Title: A posthuman decentring of person-centred care

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Abstract: In this paper we examine person-centred care through a Deleuzian posthuman lens with the aim of exploring what becomes possible when the concepts of both person and care are *de-centred*. We do so through a consideration of the sets of relations that produce 'the client' in health care contexts. Our analysis maps particular entangled material-semiotic forces producing 'M/michael', a young man with a diagnosis of Duchenne muscular dystrophy, within a rehabilitation clinic. Drawing on Deleuzian notions of *assemblage*, *affect*, and *becoming* we explore 'person-care' as an active production that dynamically enacts persons-as-clients through clinical arrangements. Persons are thus reconceptualised in terms of locally produced subject positions and their care relations, rather than pre-existing beings who can be 'centred' within health services. Paradoxically, by de-centring persons and care, we work to conjure ways to strengthen the aspirations of person centredness to humanize health practices. In doing so, we consider different possibilities for re-imagining clinical work and contribute to debates regarding how healthcare conceptualizes and addresses disability, health, and wellbeing. We suggest that such posthuman analyses can open up new ways of understanding and re/forming healthcare.

Key words: Person-centred care, Deleuze, disability, muscular dystrophy

Word Count: 7583

Humanist person-centred care within biomedicine: competing priorities

Person-centred care (PCC) has sought to revolutionize biomedical healthcare by re-orienting clinical work to caring for people rather than curing pathology (Leplege et al., 2007). While there are multiple and sometimes competing articulations of PCC, all aim to address the suppression of patient voices, support patient preferences and choices, and orient practices to their unique circumstances. Grounded in notions of 'respect for persons', more sophisticated strands of PCC (e.g., family-centred care, relationship-centred care) extend beyond the individual to attend to the needs of all persons involved, i.e., clinicians, patients and significant others, and signal a move away from 'patient'- centred care. PCC and its variants work to ensure care is meaningfully addressing patient needs and wants, ensuring respectful relationships, mitigating paternalism, and considering how the system supports or constrains these goals. PCC thus has highly laudable goals and has transformed how healthcare is understood and delivered. Despite these changes, problems persist in how PCC is operationalized by health systems, institutions, and individual practitioners. In this paper, we approach these challenges using posthuman 'experimentation', employing Deleuzian concepts to explore what becomes possible when notions of both person and care are *de-centred*.

PCC competes with other powerful forces and ideas that also significantly shape health practices and delivery. These include the persistence of biomedical/pathological framings of health and illness, positivist and reductive notions of the body as a machine, and the imposition of 'evidence-based practice' that venerates the randomized controlled trial over all other forms of knowledge production (Holmes et al., 2006). Within medicine, objective assessment 'findings' are the core of clinical reasoning processes, which are designed to logically interpret data towards determining a diagnosis and treatment plan based on 'best evidence'. Moreover, with increasing

interest in machine learning, data driven decision making tends towards reducing 'persons' to a series of data points, and 'care' to increasingly standardized sets of algorithmic procedures (Holford, 2020). Keeping persons centred is thus difficult work within these competing imperatives.

The evolution of PCC has seen it increasingly align with biomedical and managerial approaches to care. The dominance of evidence-based practice and the enthusiasm for data-driven management manifests in the operationalization of PCC in the form of checklists, questionnaires, and measures that reduce delivery and evaluation of care to a set of statistically analyzable numbers (Edvardsson & Innes, 2010). This can be seen in articulations of PCC that stress the development of quality indicators, measurable frameworks, and organisational performance (Guastello & Kay, 2019). While our intention is not to suggest these approaches are irredeemable or do nothing to achieve improvements in individualised care, we argue that the core aims of PCC may be compromised when increasing aligned with the systematization of healthcare delivery.

Despite the apparent differences between positivist biomedicine and humanist PCC, they nevertheless share common conceptions of persons as pre-formed agents, holding subjective viewpoints and preferences, and acting as autonomous beings in the world. Each approach may assign different degrees of value to 'the patient's voice', but they agree that individuals 'hold' opinions and have personal priorities that can be elicited. But there are other ways of understanding subjects and subjectivities that we suggest may be mobilized to assist PCC to realise its aspirations. Our aim in the paper is to engage in posthuman experimentation oriented to 'producing different knowledge and producing knowledge differently' (Montforte & Smith,

2021, p. 652) in order to inspire creative approaches to thinking and doing PCC. Our team is comprised of senior and junior scholars from varied social locations and disciplines that include psychology, disability studies, bioethics, rehabilitation, and health sciences. Some of us work primarily in critical and/or posthuman spaces, others in PCC and/or rehabilitation. We are/ have been 'patients', 'clinicians' and 'parents', and a host of other subject positions. In drawing on posthuman scholarship to rethink the person in healthcare, we aim to de-centre PCC- not to replace it or derail it, but to help it to thrive.

