, strict adherence to scripts and the demands of standardization could problematically objectify and homogenize care and people.

To demonstrate the functioning of scripts in mediating care relations, in what follows we explore Care Event 2 (names in the care events are pseudonyms). In the following excerpt, Ginny, a health care professional² (GinnyHCP), was conducting a home rehabilitation visit with Irene who was recovering from a stroke. Early in the visit, GinnyHCP moved to a discussion of the five goals they had previously created and recorded in the patient record. Irene did not recall some of the goals. The following excerpt is from the researcher’s observation notes:

GinnyHCP states, “We talked about the possibility of walking without an aid. So is that something you want to work on?” Irene responds with a slightly tentative “yes”. GinnyHCP says “we need to write this down” referring to the goal setting sheet that the rehab service uses. “So do you walk inside without an aid or do you use one inside? Irene responds, “particularly in the night, I always leave the stick, always, always and yesterday each time I have been always with the stick whether I’ve been”. GinnyHCP says “let’s make that a goal for you”. Irene says “mmhmm” tentatively. Reading as she writes, GinnyHCP says “to walk without the walking stick indoors and outdoors”. Irene quickly says “I always, I have a stiff leg so it’s easier to have a stick”, correcting GinnyHCP’s interpretation of her use of a stick for mobility. GinnyHCP queries “ok, but you’ve never used the stick before the stroke?” Irene confirms this – I didn’t [pointing to the indoor area] but I did outside.” “So if you used it outside, shall we say without a stick indoors?” “Probably” replies Irene. As she says this, GinnyHCP says “Irene will probably ...” Irene interjects, “I don’t think it would be helpful”. GinnyHCP says “yeah, the thing about our team is that we work on what’s changed after the stroke and that’s what we’ll help you achieve.”

Our team viewed this exchange in a number of ways. The practitioner was working to do what she saw was her responsibility and to do it well. She is rather frank about these responsibilities and links them to her clinical program’s requirements and their constraints, i.e., only “working on” what has changed post stroke, completing outcome measures, recording goals. These scripts are based on evidence, the measures are presumably valid and reliable tools, and goal setting is meant to ensure care is focused on the person’s stated preferences to counter any paternalistic imposition of the practitioner’s goals. The event however unfolds as a checklist approach to what may be profound issues for Irene: anxiety, mobility, living well.

Goal-planning is frequently aligned with PCC [27,28] but has multiple, sometimes competing, purposes in rehabilitation [29]. The care event text above provides an example of how practitioners drive what goals make it to the page and how they are assessed. In the encounter, Irene as a person, her revisions and forgetting, are a source of frustration for GinnyHCP, interfering with her work and taking up time. GinnyHCP searches within

Irene’s talk for something to record as an acceptable goal, one oriented to recovery of previous functional abilities. The encounter demonstrates that, even when patients directly identify “their” goals, the goal is never a simple or direct representation of their wants and preferences. Rather, the goal is produced in the event, in relation to how questions are framed, previous interactions, what each actor presumes is possible, what patients think practitioners want to hear, what lines of discussion are encouraged or discouraged, etc. Once written, the goal becomes the object of care. We discussed that, arguably, GinnyHCP sees this goal as what is best for Irene, and links it with meeting the requirements of her job. Would she say this was PCC given the focus on patient goals? Likely, but we viewed it as a very narrow vision of PCC, one that was practiced in a rather rote manner, where Irene the person and the particularities of her needs were largely set aside and even at times ignored.

Before continuing, it is important to note that we do not present this, or any other example, to single out the behaviors of individual practitioners. The point is that these approaches to care are common in rehabilitation and have multiple, sometimes hidden, effects. For example, other research has demonstrated that rehabilitation practitioners inadvertently privilege some goals over others in keeping with their disciplinary scope, time pressures, and presumed achievability [27]. Moreover, prevailing conceptual commitments embedded in rehabilitation, including principles of recovery, encourage these practices [12]. Our analyses are focused on the relations that generate these practices. That is, how goal setting materializes at the confluence of the forces that co-produce rehabilitation care. In doing so we are not interested in assigning blame but rather investigating how some care practices persist, and how things could be otherwise.

