

RESEARCH

Performing Normal But Becoming Crip: Living with Chronic Pain

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This article explores the tensions of crip time when it comes to the ways in which chronically pained people (or: people living with chronic pain) move in/through time in both normative and non-normative ways. In exploring how chronic pain develops slowly, and is often accompanied by disbelief and silencing, the paper considers whether crip time can include liminal spaces of becoming chronically pained, including medicalised spaces/times of testing and diagnosis. The paper then considers how pacing, which can be both a rehabilitative normalizing practice and a practice of self-care, is a part of moving through time in ways which can be read as both normative and non-normative. The paper concludes that there are multiple ways of moving through crip time, and multiple ways of living crip lives—which include liminal spaces, and spaces with conflicting understandings.

Keywords: crip time; chronic pain; pain; crip theory; fatigue

Introduction

Time is important to how we define much of disability. Crip time is a developing understanding of how disabled bodyminds are orientated in and move in/through time, and also how ableist expectations of 'normal' orientations and timespans are part of the construction of disability. Within the paper, I explore two aspects of crip time—disbelief/uncertainty and pacing—which are tangled together, each leading to and from the other. The drive to engage in and perform pacing relies on disbelief/uncertainty; this paper will look at how pacing, practiced by chronically pained and fatigued people, is both a normative and non-normative way of moving through time, and can be read as both a practice of normalisation-rehabilitation, and a practice of crip self-care.

Disabled bodyminds¹ are those who fail to perform heteronormative, flexible, independent, proper bodyliness, at the right time and in the right amount of time. Disabled bodyminds are too slow, too fast, too uncontrolled, too reliant, too different, too much and also not enough. In defining disabled bodyminds as such, I am not considering specific diagnostic categories but the broad construct of disability, as both lived experience and identity—created through ableism.² To be disabled, a person does not have to fail at performing *all* of these, but instead fail to measure up to the ideal of the 'normal' in ways which intersect with their other social markers as racialised, gendered, sexualised, aged, and classed bodyminds.

Crip time, as an aspect of crip theory, has been theorised in a number of ways. Borrowing from queer time, crip time has been defined as a refusal of the future (after Edelman 2004), and time outside of productivity (after Halberstam 2005). Kafer describes crip time as extra time, and as departure from straight time, 'whether straight time means a firm delineation between past/present/future or an expectation of linear development from dependent childhood to independent reproductive adulthood' (Kafer 2013: 34). This departure from straight time leaves a great deal of wiggle

¹ I take the term *bodymind* from Price (2015), as an active rejection of body and mind dualism, and an acknowledgement that disability—and sense of selfhood—is frequently neither located in, nor experienced as, just physical or mental. Chronic pain, for example, can be increased by stress—and periods of high pain can increase experiences of cognitive dysfunction ("brain fog") or feelings of depression, which increase stress.

² I suggest here that ableist constructions of pain as non-normative (see Sheppard 2014, 2018b) impact the lived experience of pain to such a degree that, should pain be accepted as normative, our experience of pain would be utterly different from what it is now, to the point where it could perhaps be unrecognisable to us *as pain*. In effect, the sociocultural discursive construct of 'pain' and of 'body' has a deep impact on how we know/understand our bodyminds, and what we recognise as 'body' sensation.

room (for want of a better phrase). Straight time, whether linear or developmentally conceived of, is a very narrow way of being in/through time—there is a very limited number of ‘right’ (‘normal’) ways, and all the rest can be embraced as crip time. Thus, crip time can seem really quite expansive; almost too expansive, too vague. As ‘[time] is not constituted by consciousness, nor is it a feature of the objective world, but it is an aspect of embodied subjectivity’ (St. Pierre 2015: 53), there are as many forms of crip time as there are crip bodyminds, crip ways of being in the world and being in/through time. Crip time, therefore, is defined for this paper as a failure to be on time and in straight-able time, albeit in a myriad of possible ways; rather than being defined by what it *is*, crip time is defined by being in opposition to straight-able time. In doing so, I take cues from gender studies and queer theory; just as masculinity is defined by being opposite to femininity, heterosexuality as opposite to homosexuality, crip time is defined by what it *is not*; crip time is time that is *not* straight-able time, a way of moving in/through time that has failed to be/do straight-able time. Crip time can be some, or all of: a refusal to embrace a (non-disabled) future; a failure to *have* a future; a failure to move from past to present to future in a straight line or at the required pace; a failure to progress from dependence to normatively-defined independence; a failure to progress through some, or all, developmental stages, at the right pace or in the right order; and/or a failure to ‘do’ gender, sexuality, race, class, age in temporally-dependent ways. This messy, expansive, vague-but-specific, tension-riddled and contestatory time is therefore ripe for exploration and questioning.