In what follows, we provide a Deleuzian de-centring of 'persons' and 'care' by working through various arrangements of objects and subjects implicated in producing 'M/michael' as 'patient with muscular dystrophy' within the context of a rehabilitation clinic. We then conclude with a discussion of the implications of de-centred person-care for informing the aims of PCC.

Becoming persons

We begin by introducing some key tenets of our posthuman approach and the Deleuzian concepts we employ. Deleuze's writings, and those with his collaborator Guattari, continue to exert considerable influence across fields of inquiry, including healthcare scholarship where it intersects with science and technology studies, disability studies, and the sociology of health (e.g., Buse et al., 2018; Blume et al., 2014; Moser, 2006). While there are multiple strands of posthuman theory, all challenge the humanist project, scientific proceduralism, and the centrality of Western knowledge and truth (Carlson et al., 2021).

Contra prevailing humanist understandings of humans as self-contained, closed, and autonomous subjects, our posthuman approach considers the radical openness of people and bodies. Subjects

are reconfigured as in a continual state of flux, neither encased by skin and organs nor defined by static binary categorizations such as disabled/able-bodied, male/female, person/thing, or myself/other (Massumi, 1992; Gibson, 2006). The defining features of the human condition - e.g., agency, subjectivity, identity, judgment, values, and bodies - are no longer viewed as stable properties of a contained self but rather as *outcomes* of generative processes (Andrews & Duff, 2019). In other words, humans and their capacities are reconceived as continually being made and unmade across different encounters. This decentring of the autonomous subject creates space for analyzing the interactions between human and non-human entities without privileging (or 'centring') one over the other.

The notion that no/thing is static but always in constant production runs across Deleuze's work. A subject for Deleuze is re-imagined as perpetual *becoming* through an open system of *assemblages* - as opposed to a closed and static 'subject' –that is continually reconfigured. *Assemblage* is Deleuze and Guattari's (1987) term to characterize the constantly shifting connectivities between heterogeneous material-semiotic forces and entities, including but not limited to bodies, social meanings, emotions, objects, places, and technologies. Each of these entities or 'singularities' are themselves continually composed and recomposed. Thus, there are no self-contained parts that make up an assemblage, but rather assemblages are dynamic and temporary, coming-together in specific arrangements to produce objects and subjects that have the appearance of permanence and solidity. Assemblages can be thought of as 'machines' that can be 'plugged in' to other machines that do things in the world (Deleuze & Guattari,1987). Human and other assemblages are thus neither stable or closed systems, but temporary entanglements that continually compose, decompose, and recompose, forming different machinic assemblages with other material-semiotic forces that produce different capacities. Persons in such

a formulation are particular assemblages produced through intersecting animate sensibilities and materialities. Within such a configuration, the imagined autonomous persons of PCC are radically reconfigured. Not simply an exercise in alternative description, our focus on mapping dynamic assemblages in the paper works to enact an open and affirmative person-care ethics. To do so we need to briefly sketch two related Deleuzian concepts: becoming and desire.

Becoming expresses Deleuze and Guatarri's process ontology wherein subjects as not only in flux but with a directionality that resists becoming fixed or 'territorialized'. Assemblages coalesce through capacities of assembled relations to affect or be affected. This capacity is becoming, i.e., a change of state or relations which may be physical, biological, psychological, social, political or emotional (Fox & Alldred, 2017). As Braidotti (2013) notes, becoming-machines 'stand for radical relationality and delight as well as productivity' (p. 92). Becoming is thus always an affirmative movement towards something but not in a temporal sense of futurity. As a force of production, becoming marks the unceasing mobility of collective life: 'A kind of order or apparent progressions can be established for the segments of becoming in which we find ourselves; becoming-woman, becoming-child, becoming-animal, -vegetable, or mineral; becomings -molecular of all kinds, becoming-particles' (Deleuze & Guattari, 1987, p. 272)..