Given our focus on analyzing the forces that materialize care, we worked to account for individual behaviors considering the event particulars. Some forces were inherent to the immediate situation, for example, GinnyHCP may have been running late and/or had several other people to see that day that she did not want to disappoint. The text suggested that her clinical service required her to complete outcome measures, record and assess goals, and presumably carry a full caseload. No doubt, the service instigated these practices to improve care, through standardization, creating reliable “objective” evidence, and to ensure care was person-centered. Paradoxically, however, the patient *and practitioner* as persons became lost in the processes, and instead what was made to matter was the completion of the measures and goals *for their own sake*. Thus, in this encounter, practice was “transactional” and largely devoid of the personal [30]. The scripts and tools limited the menu of “acceptable” goals, and GinnyHCP performed a particular role, as she understood it, wherein certain goals and activities were privileged over others.

GinnyHCP and Irene were aware their interaction was being observed as part of a study examining patient engagement. Thus while the excerpt reflects a dyadic communication, the interaction is mediated by the context of the study embodied by the third person in the room recording the care event. We have no way of knowing how this shaped the care relations. Regardless of whether it was a typical encounter or modified for the researcher’s benefit, the interaction nevertheless reflects the embeddedness of scripts in mediating what was performed as competent care. We all agreed that what materialized was not simply the fault of the scripts and/or the practitioner in isolation, nor was it enacted solely for the benefit of the researcher. Rather their entanglement produced particular care practices that met some

(narrow) understandings of PCC and were (woefully) short on others.

Our analytical lens also raised questions regarding how *intentions* figure into co-produced care practices. In a diffractive analysis, intentions are not read as internal to individuals, but as aggregations where matter and meaning are mutually constitutive [22]. Said differently, intentions materialize in the encounter through the interactions of various forces that are available for analysis. In shifting our analyses from the application of principles (or the exercise of virtue [30]) to the micro-politics of the encounter, we explored what happens in the doing of care as mediated by the constraints of systems but also by the people in the room, their motivations, expectations, moods, daily concerns and personal histories. We discussed that it is not the “what” of practice that matters, but “how” scripts and persons work together. Both affect practice – tools and scripts circumscribe what actions are possible, but so do the humans in the encounter. The measures and goals act as possible mechanisms for enacting PCC or not, and can also be set aside even when protocols “require” their use. Not only care practices, but persons and personhood materialize by what is possible at this time, within this timeframe, in the context of this service, and within these persons’ perceptions of possibilities. PCC is thus inevitably an act of micro-translation that extends beyond an isolated consideration of the interpersonal, the institutional, or the socio-structural. PCC emerges through the entangling of the multiple in particular times and places.

Securing compliance through “benevolent manipulations”

In the name of good care, practitioners engage in practices of persuasion aimed at supporting patients to make good choices. We say “supporting”, but “convincing” would do just as well. Persuasion aims to convince. These practices were apparent to a greater or lesser degree in all nine of the care events we explored. Persuasion is tricky business in health care. Sometimes it is seen as a moral good (e.g., “the patient will thank me later”, “the patient was having trouble deciding”, and/or “the patient did not really grasp the longterm consequences”). Everyone on our team had witnessed instances where well-intentioned practitioners framed information in ways that privileged particular choices, and then finished with some kind of statement of “but it’s up to you” as a supposed gesture of PCC and/or enabling “free” choice (for an extended example, see [19]). “Persuasion” is a term that can make practitioners uncomfortable. They might prefer “patient education” even when the primary goal of that education is persuasion. Perhaps some forms of education are simply concerned with sharing information, e.g., regarding pathological processes, or the risks and benefits of different treatment options. However, we agreed that practitioners will never be able to present information completely dispassionately. Unavoidably, they frame, select, and convey information in a certain way, usually with the expectation that patients will follow their good advice [31].

We are not saying persuasion is always or necessarily wrong, and indeed our discussions often circled around the question of if, when, and what kinds of persuasion might be consistent with PCC. Arguably, knowledgeable practitioners have at least a general sense of how to help those they serve and have a responsibility to convey their opinions of the best course of action [32]. An occupational therapist from Care Event 3 put it this way: *I think patients need to have a level of trust in the clinician and to know that their knowledge is current, research-based, and evidence-based. Clinicians are not just (giving advice) because they think it’s*

a good idea – (they know) that it actually does work. Practitioner knowledge, however, has its limits. It arises from research evidence, training, and experience but also from professional conventions, the assumptions underpinning outcome measures and how evidence is produced, social messaging regarding disability and/or what counts as good life quality, the services offered by rehabilitation programs, and practitioners’ individual histories, values and experiences. Recommendations thus materialize out of a multitude of obvious and hidden interacting forces that perpetuate some truths and suppress others. Doctor does not, and cannot, always know what is best.