The contestatory nature of crip—of being crip, of living in crip ways—destabilises normative notions of time, and includes ways of being in and moving through time which are distinctly (and sometimes deliberately) crip, but also leaves space for ways of being in/moving through time which are less than distinctly crip and include more normative-seeming ways of being/moving. It is this tension which the paper will explore, asking if crip can include choosing or trying to be in/move through time in ways which can be read as normative, and if normative ways can be made crip, or read as crip on closer reading.

It is important to note that not all the participants explicitly identified as crip. All identified as disabled people and saw a political facet to their identification as disabled. We did not explicitly discuss ‘crip time’ as a concept or experience, but we discussed time, pacing, and living with chronic pain and fatigue. Crip time, here, is therefore a critical, theoretical term, albeit one that has been long used by disabled and crip people (particularly in the US and Canada) to describe ways of being in/through time (Kafer 2013). In describing and theorising crip time, I seek ways of understanding non-normative ways of being in/through time.

Methods

To explore pacing, this paper will explore discussions of living with chronic pain and fatigue, carried out as part of a completed research project (Sheppard 2018a), which explored participants’ embodied experiences of chronic pain. Over the course of the project, a set of three interviews were held with five people (Natalie, Catherine, Julie, Charlie, and David) who lived with chronic pain, making 15 interviews in total, and three single interviews were held with three people (Rita, Edward, and Michelle) who lived with chronic pain, and could no longer for various reasons participate with further interviews. All of the participants were British, living in England, and seven of the eight were white. They are represented here by pseudonyms. Of the eight, there were four cisgender women (Natalie, Julie, Rita, and Catherine, although she also identified as gender-questioning), two cisgender men (David and Edward), and two genderfluid people (Charlie and Michelle).

Chronic pain, for the purposes of the project (and thus this paper), was defined as pain experienced for at least 12 weeks, either continuously or intermittently, with or without known cause, and for which the pained person has no expectation of the pain ceasing. This definition uses the IASP definition of chronic pain (Merskey and Bogduk 1994) which, while rooted in medicine, is nonetheless useful as a starting point. We can understand chronic pain as part of the broad umbrella of disability; people may experience chronic pain as a part or effect of their disability, or they may have chronic pain as their disability or impairment. Chronic pain often occurs as part of chronic illness, which can be ‘understood to be illnesses that do not go away by themselves within six months, that cannot reliably be cured, and that will not kill the patient any time soon’ (Wendell 1996, 20). This second definition works well alongside the first, medicalised definition, to give a broad understanding of chronic pain as long-term, possibly permanent, and poorly understood; chronic pain is a departure from the expected/ideal norm in that it is pain that does not stop, and cannot be ‘cured’ (Author 2018b). For the research participants, six of the eight participants had multiple causes or diagnoses for their chronic pain, with only Natalie and Edward having a singular diagnosis. Between the eight participants, they had fifteen (confirmed or possible) diagnoses relating to chronic pain. Charlie, David, Michelle, Catherine, and Rita had other disabilities which did not include chronic pain, including neuroatypicality, mental illness, and physical disability.