Deleuze and Guattari (1987) see the individuation of the subject as limiting *desire*. Desire is not a want or a compulsion to address a lack of something but rather, it is a positive and productive force (*puissance*) of becoming. Linked with the concept of *affect*, desire is the ability to affect and to be affected, to form emergent unities (assemblages) that retain the heterogeneity of their components (Deleuze, 1978). Affective forces amplify and compel awareness, movements, thoughts, or expressions and are transmittable within and between bodies, things, and

environments (Shouse, 2005). Emotions/ideas/thoughts are related to affect but are produced through relations rather than belonging to individuals. Moreover, while concepts like affect, becoming and desire have a consistency in Deleuzian analysis, they do not have an essential identity (Smith, 2020). Rather than a problem, the becoming of concepts opens thought to creative possibilities, or affirmative 'lines of flight'. The unthought becomes thinkable.

What does this mean for PCC? We begin by rejecting the notion of a care encounter occurring between autonomous 'persons' within a static healthcare 'setting' and according to hierarchical (Deleuze might say 'arborescent') divisions of micro/meso/macro 'contexts'. In doing so, we endeavour to move beyond a critique of the actual (what is, or more precisely, what is ceasing to be) to creative actualization of the virtual (the possible processes of becoming) (Braidotti, 2019). De-centred care in our exploration is an affective and affirmative production, a shifting 'becoming person-care assemblage' that is made by and responds to a set of relations with multiple effects that open opportunities.

Becoming – M/michael

To reconsider person-care, we map becoming person-care assemblages with their compositions, flows, and entanglements across time-space events. Our analysis takes as its entry point a young man named 'Michael' who participated in an earlier observational study exploring children's rehabilitation care practices (Setchell et al., 2018; Abrams et al., 2019). In PCC, Michael would be 'the client' (or patient) around whom care would be centred, considering how the values, perspectives and needs of all 'persons' in a clinical care encounter could be respected. In our analysis, Michael is understood as a conglomeration of forces that produce the enduring subject position that is recognized as Michael but continually changes in different iterations (different

'michaels') as he moves through the world. We deliberately switch to a lower case 'm' here to signal there is no essential 'Michael' but several possible iterations, several michaels, none of which can be labelled 'him' (Michael self-identified as male/man). Thus, in the paper we use the upper case to refer to the Michael of the clinic, lower case for becoming-michael, and M/michael when these positions overlap.

We first describe M/michael in somewhat conventional terms of a humanist 'case' recognizing that in so doing we produce a particular michael assemblage (casing the case, *c.f.* Sandelowski, 2011). We deliberately use this familiar (in healthcare) style of presentation to examine the kinds of subjects that are produced in representation, recognizing that we as authors are implicated in these productions, and that the case does not pre-exist but is produced as part of a research assemblage (Fox & Alldred, 2018). We then use the case as a point of departure for decentring Michael-as-person by re-assembling the case through two different re-composing experiments: becoming-chair and becoming-death/life. Writing and representing posthuman subjects is a tricky business but here we have chosen to employ 'becoming' as a shorthand modifier for the decentred assemblages that we map, recognizing that we risk a reductive reading of becoming which we return to below. Each iteration draws from a set of observation notes produced in a Canadian study examining clinical practices with a children's rehabilitation team, the details of which have been published elsewhere (Setchell et al., 2018).

'Michael' as research case

Michael (all names are pseudonyms) was a 16-year-old in grade 10 at a Canadian high school. At the age of five, he was diagnosed with Duchenne muscular dystrophy (DMD). DMD is described in medicine as a life-limiting condition characterized by progressive muscle weakness which

leads to a loss of function and mobility, and eventual respiratory failure. Life expectancy ranges between 25 to 40 years but is highly uncertain (Landfeldt et al., 2020). Michael lived at home with his mum, dad and older brother. His mum, Jee, did most of Michael's personal care (bathing, dressing, etc.). Michael spent much of his spare time watching anime which he said was his 'favourite thing to do'. He started using a manual wheelchair at age 12, but it was increasingly difficult to self-propel and the family had recently purchased a power chair that Michael was using at school. At home he used a wheeled office chair that Jee pushed for him. Members of his clinical team expressed concern with Michael's continued 'reliance on Mum' for mobility and transfers, and the effects this had on her physically, psychologically, and socially.