Persuasion is consistent with at least some variants of paternalism. In moral philosophy, a distinction is made between hard and soft paternalism [33–35]. Coercion is associated with hard versions of paternalism and is intended to override personal autonomy to protect an individual from harm. Persuasion (and education) are consistent with softer forms, intended to help individuals make choices that practitioners view as better or best. The language is different, but in practice, these distinctions are harder to make [36]. Well-meaning efforts to educate are risky in that they are often also, with or without intentionality, acts of manipulation oriented to securing compliance. Well-meaning, so we call them “benevolent” manipulations.

Below we discuss the functioning of benevolent manipulations in relation to two care events. The first is from Care Event 5, an interview study exploring practitioner approaches to “patient self-management”. In her interview, a physiotherapist (KarenPT) noted that education was a “huge part” of her role and suggested that successful patients were those that were “more self-motivated”. She went on to add:

The (patients) that are most successful are ... the ones that listen to you. So, we’ve had patients who have been really motivated but probably too motivated. They go and they do too much, or they do the wrong type of exercises. They’re still really motivated, cos they wanna get back to where they were, but they’re not listening to you, so they’re doing too much.

The interviewer in the care event was a student, which positioned KarenPT as the expert in the room imparting wisdom on a novice. KarenPT presented as confident, that she knew what “success” looked like, and suggested that the patient’s role was to comply with advice. We discussed that this was not necessarily “wrong”. KarenPT’s likely motivation was to help patients to recover according to the logics embedded in rehabilitation, to return to “where they were”, as she put it. Her comments suggested that setting limits can be a useful form of advice. Presumably, her frustration came out of feeling that she knew the right course of action, but could not convince some patients to follow her instructions.

Our team discussed how persuasion functioned in relation to PCC. KarenPT’s comments suggested that she decides independently what is best, and works to persuade patients to comply. We agreed that her approach is consistent with soft paternalism, but does it achieve PCC? Perhaps, in some very narrow ways, yes (in the guise of ultimately working towards what is “best” for her patient), and in other ways no. At least some agreed upon elements of PCC appear to be missing in the approach she described (e.g., reciprocal care, negotiated care plans). We discussed the risks, both for practice and research, of deciding in advance what practices and approaches are laudable. Care has multiple effects and can be helpful and harmful in the same event. The danger is in the certainty of assuming what is the right thing to do and how to achieve it. In both of the care events we have presented so far, the practitioners’ assuredness and impatience felt

misguided, made us uncomfortable, and we easily agreed was not how we understood PCC.

The latter exemplar also raises questions regarding what is at stake in care encounters. We said above that in a diffractive analysis, intentions are not ascribed to persons and their psychic states, but read as produced through entanglements. Persuasion is tied up with intentions to do good for patients, but more is at stake than simply a desire to help others. Across the care events, practitioners expressed gratification for a job well done, not only when patients achieved clinical goals but even when they simply complied with instructions. Practitioners saw treatment failures and successes *as their own* and these investments exceeded professional duty or moral obligations of care. The patient-as-person's notions of successful care mattered, but was not all that was made to matter. Across the care events, practitioners' investments in care were entangled with patient preferences and clinical outcomes which together shaped, and were shaped by, care practices. Care encounters thus materialize the subjectivities of all involved in ways that might be intended or not, welcomed or not. Said differently, PCC and other practices shape the personhood of all persons in the encounter, not only the "patient" [2,30].

The most challenging debates amongst our team arose in relation to those benevolent manipulations that produced multiple, incongruous effects. We struggled with if and how these care practices were consistent with PCC or not. Care Event 1 provides an example. The excerpt below focuses on James, a 13-year-old boy with muscular dystrophy who was observed during a quarterly visit to a multidisciplinary assessment clinic that he attended with his mother (JaniceMum). The research assistant's observation notes detailed the following interaction in which two practitioners (AllieOT and AnnaRN) attempted to convince James to be weighed using a lift and sling system that would mechanically raise him from his wheelchair. Weighing was necessary to calibrate his medication dosage. James had used the lift before, including earlier in the day at another appointment. He always found it frightening. Throughout the interaction, James had a worried expression on his face, and from the beginning explicitly stated that he did not want to be weighed. AllieOT and JaniceMum responded to his refusal somewhat impatiently by outlining the clinical rationale, and stating it can be done "quickly and safely". At this point AnnaRN interjected:

AnnaRN asked, "What is it that makes you not want to use it?" She added "We can help you with that." After a few moments, James said again, "I don't want to." AnnaRN asked in a gentle and concerned tone, "Do you feel nervous? Is it scary?" There was a pause before James answered, "Yeah." AllieOT indicated they could do it in the same way as they did it last time since he seemed okay with it. James thought for a moment and then said, "no" with a concerned look on his face. AllieOT then asked, referring to last time, "Did it hurt?" James looked at her and slowly said, "No." She asked, "Were you comfortable?" James slowly said, "Yes." She asked, "Did you feel safe?" James said, "Maybe?" almost as though he wasn't sure... There was a slight pause in the conversation and then James said very slowly, "I don't know why I have to do it again." He gazed out of the window as he said this with a look of annoyance on his face. JaniceMum sternly said, "She already explained it!" ... AllieOT said that they wanted to try the lift again today because he will need to use it when he goes to high school [for transfers and toileting]. "Does that make sense?" James looked out the window and said a very unconvincing "Yes." He then immediately said he didn't understand why he had to do it again when they just took his weight at the other facility... AllieOT looked like she was about to say something but AnnaRN jumped in, "Okay, we won't force you. It's your choice." James looked at AnnaRN and said he didn't want to do it. JaniceMum looked upset. AllieOT then said in a stern tone that he will have to use the lift the next time he comes for his clinic visit. AnnaRN said with a calm voice, "We'll do it next time, don't worry." James looked at AnnaRN and said, "Ahhh, maybe." JaniceMum shook her head.

Much can be said about this interaction but here we focus on the acts of persuasion and resistance. Multiple tactics were attempted to secure James' compliance, including several appeals to rationality through the provision of logical reasons for the weighing. Emotions also exerted pressure – AllieOT and JaniceMum's insistence and obvious frustration provided little space for James to refuse. AnnaRN used a different approach, wherein she worked towards engaging James and used a calmer and gentler tone. She explored James' reasons for refusal, expressed a commitment to address these, and, ultimately, accepted his decision. As a team, we discussed that AnnaRN's approach felt more like PCC, but was still nevertheless an attempt to persuade, to manipulate benevolently. Both practitioners repeatedly sidestepped James' stated refusals. Whether or not this approach is consistent with PCC is debatable. Exploring the reasons behind a dissent and determining if they can be addressed may be, in many cases, a defensible approach to negotiating a possible compromise. However, James' distress and the need to voice repeatedly his dissent to three adults gave us pause. The "how" varied in the encounter, and was what made AnnaRN's approach feel qualitatively different, more empathetic, and thus better aligned with PCC. We noted however that James did not appear to respond differently to AnnaRN. He was distressed throughout, and the attempts to give him space to explain his reticence only seemed to escalate his fears. Likely, he felt that he would never be able to provide a "good enough" reason for refusal. The encounter suggested to us that PCC is risky, subject to failure, and has to be continuously adapted in the moment.

In this care event, battling care principles materialized as an unresolved tension regarding how to act. All the adults, but particularly AnnaRN, worked to uphold James' autonomous choice while at the same time attempting to persuade him to comply with what they viewed as a needed intervention. Note as well that in children's muscular dystrophy rehabilitation, scripts are not oriented to recovery but to optimizing life quality. Practitioners nevertheless get caught up in equating biological impairments with poorer quality of life and this is reflected in the clinic's processes and routines. "Weighing James" was the task they were meant to complete, their work product, the thing that needed to be done today according to the scripts of the clinic. The outcome of the interaction could be understood as both success and failure: autonomy was upheld (for now) but the planned care was not provided. However, more is going on here. We discussed that focusing only on outcomes risks marginalizing the importance of the *doing* of care, the *how*, which had consequences that were made to matter alongside the more obvious outcomes. Said differently, people can be harmed by care processes. The *how* produces effects: James was distressed throughout the encounter, JaniceMum was frustrated, the professionals were unsure about what they did. How matters but its consequences can be unpredictable.

The ongoing challenge for practitioners might be understood as a question of how to temper persuasion ("This will make the patient's life better and they will thank me. I know, I am an expert"), with humility ("I only know so much, need to apply it to this person's situation, and there may be another way of thinking/doing in this case"). Such an approach requires diligent reflection, uncertainty and, as we discuss below, "tinkering". It means recognizing one might not be right, or that an approach that works in some situations may not work in others, and ascertaining if, when and how to

convey this flexibility to the recipients of care. To help work through these ideas in more detail, we turn to discussion of a final exemplar, one that we saw as exhibiting practices consistent with PCC.