The semi-structured interviews were carried out face-to-face, over Skype, and over email, ways which accounted for participants’ (and my own) energy, fatigue, and geographic location. The sets of three interviews took place over roughly a year, with all the interviews taking place over the same eighteen-month period. This slow process gave time and space for narratives to be explored carefully and reflected on in the next interview.³ Interviews were analysed using a critical narrative analytic approach, identifying common points and themes. Tensions exposed during the project included the

³ It also allowed for periods of illness, and other commitments—from participants’ work to my teaching—to take place alongside fieldwork.

pressures of performing as 'normal'—as able-bodied individuals without pain or fatigue—but also the desire to be as close to 'normal' as possible, to be in/move through time in normative ways. These experiences are in tension with a desire to live happily as disabled, a desire to find a measure of self-confidence, given that the participants are perfectly cognisant that they are unlikely to become non-disabled in their near future.

Crip Time as Disbelief

The participants' experience of crip time included the understanding of crip time as extra time (Kafer 2013), but also presented an additional aspect of crip time: a time of uncertainty, disbelief, and changeability. Crip time, rather than being a time exclusive to disability, can be expanded to include prolonged times of illness, of bodyminds failing to fulfil normative expectations. This is not about the time you got a cold, or the days lost to food poisoning (although it could well be; there is a peculiar liminality to being unwell), but the longer period of illness, embracing diagnosis, prognosis, and progression of an illness. Time plays a key role in these periods of illness, especially within medical spheres; time is a key part of the discourse of disease and medicine, in the clinical gaze and in the progression of disease and recovery/rehabilitation (Foucault 1973). Time is implicit in the meanings of 'chronic' or 'acute', 'acquired' or 'congenital', 'in remission', and 'relapsed', as well as the very notion of prognosis and treatment itself. It is impossible to consider chronic pain without acknowledging—whether critically, or accepting at face value—the role of medicine in the daily lives of chronically-pained people, from daily medication to the struggles of non-recognition. That non-recognition was the first experience participants all shared, and the liminal time of *becoming* chronically-pained is a distinctly uncertain time. I am starting with this first point of shared experience—of not being recognised as in pain, or their pain not being acknowledged as *real*—because it underlies their ongoing experiences of living with chronic pain. The expectation of disbelief, of non-recognition and invalidation (which I will get to shortly) underpins and leads to new ways of moving in/through time, which are covered in more detail in the second part of the paper.

Becoming chronically-pained does not happen in an instant. A new pain must first be an acute pain before it becomes chronic; participants did not report waking one day knowing they were chronically-pained. It is a slow process, taking months and even years for pain to be recognised as chronic pain, both by the pained person and by others. For David and Charlie, who experienced pain caused by injury, and Rita, who experienced pain from childhood surgery, aspects of their pain had a known cause, and a known beginning; but for all of them, their pain, and their lives with pain, had changed significantly since that point, as their bodyminds aged and grew. For Charlie and Rita, that pain-with-cause was joined by pain-without-cause—pain they experienced but had no diagnosis for, and those diagnoses suggested (and dismissed) by medics fell under the broad umbrella of diagnoses not fully understood or explained by modern Western medicine.⁴ For five of the eight participants, their experiences of what Mollow (2014) terms 'undocumented disabilities' went hand-in-glove with their chronic pain. Their pain is one of the many 'impairments that are 'invisible' (i.e. unapparent to the casual observer) and not definitively measurable by mainstream Western medical technologies' (ibid 2014, 185).

Acquiring an undocumented disability is not a matter of clicking one's fingers. For all the lack of definitive measurement, there is nonetheless a great deal of testing, of going back and forth between specialists in search of an explanation, as many undocumented disabilities are diagnoses of exclusion, of testing to eliminate possible alternatives or stumble upon a possible cure. There is uncertainty; is this a passing illness, is this the result of some action or inaction, is this something others can see in me? For Charlie, who was in the process of being diagnosed with 'sort of a pain syndrome, kind of a chronic fatigue syndrome ... kind of just a bit nebulous really' (Charlie, interview 1), this lack of certainty about the *what* and *why* of their chronic pain did not mean that they were not in pain. It meant that their pain—and thus their disability—was immediately uncertain, and open to question as to whether or not it was 'real'. As others writing about living with chronic pain and chronic illness, this time of uncertainty can last for years, if not indefinitely (Wendell 1996; Haagaard 2017).