Michael attended an outpatient medical clinic at a children's rehabilitation hospital every four months, usually with Jee. During these appointments, the family would sit in a clinic room while six to eight multidisciplinary clinicians took turns coming in to conduct various medical assessments, and to discuss challenges, treatments, and other supports. The following observation notes were made over the course of two clinic visits. Some of the details have been altered to protect confidentiality:

When the physiotherapist (PT) asked how well the office chair was working for the family, Jee said 'I am not completely happy with the chair, but it's what Michael wants.' She added that she was looking into getting Michael a better manual chair to use around the house, so that 'he can be more independent and not have to always call me for help'. When the PT agreed that this was a great idea, Michael turned to his mum (Jee) and slowly said 'I don't want it. I won't use it'. The PT expressed concern with his use of the office chair, particularly in terms of joint alignment issues and an increased risk of falling, especially during transfers [the office chair does not have

brakes]. *Jee and the PT tried to persuade Michael that using the more supportive wheelchair would 'be better for him'. Michael continued to refuse. The PT reiterated the benefits of using the manual chair, such as moving himself around the house when he wanted something. She then asked him, 'is that important to you?' Michael shook his head and responded, 'no'. Jee, expressed frustration, and asked Michael if he just wanted her to 'continue to do everything' for him, to which he replied, 'yes'. The PT and the social worker offered to help the family apply for funding to buy an adjustable desk. Michael refused, and said, 'I don't see the point'. When asked why, he said with annoyance, 'because I don't want to'. Jee suggested the only reason he did not want to try a new manual chair in the home was because he 'won't be like everyone else'. She added that when the family goes out to a restaurant, Michael sits in the restaurant chairs and gets her place his wheelchair out of sight.*

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At a later visit to the clinic, a recreational therapist talked to the family about an employment mentorship program:

The therapist turned to Michael and said, 'I remember you were interested in employment, right?' Michael did not respond. The therapist waited for a moment. She then asked, 'Not interested?' Michael slowly said, 'Not really' and looked away. Jee, sounding annoyed, asked 'Why not? This mentor could really help you. You're going to be an adult soon!' The therapist waited for Michael to reply but he did not. She then turned to Jee and said he would not be eligible to register again for another six months, but in the meantime, he could think about it. Jee nodded and asked who they needed to contact to register, but Michael said to her with annoyance, 'Why? I won't change my mind'.

Posthumanist re-composings

The case reveals the mechanisms by which care practices and persons are enacted through entangled material-semiotic forces. The different forms of care in clinic can be understood as 'events', that is, they are made and unmade through entwined human and non-human, animate and inanimate, material and abstract forces. The diagnosis of DMD catalyzes different ways of knowing and doing of michael and family. The 'client', 'Mum' and the 'client's family' are produced as particular kinds of persons in PCC through biomedical logics - assessments to identify problems, treatments to enhance capacities, psychosocial and material supports, and discourses of child development, independence, biophysical decline, hope etc. Clinicians employ certain treatments, suggestions, 'patient education', and approaches which draw on particular dominant logics and discourses embedded in medicine; and work to particularize options and solutions to child and family capacities, life circumstances, and stated preferences (Mol, 2008). In this, they occupy subject positions of responsible clinicians who perform in accordance with the entangled webs of knowledges, practices, values, temporal rhythms, and conventions that permeate clinic spaces and extend into the social worlds of families and diagnosed children. Interacting forces, including the powerful imperatives of biomedicine, actively produce different forms of care, which then work to reinforce, or for Deleuze and Guattari, 'territorialize', certain ideas and ways of being while negating others. Thus 'persons' and 'care' are relational and temporary productions enacted through clinical events forming person-care assemblages that serve particular interests and not others.

A clinic visit entangles with other events to re/produce michael-with-DMD. Michael's refusals to engage in conversation or accept clinical advice differentially produce becoming-michael. Becoming-michael is an affirmative expression of desire, a line of flight that resists capture by the forces that conspire to territorialize a client-subject. In the encounter described above,

M/michael enacts 'acceptable' forms of resistance without having to articulate/examine/know the range of internal and external forces that drive choices, i.e., he shrugs, says no, and/or does not engage without ever fully articulating a rationale or explanation. These gestures disrupt the clinical assemblage, becoming something other than client-with-DMD (Callon & Rabeharisoa, 2004; Abrams et al., 2017). Refusals to use a wheelchair act against an imposed identity in a world where to be marked as disabled is to '*dys*appear' (Leder, 1990), that is, to appear as different in a negative register. Elsewhere we have suggested that the social practices and rhetorics that surround childhood disability draw on and sustain ideas of disability as tragedy, compelling a host of activities oriented to achieving or approximate normalcy: normal bodies, normal development, normal social roles and normal function (Gibson, 2014). These forces are implicated in clinical work but also in family and social life where subjects are produced through the doings of everyday life. The only rationale for refusing the wheelchair is offered by Jee: because he 'won't be like everyone else'. Without words, this rationale is silently rejected in the clinical space as not good enough. Michael never articulates this reason or any other. In his resistance, he becomes both normal and different - in different ways in different spaces and renderings. Becoming-michael thus unfolds along affirmative trajectories, decentring PCC and 'client-with-DMD' by resisting the logics of the clinic. He becomes otherwise: A teenager who sits in regular chairs. Both banal and radical, this becoming-chair-body-michael, as we explore below, enacts desire - collectively reworlding the clinic space by 'processing negativity and producing affirmation' (Braidotti 2019, p. 51).