Care(ful) tinkering

Sometimes referred to as “doctoring”, tinkering is an approach to care that emerged from new materialist strands of Actor Network Theory [37,38] and has been articulated in relation to rehabilitation [39–42]. Mol [43, p. 177] notes that doing good in healthcare “does not follow on finding out about it, but is a matter of indeed doing. Of trying, tinkering, struggling, failing and trying again”. Broadly speaking, tinkering refers to a flexible approach to care that adapts to the situation at hand. In relation to the rehabilitation, Struhkamp et al [41, p.56] discuss tinkering/doctoring in terms of experimentation or an “articulation of the fuzzy, complex, and adaptable style of knowing and acting that is crucial to clinical settings.” Uncertainty, humility, doubt in one’s expertise, and risking failure are inherent to tinkering which involves a continual questioning of what to do, what is best, and what is PCC within each context. In what follows, we explore these ideas in relation to Care Event 8.

Care Event 8 was a treatment session involving a patient (Tony), a physiotherapist (PamPT), and a physiotherapy student (MichaelaS). The session was observed by a member of our team, Gareth. Tony, a wheelchair user who had sustained a spinal cord injury many months previously, was preparing to stand with the assistance of PamPT. In order to facilitate standing, a harness was suspended from an overhead beam and attached to them both. As they were preparing for the stand, Gareth recorded in his observation notes that Tony became visibly nervous. The note continued:

Despite having [used the harness together] before, the physios would remind Tony of each of the steps they engaged in, and the reasons for them – they took turns doing this. Safety was emphasised, but language of comfort and togetherness were used as well, e.g., “This will help us...” “It will make things more comfortable for us...” There was definitely a shift from motivating to soothing at this point (“This will be fine...”) as they seemed to recognise that Tony’s investment wasn’t quite what it had been.

Our team discussed the shift in tone and its effects. The physiotherapist here was nimble, interpreting Tony’s anxiety from bodily and verbal gestures, and modifying her approach in response to his anxiety (from motivating to soothing). We saw this as a fine example of tinkering – perhaps “emotional” or “tonal” tinkering. Gareth noted that, to this point in the encounter, everything had been very business-like, but PamPT adapted to the anxiousness produced in commencing the stand. We interpreted this as a positive, thoughtful, and empathetic gesture. It served to calm Tony and therefore allowed the treatment to continue. The shift was caring, but also worked towards securing compliance, and is thus also an instance of “benevolent manipulation”. Standing was Tony’s goal, but standing was also the work product of the practitioners. They want to help Tony, but as discussed above, they were also invested in success for professional and personal reasons. Persuasion takes many forms including empathy, listening and encouragement, and does not need to be intentionally aimed at (only) compliance. Compliance may be produced nevertheless.

Without persuasion much less would get accomplished in rehabilitation, including progress and achievements that patients welcome and expect. If persuasion can be conceived of as consistent with PCC, then it is expressed at least in part through

“knowing” when to push, how to push, and when to ease off. Moreover, it requires multiple and varying forms of partnership to “negotiate needs, goals and praxis to personalize and optimize therapy” [12, p. 4]. PCC as tinkering is a dance in which each partner responds to the other without necessarily articulating the steps. We might say that these forms of soft paternalism are justified when they serve a patient’s goals. The risk is that patients may not still/want the same goal, want a break, may not want this particular intervention, may not immediately know what they want, and/or may change their minds. More importantly, they may not recognize the different forms of persuasion, and some of these hidden forms are very hard to resist. We might thus suggest that the person-centered practitioner approaches tinkering by reading the body, responding to the situations, listening to others, interpreting expressions of doubt, and all the while keeping an eye on everyone’s safety. There is no guarantee of getting it right, no general “principle of tinkering” that can be universally applied to all situations.