It is this uncertain time, this time to move from definitively-not-disabled to disabled-maybe-possibly-yes, which hovers on the edge of crip time. It is an in-between time, a time of uncertainty; a time of the 'eternally changing borderlands' (Erevelles 2014) of disability, where participants were neither disabled or non-disabled, neither sick nor well, or where their disabled selves contended with the possibility of a change to how they experienced the world. In this crip time, which is far too long to be called a moment, all of the participants with undocumented disabilities spoke of what Wendell (1996) called 'epistemic invalidation'; the experience of having their lived realities disbelieved, by medics, by colleagues, by friends and family and total strangers. Against this, chronically-pained people must undertake a reimagining of the self; and as 'having or being a self ... is a social accomplishment' (Young 1997: 81), this reimagining is dependent on how others see us and how we interact with our social worlds. Participants found their selfhood was (and continued to be) questioned on all sides and from within. Others' doubt and disbelief of their lived realities was doubt and disbelief of their selfhood. And so crip time becomes a time of uncertainty, disbelief, and loss.

The development, or perhaps acquisition, of chronic pain, like the acquisition of other disabilities and chronic illness, is socially positioned as a loss, particularly by non-disabled people. This assumption of loss is at first read as the result of

⁴ Examples include fibromyalgia and chronic fatigue/ME—chronic illnesses for which there is a name, and a loose collection of symptoms, but no cause and no cure.

disability being viewed as 'less than'; but as Kafer (2013) and others have pointed out, stems from the loss of an imagined non-disabled future. However, in exploring Natalie's experience, it is possible to see another interpretation, that the change in capacities is experienced as a stepping back in time, a regression to a state of greater dependence, especially in the eyes of those she turned to for care. This is a regression which is only experienced as a loss because, as Rice et al. (2017: 216) explain, 'the normative life span reflects and reinforces a hopeful story of western culture itself, one premised on belief in human progress and perfectibility'. The change in capacities is not regarded as an improvement, as a sign of that individual's progress, and thus it is read as a *loss of capacity*, or a loss of ability, and something to be mourned. In this way, the newly-disabled, or newly-differently-disabled person ceases to be normatively orientated in time, and begins moving in crip time. The loss of capacity in one aspect of life is assumed to be a total loss of capacity; due to assumption of what Wendell calls 'global disability' (2001), the non-disabled assume a disabled person is multiply disabled, that their physical impairment reflects cognitive impairment, or that their cognitive impairment is accompanied by a loss of hearing and ability to voice their own needs. For those adjusting to their changed capacities, and dealing with the uncertainty and invalidation, this time of uncertainty fuels a desire to pass as normal. We will return to this point.

The change in capacities that comes with chronic pain and illness led to a period of what Julie described as mourning, writing in her email interview:

'Over the last few months I've lost a lot of confidence in my body as it has failed. ... I can't be the big and fun me any more, it's got lost in the pain for the time being. Having to hold onto to the hope I'll get "me" back. ... Loss of control is a big part of disability when it is a progressive condition like mine. I've slowly had to give up things that I thought were important or vital to life' (Julie, interview 2, by email).

In her mourning, she mourned not just the loss of her previous capacities, but also the loss of the imagined futures her previous capacities could have been part of. Kafer (2013) explains that the imagined future – towards which we progress – is an able one; but it is significant to note that Julie was not contemplating a disabled future as a previously non-disabled person, but as a disabled person whose bodymind was experiencing a change in her capacities. Her previously imagined futures were those of a disabled woman, imagining a disabled future – and it is this particular vision of her disabled future she mourned. For her, and for other participants experiencing a change in capacities, the assumption that the past was non-disabled—and thus pleasurable (Patsavas 2017)—while the present and future were disabled and painful no longer stands, and thus complicates their movement through crip time. Not only are they non-normatively orientated in time, but their movement through non-normative crip time is re-orientated once again.