The discourses of loss, decline, death and what-to-do are integral to the co-productions of person-care and their particular forms. The assumed 'tragedy' of loss hangs over the clinic encounter. Michael is getting weaker, more impaired, he will die young. This is too difficult to speak about

and yet it is present in talk of risks of the office chair, the need for a new chair. The affective weight of decline co-mingles with clinical imperatives to 'inform and educate the patient' - Life will be better if/when you relent. An unspoken principle of shared decision-making shapes clinical practices. This too is a force of production. Listening to the client's articulated preferences is an integral part of PCC. Conciliatory gestures and comments are made. 'Is that important to you?' Discomfort circulates through the assemblage as emotive forces weigh in and on. They set aside the discussion. A mix of emotions such as fear (of humiliation, of decline) and anger (at insistent adults) conspire to produce [michael's] resistance and [adults'] insistence. This was evident in facial expressions, body language, speech rhythms and tone which became more apparent as the visit progressed. Emotions are productive, but also packaged in particular ways to explain and manage them: Not included in our excerpt was a moment when a clinician asked if Michael was 'depressed'. Medicalization essentializes, controls and diminishes the significance of feelings which are explained away through a potential diagnosis and form the explanation for 'non-compliance'. M/michael 'takes' a position as resister. But did he 'choose' this position? Did clinicians and 'Mum'/Jee decide their roles? The emotions, rhetoric, expectations, stigma, identities, responsibility, biological decline, weight, mum, and michael intermingle to produce entreatments and resistance: Please? No!

The decentred person-care that we propose works against the centring of individuals to consider care doings, that is, how persons and care are made within healthcare processes, and what is made to matter. Instead of individuals, we consider the *intra*-acting (Barad, 2003) forces that produce assemblages and the possibilities for reimagined person-care. These forces and assemblages are many including emotions, actions, stigma, personal commitments, compliance, resistance, hope etc. These are not the intended outcomes of human(ist) interventions but the

results of coalescing forces that conspire to produce particular worlds that have effects on living and dying. De-centred analysis thus maps the making of material lives and circumstances. What assemblages enable a better life? Who is involved in asking and answering this question? How do clinical events and assemblages flow over other life events and relations?

Experiment: becoming-chair

An appreciation of de-centring is aided by moving beyond mapping persons and choices to re-considering the materialities that we have alluded to above. We thus map a different assemblage (map the assemblage differently) - that of the becoming-chair. Becoming-michael is enacted in the production of becoming-chair (hereafter 'chair'), but we suggest that neither precedes their coming together, nor can they be understood as distinct entities. Chair does not 'contain' michael but is rather an expression of michael and of chair: becoming-chair-body-michael (demonstrating the limits of categories and language). With this in mind we case-the-case as assemblage.

Chair co-resides in michael's home. It usually rests beside a desk and was manufactured as an 'office' chair. As such it has particular features: adjustable height, wheels, removable arm rests. It can be made to fit different human bodies, to enable deskwork. It is made of sturdy metal, plastic, and upholstery designed for frequent use. Chair is assembled from components and imbued with meanings of design-for-purpose uses. It evokes affection and feelings of ownership (my chair) and trepidation (unsafe chair). It forms assemblages with desk, floor, computer, bodies, preferences, emotions, tasks, values etc. It invites work-sitting but of course it affords other uses: a dog curling up, a child's spinning play, an unstable standing platform to change a light bulb.

Becoming-chair-body-michael (hereafter body-chair) forms an anime assemblage with a computer which produces pleasure. Along another line, the pleasure assemblage produces body-chair of a particular type: the subject position of the chair. The assemblage is thus an enacted doing. It does and makes many things and then it splits apart, components plugging into other components to do and make otherwise. Body-chair fits under the desk enabling the viewing of anime on a computer screen, becoming-with online community. Forces of hunger or an urge to urinate affect a break. This is a break from a task but also a break in the assemblage. The body speaks. Body-chair connects with becoming-jee and together they move to another room, incorporating other objects, to form new assemblages, actions, affects.