As the treatment session continued, other instances of tinkering were observed:

PamPT was harnessed to the front of Tony, while the student MichaelaS stood behind. She was worrying about what to do with the chair just as Tony’s nervousness seemed to be getting more apparent. There was a flurry of talk and activity and Tony was pulled upward into standing. Things went immediately downhill. Tony standing at 6’5” for the first time in a couple of years immediately demanded he sit down, but the wheelchair had been moved away. PamPT moved straight into 100% soothing (“you’re doing great...” “this is good...” “just breathe...”), but Tony’s agitation only increased. PamPT asked Tony if he definitely wanted to sit down and he responded with a keening wail, and this persisted for the remaining standing time. A number of people came out of offices and other spaces to see what had gone on. The communication between physios at this point was difficult as PamPT was focused intently on engaging Tony, using soothing words, emphasising her closeness, telling him to focus on her. MichaelaS finally got the chair and positioned it near to Tony, and PamPT eased him back. The debrief following this moment was fairly intense. ... Only about half of Tony’s appointment time had been met at this point, but there was no effort made to return to any task-based process. PamPT stayed crouched in front of him talking gently and quietly, her hands still making contact with his legs. Touch did not seem taboo at any stage in this process, but particularly when trying to comfort Tony. As his agitation reduced, this engagement continued, with no apparent expectation that things would be “resolved” in the session. There seemed to be a lot of effort going into making sure that Tony was going to be OK.

Gareth, who is not a clinician and had not previously observed such an encounter, was moved by the intensity of this event and everything that, rather quickly, happened at once. He noted that Tony was a large man and the (smaller) physiotherapists were expert in managing the transfer to and from standing safely, all the while addressing Tony as a person experiencing intense emotions and sensations. Two members of our team who are experienced physiotherapists saw this encounter as rather run-of-the-mill. Gareth’s reaction helped us to remember that quotidian practices are extraordinary in their ordinariness, that good care happens all the time. We all agreed that there was a lot going on in this encounter. Three bodies, equipment, expectations, endpoints, and emotions came together to produce standing (and anxiety, and soothing, and learning, and PCC). PamPT needed to decide in the moment how much was too much. Tony was literally in her hands. He could express that he wanted to sit down – through a “keening wail” and his bodily responses – but sitting down required a collective effort that he could not easily, or safely, initiate.

PamPT and Tony tinkered together. PamPT used “soothing tones” to address Tony’s agitation, and inquired if he wanted to

sit. She did not, however, immediately respond but rather prolonged the stand a few moments more. In so doing, PamPT experimented with PCC. She navigated between a narrow version of respecting autonomous choice (patient has indicated he wants to sit), compassion for his emotional state, and effecting a successful rehabilitation session that advanced the goal of standing. And she did this *with* Tony, in response to his overt and subtle indications of tolerance and preferences. She did not push further. She sensed, without asking, that a limit had been reached. To ask more of Tony would have been to “lose” him. He might not return, or if he did, might not trust the treatment propositions. The effects of tinkering are both proximal and distal and all must be addressed at once. Tinkering in the event was thus pushing and releasing in a delicate balance. Within this, PamPT modeled her interpretation of PCC for MichaelaS. Tinkering can be benevolent, and can be manipulation, and each of these can be PCC. But sometimes they are not.

PCC was co-produced within care events. Tony was not merely objectified as a body that needed to stand, but neither was he an autonomous subject making free choices. Tony-as-person can be said to be neither object nor subject in the encounter, or rather he was both at once: an object of care and the subject of affects and attentions. Pols [44] helps to rethink the “person” in PCC through her work interrogating patient “perspectives”. She notes: “Instead of the subject being an active, autonomous and authentic individual with a perspective on the world, the subject becomes a co-production, a result of interactions with others and a material world” [44, p. 211]. We can think of Tony as a co-production, but the same can also be said for PamPT and MichaelaS, as well as Gareth who was not neutral but complicit in the doings. Care and personhood were enacted through these entanglements. Moreover, the structuring of the social space and its material organization mediated these productions. That other people could and did come out to see what was happening was part of the encounter and its effects on those involved. In these entanglements, tinkering is perhaps all that is possible. PCC cannot be determined in advance but emerges in the doing-together.

Final thoughts: Tinkering with PCC

Our team’s diffractive considerations of PCC drew on our multiple subject positions and academic inclinations to map the doings of good care across rehabilitation care events. We did not always agree on how to interpret action, or indeed, what could be labeled PCC, and have attempted to include in the analysis our range of viewpoints and points of tension. Throughout, we have emphasized that we are not interested in finalizing any one way of understanding or doing PCC. What we all agree on, however, is that PCC is mostly nothing grand but rather, infinitely small, nimble, and cumulative through micro-acts of care.