This is not to say that experiencing a change in capacities where they are no longer able to do something they once could is not experienced as a very real loss; it brings with it feelings of sadness, anger, and frustration. It is not to say that it should *not* be experienced as such. That experience, rooted in others' disbelief and invalidation of lived experience, and the feelings of sadness, anger, and frustration, are real and valid. But the experience and assumption of loss—and where newly-acquired limitations sting most—was tied to a pressure to perform as normal, or as close to normal as possible; to forcibly re-orient themselves in normative (or normatively non-normative) ways, and to deny the loss. Accepting the loss, and accepting the change in capacities, is assumed to be impossible, not just because it means accepting something that should be (and is) saddening and frustrating, but because it means rejecting the normative standard of ability. Rejecting the normative standard opens the chronically pained up to forces of ableism and abjection—the abjection from others which is 'contingent on [their] expressions of normativity' (Tyler 2013: 37)—their performative abjection of the disabled to reinforce their own normativity, as well as their fear of disability happening to them (Kumari Campbell 2009).

As participants became accustomed to being chronically pained, they did not cease to be orientated in crip time, but their relationship to and experience of crip time changed. Chronic pain becomes a part of their everyday phenomenological experience, a part of their bodymind and their movement through the world (Sheppard 2018a). Their crip time included ways of living with pain, perhaps deliberately chosen, perhaps established by chance. Like many chronically pained people, the participants also experienced fatigue from their pain—and some experienced fatigue as a part of their disability or illness as well—and for all, ways of living with pain were also about ways of managing pain and fatigue. Chronic pain became something they all sought to minimise at times (some more often than others); pain can be overwhelming, no matter how familiar it is. There were also times when they sought to engage with their pain, even to embrace it. The next section will address how pain management practices shape and are part of crip time.

Crip time as Pacing Time

Pain management was, for all of the participants, primarily about minimising pain (and fatigue). For participants who had been non-disabled, minimising pain was about the previously-mentioned change in capacities, and the ableist pressure to regain lost capacities, as well as the pressure to present as normally as possible. They push to move as though they were normatively orientated in time, without pain or fatigue, and those incapable of doing so are pressured to present as though they desire nothing more than to be non-disabled. Disbelief and invalidation (as discussed in the previous section), combined with experience of loss, leads to self-doubt. Chronically ill people begin to doubt their own

experience, feeling that perhaps they *are* imagining it (Wendell 1996), and this adds further to the pressure to present as normal, and to regain lost capacities. This pressure comes from non-disabled people, from their disbelief, and from their wish for reassurance that disability is not unbearably awful (as they assume any non-normative experience must be awful). As Kumari-Campbell (2009) explains it, the non-disabled are shying away from the ontological impossibility of their own possible disablement. Or, as Charlie put it:

'People don't like to think of you in pain and not be able to do anything about it. People don't like to think about the concept of pain in case they might experience pain. You know, it can be very... people that care about you might want to do something about it, people that are a bit more self-centred might be, like, "Oh gosh, I can't deal with this person in pain, it just makes me think about pain, I don't want to think about pain,"' (Charlie, interview 2).

Expressing a desire to be normatively orientated in time, or expressing a desire to be in less pain, or have more energy, can be understood as a desire to not be disabled, but can also be understood as a response to pain and fatigue when faced with overwhelming ableist social structures and normative expectations of time. For participants whose pain was not consistently recognised by others—who had to remind others of their pain, or had their experiences dismissed or disbelieved—the pressures of normative time demands and the pressure to present as desiring normativity combined with the pressures of that epistemic invalidation; to be non-normatively orientated is to open oneself up to violent disbelief again and again, and thus they desire to move out of the time of disbelief. Passing—deliberately or through silence and 'trickster strategies' (Price et al. 2017) which simulate a normative orientation in time—is sometimes just *easier*, as Julie explains. Having her pain go unseen means she avoids the emotional toll of disbelief, even as it opens her up to other forms of hurt:

'People don't see my chronic pain. I avoid admitting the levels it is at. For fear of some level of bad response. Because the "aww, I'm sorry" frustrates me, the "you must be weak" hurts me, and the "stop complaining" breaks me. So I don't accept it at some level, I certainly don't project it outwards unless I have to. So nobody validates that chronic pain. Out of my own choice and so they just see me and don't ask questions.' (Julie, by email between interviews 1 and 2).