The virtual life afforded by anime is constructed in clinic and family life as 'problem' within which chair is complicit but, at the same time, body-chair as process is an affirmative act of becoming otherwise. Body-chair enacts pleasure within virtual spaces that are both grounded in and reconfigure the materiality of body and chair, actualizing the virtual through desire, becoming dispersed. The chair-anime assemblage entangles with masculinized teenage spaces that produce their own logics. Body-chair does not escape lines of gender, age, class, or race, but is complicit in making and unmaking them. Chair with (and without) becoming-michael is thus productive of and produced through the micro-affective politics of the assemblages it forms. It enters into and makes relations that compel actions and have consequences.

In clinical assemblages, biomedical surveillance produces *at-risk* body-chair. The latter provokes anxieties enacting different subject positions in the clinic: The client's body may be damaged (clinician), the mum is overworked (clinician and parent), chair may be taken away (client), 'Am I a bad mum?' (parent), 'I am not properly educating this family' (clinician), 'I am afraid of what

happens next' (client). In the entangled clinical event, body-chair is rationalized according to clinic logics and imperatives of safety. It is a path to normalcy, to be 'like everyone else'. These semiotic forces position body-chair as problem and it is placed into peril. Body-chair works to survive not through mobilizing other logics but through affective utterances: "Because I don't want to". Such talk entangles desire, disrupting the logics of the clinic and the rhetoric of PCC toward an affirmative becoming of doing DMD otherwise. It is a line of flight – plugging in differently, refusing to play the game of 'clinical question-rational response' that cannot be won. Chair-body-michael continues becoming.

Interlude: care-full caring

The concept of 'care' in the provision of health and social services has often been viewed with suspicion. In relation to disabled people and others, so-called 'caring relationships' have resulted in significant harms, including physical, sexual and emotional abuse (Saxton et al., 2001). Care scholarship has often focused on developing a care ethic that could address the implied paternalism in service provision oriented to enabling more equitable care relationships. However, these attempts are delimited by humanist ideals of choice, autonomy, and self-determination and they may obscure the significance of the affective relations at play in care encounters that PCC works to address. Posthumanist scholars have proposed the notion of 'care-full' care enacted through diverse and open intra-active care assemblages that support becoming (Fullagar et al., 2019).

Our posthuman approach to care-full care aligns with Kelly Fritsch's (2010) relational ethics of intercorporeality which posits that it is 'through becoming in-the-world-with-others …that we can begin to conceptualize care' in beneficial ways (p. 3). The different forms of care in clinic encounters can be understood in terms of entangled human, non-human, material, and abstract

forces co-mingling to produce different forms of person-care. In de-centring the person, we have rejected the notion of individuated agents engaged in the transaction of giving and receiving care. Instead, we suggest that person-care is dynamically produced through relational assemblages. This approach forces an examination of the ways in which subject positions (and bodies) are produced in particular configurations. Thinking through the relations and extensions of caring (desiring) bodies that exceed their autonomous containment is not simply to point out the ways in which everyone in the care relation is 'interdependent'. Rather, it problematizes the separation of giver and receiver, acknowledges that more than individual human agency is at play, and demonstrates the active production of becoming. We explore these ideas further below, but first map a second experiment.

Experiment: becoming-death/life

We move now to consider temporalities of DMD and how 'the client with degenerative disease' is varyingly constituted across socio-temporal spaces in relation to decline and death. Death myriadly differs from an office chair but is similar in that it is also a force of production imbued with particular meanings and materialities. It thus functions as an assembled object in ways that overlap with the doings of chair. In the context of DMD, the twinned notions of decline and death act as agentic absent-presences that make and unmake person-care objects and subjects of particular types.

Death has a rich and complicated history. While an exploration of this history is beyond the scope of this paper, a couple of remarks are needed before considering death in relation to becoming-michael. The frequent personification of death in literature, religion, and popular culture speaks to its powers of intervention, and its ontological status is an ancient and continuing

point of philosophical debate. Deleuze for his part rejected notions that life is oriented towards death, that death does or should mediate how life is lived, or even that death is an endpoint of life (Deleuze, 1988). He saw such formulations as inventions of a territorialized structure that limits possibilities and impedes lines of flight (Baugh, 2000). He nevertheless acknowledged the need to 'keep enough of the organism for it to reform each dawn' i.e., not to deterritorialise too much or risk dying (Deleuze & Guattari 1987, p. 160). Deleuze's notions of death paralleled his rejection of the static subject contained within a biological body, i.e., becoming cannot accommodate death as endpoint because there is no individual to perish. In defanging death, he called for an open-ended plugging in of desiring machines, forming and reforming assemblages and achieving intensities.