In coming together to consider how good care is understood and accomplished, we discovered parallels and possibilities inherent in the notion of tinkering in relation to current articulations of PCC. We began the paper noting the recent critiques in the PCC literature leveled at efforts to standardize definitions of PCC and the proliferation of related models. We suggested that such conceptual diversity is inevitable and, while it creates challenges, can be valuable in articulating the richness of PCC. Through our diffractive analyses, we have encountered the challenges of articulating the complexity of PCC and its varied applications across different rehabilitation care events. Our analyses are, at least in part, consistent with the central critiques of the recovery model

and the normalizing tendencies of rehabilitation embedded in the “ultrabilitation” approach that grounds this special issue. Its reconfigured goal of supporting human flourishing helps to move care away from notions of recovery. This much more open-ended concept holds considerable promise in guiding future developments and debates in rehabilitation, but also raises new questions of what counts as human flourishing. We draw again from Mol and her notion that good care (or what human flourishing looks like) cannot be known in advance but must be specified within care practices. Tinkering, we suggest, provides a way forward that accommodates this complexity by acknowledging the multiplicity of interacting proximal and distal forces within care encounters. Mol [37, p.56] describes this “experimental” approach as follows:

Let us experiment, experience and tinker together – practically. This is far from easy. Shared doctoring requires that everyone concerned should take each other’s contributions seriously and at the same time attune to what bodies, machines...and other relevant entities are doing. Those who share doctoring must respect each other’s experiences, while engaging in inventive, careful experiments. They must attune all variable variables to each other, while attending to everyone’s strengths and limitations. They must change whatever it takes, including themselves. Shared doctoring requires us to take nothing for granted or as given, but to seek what can be done to improve the way in which we live with our diseases. And remember that failure is inevitable and death the only security we have.

Tinkering does not suggest that “anything goes” but it does suggest a particular ethics. Because facts and values are always intertwined, there can be no ethics separate from the practical doings of care, no way of knowing if or when one has got it right. So there is no way of knowing what to do in advance. In some of our team’s initial conversations, the notion of the importance of establishing and maintaining trust emerged as crucial to PCC. However, we considered that PCC might be better served by professionals encouraging people *not to trust* them. That is, it is important to question each other, to question oneself, to question the scripts that state what one should do or what is “best” practice. To “change whatever it takes” as Mol says; to respond to moments of moral discomfort [12]. To tinker. We can label this as PCC, or ultrabilitation, if it accommodates a full range of behaviors, which – within certain events and their constitutive arrangements of people, objects, emotions, desires, and constraints – produces good care. Regardless of how it is labeled, our point is that ethical care can and will include some acts of paternalism/benevolent manipulations. To say otherwise would be to discount the potential good that comes from education and other forms of persuasion. But of course this does not mean that paternalism is always, or even usually, justified, only that categories and labels such as “PCC” and “paternalism” have to be continually opened to scrutiny.

We conclude with our own uncertainties and the opportunities they open. Critiquing something that we feel strongly about, PCC, is risky business and, in experimenting with research approaches and writing conventions, we may have succeeded in some ways and failed in others. In this we welcome critique, debate, and further discussion. Post-qualitative research is only beginning to emerge in rehabilitation and we would suggest that it offers a fresh avenue for tackling some of its most tenacious problems. Our analysis can be read as an example of this emerging research tradition. Potentially fruitful areas for further scholarship include deeper explorations of the concepts of “person” and “centredness” within new materialist approaches that explicitly work to decenter human exceptionalism. Beyond PCC, these analytical approaches can be applied to any area of practice to help imagine rehabilitation differently (see for example [39–42,45]).

We also acknowledge that there is more to do within the work we have presented here. Even with our small number of care events, there was so much more we explored that did not make it to the page. Moreover, we were composed of a particular group of researchers and practitioners who made choices in constructing our data set and mapping the relations. Notably absent from our group were the perspectives of multiple and diverse recipients of care. Such work is needed and rather sparse in PCC research [9]. To that end we see multiple possibilities for pursuing further inquiry.

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The authors report no conflicts of interest.

Notes

1. The Centre for Person Centred Research (PCR) at Auckland University of Technology is an interdisciplinary research centre focussed on 'rethinking rehabilitation'. The core principle underpinning PCR research is person-centredness, which informs the focus of inquiry and how research is conducted. <https://cpcr.aut.ac.nz/>
2. To protect confidentiality, we have not provided the practitioner's discipline.

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