Pacing is one of the strategies some participants engaged in, in order to re-orientate themselves normatively, to pass as normal. Very simply, pacing is the activity of scheduling a daily life, particularly rest and low-activity periods, to either reduce the likelihood of a period of high pain or fatigue from occurring, or to enable them to do other higher-energy tasks and, significantly, to conceal the impact of those high-energy tasks as much as possible. Pacing may be forced upon the bodymind by pain or fatigue as well; it can be the time and inactivity needed to rest and recover. Pacing is a self-management technique taught as a part of rehabilitation for chronic pain and fatigue, but it can also be a self-management technique discovered by individuals as a way to mitigate the impact of fluctuating capacities on everyday lives. Pacing can be an ableist rejection of chronic pain and fatigue, but also a crip embracing of living with chronic pain and fatigue. Pacing can thus be considered a trickster strategy, a way of passing as non-disabled while simultaneously embracing a disabled life, but it can also be a site of conflict, of internalised ableism simultaneously. As a way of moving in/through time, pacing is both normative and non-normative, read in opposing ways at once.

As a promise of rehabilitation, pacing is enticing, especially when framed as a cure, or at least a solution to one aspect of chronic illness. In the UK (where the participants were from), pacing forms a part of chronic pain management programmes, along with mindfulness and cognitive behavioural therapy, although provision for such management programmes through the National Health Service (NHS) varies depending on the geographic area, and some areas have little to no provision at all (British Pain Society and Dr Foster Intelligence 2011). Several of the participants (and, it should be noted, the author as well) had gone through variations on such programmes, which intended to teach management of chronic fatigue and/or pain. In these, pacing is described as a way to unfailingly and reliably minimise pain, and a reliable way for a person to re-gain the capacities they have lost. Pacing is presented as a way of being productive (and regaining lost productivity) within the fast-moving neoliberal workplace, with the emphasis very much on completing 'normal' income-generating activities, or maintaining an idealised level of health (at least during working hours). This promise of a return to normality, and of no longer being disabled with pain and fatigue, presents a seductive picture, especially when positioned in terms of a boom and bust cycle reminiscent of critiques of modern capitalism. It is perhaps ironic that pacing programmes present a critique of capitalism as a way to become a better capitalist worker.

However, as Catherine pointed out, pacing is never enough. There is inevitable failure, as pacing cannot prevent pain entirely, only give a framework to organise rest and action as pain-avoiding or pain-minimising. Added to that, pacing itself can be frustrating:

'I'm relatively good at pacing, practically speaking. Emotionally it kills me - especially while I've got a lot to do, like right now. If I have a list of tasks and have to go to bed, I get REALLY angry with myself. Like "what are you even for?" angry.' (Catherine, interview 2).

The demands of keeping up with an ever-increasing pace of life and ever-increasing expectations of production can never be conclusively met, as neoliberalism keeps bodies as always debilitated in order to sustain profit and markets (Mitchell and Snyder 2015; Shildrick 2015). There is always room for improvement, to do more, to do better. In addition, rehabilitative pacing does not present a way of resisting neoliberal productivity discourses—particularly those around flexibility (McRuer 2006) and around pace of life (Crary 2013)—but instead lays open the chronically fatigued and pained person to internalised self-shaming and loathing due to their inability to be enough. Pacing will inevitably fail, and they will inevitably be insufficiently productive. For Catherine, there is always another deadline, another project, another task, and she finds pushing herself to rest and disengage as frustrating as times when she is too tired to work; and thus pacing itself becomes an ableist expectation, a restrictive normative orientation in time, rather than a trickster strategy. The line between the two is not clear, and not impermeable; sometimes pacing is one, sometimes the other. Sometimes, it is easier to fit in than stand out. Sometimes, we are in too much pain and are too fatigued to fit in.