For our analysis, we similarly avoid anchoring death to essentialized persons while still considering it as a constructed force of production pervading biomedicine, clinical encounters, and the doings of everyday life. In the clinic, decline-towards-death functions as a material-semiotic object that interacts with diagnosis and other forces to territorialize DMD and instigate a host of activities. Dominant notions of death [as well as life] are affective. They do things, make subjects and lives of a certain kind. In the DMD clinic, loss of muscle strength is understood as degeneration and decline; similarly, DMD is positioned as a 'life-limiting' or 'palliative' condition. In coming into relation with DMD, decline thus marks the body as disabled in a negative register. The doings of the clinic, oriented to preserving life and slowing decline, produce and sustain affective spaces of loss, hope, struggle etc. With these ideas in mind, we return to becoming-michael.

Medical research suggests that 29 years is the average life expectancy of DMD (Landfeldt, 2020). We use this wording deliberately - DMD lives to be 29, maybe longer. There are new treatments and drugs. Sometimes DMD lives to 40 and even 50 in particular configurations of biology, treatments, resources, motivations. DMD is always becoming-death but also becoming-life. M/michael is implicated in this assemblage of becoming-death/life and its effects in and beyond clinic spaces. Death entangles with becoming-michael, with the family, and with the clinicians. Or instead of 'with' we might say that death makes michael and michael makes death in a unique co-production that vacillates with other forces, bodies, settings. Different material-semiotic objects (michael, death, decline, family, clinic, diagnosis) are enacted, centred or de-centred, through affective acts of categorization with a 'looping' effect (Hacking, 2007). DMD is, amongst other things, teen-becoming-death/life with unique properties - a relatively short life trajectory that remains highly uncertain and varies widely. In clinical encounters, uncertainty intersects with hope but also despair, as different affordances create opportunities to enact or block affective flows. Obligatory hope circles into the flow when there is an advance in biomedicine - a new drug, genome editing (Ousterout et al., 2015). Client/son/teen-with-DMD might not die tragically, because new interventions might become available.

Within the biomedical cure-hope assemblage there is little space for living well in the present or alternative notions of what comprises a good life/time (Gibson et al., 2009). Becoming-michael's refusals (of employments programs, of the wheelchair) reject the logics of futurity, preservation, and prevention that pervade clinic practices. Safety protocols and employment programs disavow creative possibilities for life in the present, of new ways of being and doing. Biomedicine produces declining-body through quantitative measures, protocols for maintaining the numbers - fixing the body, elevating mood through drugs. Through rehabilitation processes, declining-body

is client-with-DMD, the putty for a normalization project, the making of a life that approximates normal function and independence. Within these configurations, becoming-michael-chair-anime-home-pleasure, to return to our first experiment, is differentially enacted to deterritorialize dying-client. Multiple assemblages co-exist in the micro-politics of care but that does not mean that no-body suffers.

Becoming-death/life raises a consideration of a posthumanist affirmative ethics. Within the spectre of decline, assemblages are enacted, not always experienced as positive but not always conventionally 'tragic' either. Smith (2012) suggests that the fundamental question of a Deleuzian ethics is not '"What *must* I do?" (which is the question of *morality*) but rather "What *can* I do", what am I *capable* of doing (which is the proper question of ethics *without* morality)' (p. 176). Drawing on this ethics, he suggests a set of questions that might inform person-care in our project: 'Given my degree of power, what are my capabilities and capacities? How can I come into active possession of my power? How can I go to the limit of what I can do?' A 'good' or 'healthy' life in such an ethics is open-ended and available to all. This creative expression of life works towards maximizing capacities in new, multiple, and different modes, plugging into other assemblages, exploring what can be done. In the clinic, care towards death is always staving-off rather than becoming. Abrams and Adkins (2020) in sketching an affirmative understanding of tragedy suggest that treating decline and disability as an intrusion on life rather than life itself cannot embrace life. Given these notions, how then can person-care reorient to affirming life, desire, power?

If health/life is a process rather than outcome, maximizing capabilities invites differential modes of becoming for M/michael. The context of DMD and its relations, where life expectancies are

shortened and highly uncertain, affords a line of flight from dominant social and medical life/time temporalities, for becoming-healthy otherwise. M/michael's refusals coalesce opportunities to become-healthy in ways that are not limited to medical goals: maximizing potentials to connect with others (humans and things), live well in the present, becoming normal differently, actualizing the virtual. Becoming-healthy for M/michael may, for example, include being supported to explore the joys and possibilities of plugging into an anime community, enacting a here-and-now life that departs from the biomedical rendering of the 'deteriorating' body-at-risk. The clinical care encounter could work more deliberately to help coordinate actions and build communities to enable such pursuits. Such efforts include, but do not always or necessarily prioritize, maximizing physiological functions or promoting employment/productivity goals along normalized life/time trajectories.