Normative discourses of pain place the blame for pain squarely on the shoulders of those in pain (Author 2014, 2018a; Patsavas 2014); but when pacing and other rehabilitation practices fail, the blame is placed *not* on rehabilitation (or the ableist desire to cure disability and illness at all costs) but on the chronically pained and chronically fatigued person (Price 2015). This responsibility for pain, and the inevitability of pacing as inadequate, makes it easier for us to claim the failure of pacing as crip failure (Mitchell, Snyder, and Ware 2014). At the same time, in the practice of pacing itself there is a queerness, a cripness, to ‘waiting rather than consuming... [which] produces an alternative landscape of queer time’ (Vaccaro 2010, 261). This is at odds with the normative ethos of delayed gratification (Jain 2013), which makes pacing much more than the trickster strategy and unknown normative orientation in time, and much more than an inevitable (albeit cripily inevitable – or inevitably crip) failure.

The inevitable failure of pacing did not mean that participants ceased to practice it. Instead, despite its inevitable failure, its frustrations, and its role in rehabilitation, pacing was embraced by some participants as a part of queer-crip subversion of normalisation, producing a flexible normalisation (Stephenson and Papadopoulos 2006; Bauer 2014), where they could pass as normatively orientated in time if they had to, or if nobody looked too closely. This is one of those trickster strategies where it is difficult if not impossible to tell where normativity ends and crip begins, what is normal and what is abnormal. There could be joy and pleasure in pacing, and in deliberately engaging with their bodyminds.

For some participants, such as Natalie and Catherine, pacing could be used to justify missing events, which was read frequently by others as a selfish act, but which for those participants was instead a source of pleasure, a rejection of the norms and pressures of social engagement which they disliked (while still allowing them to be social when they wished to, if not always consistently). For Julie, pacing allowed her energy and time to engage in more gratifying activities, ones which would have been impossible without pacing and conserving her energy. As she expressed it:

‘I appreciate the world more for my disability, in some odd ways. I can enjoy life more with the limitations, rather than feeling I have to do everything and anything because I can. Having to slow life down makes me appreciate the little things all the more. ... I don’t think I would have considered all my options and found what I enjoy the most if I hadn’t had the time to just be and think.’ (Julie, interview 2, by email).

For Julie, and for other participants, there could also be a pleasure in choosing to engage in actions they knew would cause an increase in their pain or fatigue, sometimes in ways which deliberately induced yet more pain. There is an expression of agency in ‘living in a way that defies normative ideologies about health’ (Hickey-Moody 2015: 142), and for Charlie this was as much about endurance, and pushing beyond what they felt the boundaries of pain and fatigue were, as well as maintaining a level of activity:

‘If I just went into my fatigue, I wouldn’t get off the sofa ever, or something. You know? But you have to then figure out what are the times when you can try and work with... you know, continue through it, or when you do just have to sit with it ... Because you could just sit with it all the time and do nothing, but there’s also the danger of going the other way and trying to push through it when you’re not going to be able to get through it. It’s just going to make it worse. So it’s about staying active in a way that is sustainable, or is safe, that is not going to have the same... But you can’t always predict it’ (Charlie, interview 2).

As I have discussed elsewhere, this endurance is about demonstrating control of self (Author 2018b), but also about the acknowledgement that the rest is unreliable, and that activity is always painful or tiring albeit in unpredictable ways.

This control also forms a part of deliberate strategies to orientate themselves in time; crip time thus becomes about an active engagement in moving with and through time in ways which are not normative, but also carefully chosen. As Julie explained ‘I can choose to work from home giving myself that much more energy that by ... Friday evening, I could have a night at the club’ (Julie interview one). Although this option is not open to all, and Julie was well aware of her relative privilege in being able to work from home on occasion, she took a great deal of pleasure in controlling her movement through time, and thus her pace of life. This pleasure in control, in choosing how and sometimes even

when to increase pain and fatigue, took on a distinctly crip outlook, in both an awareness of a lack of improvement or cure in the future, and a subsequent embrace of a disabled future, whether this was a newly disabled future or a new change in disability.