Decentred person-care

Our posthuman experimentations suggest some openings for reimagining persons, care, and thus person-centred care or, as we have suggested, 'person-care'. De-centring signals that person-care is an act of worlding that is always already mediated and re/produced. Becoming makes care and makes persons through a care-full ethics of openness that approaches care as an in-the-moment recognition of productive potentials for doing differently. When care is approached only as a means-to-an-end it continually re/creates the biomedical client-as-lack – a body-object in need of care. In so doing, the binary of patient/carer, the separation of humans and 'context', and the individuation of persons who need to be centred are reasserted. Instead, de-centred person-care is care that explores possibilities: What can this assemblage create or produce that is care-full? That affirms becoming-life? The point is not to ignore the interpersonal, but to highlight that in assemblages of becoming, new ways of being are created that resist reinforcing inequities and

anxieties. The emphasis, then, is placed not on 'what can you do for me?' but rather 'what we can create together?' (Fritsch, 2010). How can one act/ think/ feel to affirm life, desire, power? To activate powers of production towards making a life, asking what capabilities and capacities are available, what powers can be mobilized? How can life go to the limits of what it can do?

Elsewhere we have described creative and open clinical processes using the terminology of tinkering (Gibson et al., 2020). Tinkering is emplaced doing, asking: What is going on here? How can the tools at hand be mobilized to make life better? Toro and Martiny (2020) refer to reciprocal "we-interactions' between professionals, patients, and families as facilitating PCC. We agree but suggest that the 'we' extends beyond the humans in the room and acknowledge all of the material-semiotic forces that conspire to produce person-care. Decentred person-care mobilizes forces of production, imagines new assemblages, new doings, and tinkers with the im/possible. Everything is available from office chairs to death in making life. What affirmative machines can be made?

Becoming-michael's refusals could have catalyzed re-fusing, that is a reordering of the territorialized imperatives of safety and normalization that pervade clinical practices. Something amiss with michael could instigate change, new person-care becomings. How to pivot from becoming-anime affective pleasures to creatively actualize the virtual yet-to-be michaels? What else can be done to enable becoming-michael that cares for and about Michael-client, and about Jee-parent? Refusal is not an end point or something that needs to be 'dealt with' (through 'patient education', cajoling, reasoning) it provides a time-place to stop, swivel, plug in differently. Could the professionals set aside concerns for joint alignment or safety and work with the creativity of body-chair? What capacities coalesce with body-chair; how else could it plug in?

Decentred person-care experiments with thinking-as-usual towards re-envisioning differences as potentials rather than deficits. What is blocking desire and how might it be rearranged? What 'ontological styles' can be created that exceed the boundaries of body, chair, and subject? This is not easy or necessarily 'better' but is an available alternative for affirming life. Such approaches bring other forces into the mix, they recognize the driving affects that produce client-with-DMD, recognize what subject positions work to achieve, look for other possibilities to help parent-child affirm life.

The analysis of person-care is not utopian but grounded in reimagining ossified modes of practice in contemporary healthcare environments. Theorizing difference though experimentation works to disrupt the entrenched and remake the world, resisting territorializations of care, and opening new ways of re/forming PCC and health care practices. New understandings of emergent care processes are brought in conversation with existing ways of doing and knowing to generate something new. These analyzable events and assemblages transform the unimaginable into the doable (Ness, 2011) and new ground is gained in making livable worlds.

Coda

Our task was one of problem-producing rather than problem-solving. The latter tends to close off creative modes of thinking. In conceptualising PCC differently, in making new problems that did not previously exist, we worked to expand and transform the limitations of dominant methodologies and epistemological commitments. As a clinician-researcher assemblage, we reflexively sought to discover how our positions, experiences, and commitments informed our analyses and challenged ourselves to sit with discomfort and uncertainty in experimenting with PCC. In these efforts, there are inevitable gaps and interpretations that led us to map assemblages

in ways that are always and necessarily partial. An assemblage can have an entry point but never an exit. Indeed, in this particular 'case', questions may be raised about all kinds of 'missing' facts and forces, for example related to other social positions and political realities that enact the subject positions of michael and others. We attend to these ideas with a deep humility, knowing that we saw and attended to some forces and not others, and in this risk contributing to various harms that may not be easily identified or named. These particularities highlight how cases are always partial, and that the sort of analysis we had embarked on opens as many questions and possibilities as it attempts to produce. To this end we welcome further debate and discussion.

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