Embracing a disabled future is somewhat different from the pressure participants experienced to have a happy disabled identity—to be outwardly content, even cheerful in being a disabled person. This pressure is of course a distinctly ableist notion; participants experienced pressure to reassure friends and family that they were happy, that their pain and fatigue were not overwhelmingly awful. However, there was also a sense of not quite fitting, of being misfit amongst the misfits (Garland-Thomson 2011); other disabled people also sought this reassurance as un-pained people, resisting hearing expressions of pain or fatigue. This lack of willingness to hear about pain (sometimes misread as the impossibility of communicating pain (Author 2018b; Price 2015; Patsavas 2014)) contributes to the previously-mentioned sense of epistemic invalidation, but also to the pressure to pass, to contain and control pain. The ableist routes of this pressure stem from the desire, or possibly need for reassurance—reassurance for non-disabled people that disability will not happen to them, but those who it does happen to are nonetheless happy, in the same way that people of colour are pressured into silence about racism, and women are encouraged to express joy in filling traditional gender roles. This same root gives the pressure to pass as normal, not to be subjects to the pity and infantilization that comes with being obviously and physically disabled. It is this pressure which presents pain management as normalisation, rather than crip. It also comes out of the normative pace of life demands, the pressure to be seen as able to keep up with non-disabled people, if not to perform better than non-disabled people, rejecting narratives of victimisation and weakness.

Natalie spoke of the pressure to manage her pain and fatigue, and to be normal, going hand-in-hand within infantilization. As previously mentioned, her loss of capacity and ongoing lack of energy, combined with her need for day-to-day care, meant she sometimes felt as though she was treated like a child, regressing from her relative adulthood and independence, especially as her disability became more 'severe.' Others experienced that same infantilization from friends, and particularly from those they relied on for care; their non-normative orientation in time was read as asynchronous, never fully mature (Andree 2018). This invalidation and assumption of foreshortened maturity—of going backwards in time—could also come from disabled people, those not experiencing chronic fatigue or pain.

Resisting this pressure to perform pacing exclusively for normalising reasons, as rehabilitation practice, was where embracing a disabled future came in. This does not necessarily require *joy* for participants to see themselves as worthy of their own regard, as well as the regard of others, for them to listen to their own pain; however it does require self-acceptance. Crip pacing thus becomes a form of politicised self-care (Ahmed 2014; Lorde 1988), an act of resistance against ableist social structures. It becomes about accepting engaging with the bodymind, with the self, as a part of self-regard, and even about taking pleasure in engaging with the bodymind. To return to Julie and Natalie's experience of pleasure in the apparently selfish act of saying 'no' to activities, they paced, and they enjoyed doing so, and in doing so they considered themselves worthy of care.

Care can look very different to different people; self-care is complicated when care requires assistances from others; but access to appropriate assistance (when wanted) is needed for crip self-care to be possible. Crip self-care can even look like self-*harm* at first glance, especially when it involves pushing beyond limits and deliberately causing pain. Examples from participants include Natalie undertaking a car journey she knew would be painful, or Julie seeking power-play to go with her erotic pleasure. For others, assistance here meant causing pain, but also accepting the chronically pained person's self-knowledge and expertise in saying that this pain was welcome, or the pleasures of the activity were worth the pain they knew would result.

We can perhaps then consider crip pacing not as self-management, but as the time needed to engage with the bodymind in meaningful ways, with or without interacting with other bodyminds. Crip time, crip pacing is an active statement of self-worth, rather than an attempt at rehabilitation.

Conclusion

Throughout the project, tensions came to light which could only be fully appreciated through a crip theory approach. Acknowledging the complexities and multiplicities and shared commonalities of chronically pained people's lived experiences allowed for those tensions to be explored. Exploring those tensions is a necessary part of finding ways to 'sustain a politics of mutuality while attending to differences that cannot be easily subsumed' (Mitchell and Snyder 2015: 134).

Crip time is not straight time. It is messy and untidy and moves in unexpected ways, just as crip bodyminds can be messy and untidy and move in unexpected ways. Crip time includes—must include—time to be unsure, ambivalent about disability, and time to mourn future possibilities that can no longer be. We need the time to be sad, to be frustrated, even as we acknowledge that the reason for our sadness and frustration is ableist structures, norms, and expectations about how our bodyminds work and move through places and times.

This time for sadness and frustration—and every other possible negative emotion—is not a rejection of disability. It is an acknowledgement of the complexities of crip lives. Pacing might at first be about normative ways of moving through time, but the inevitable failure to continue doing so, and the inevitable pain and fatigue resulting from that failure,

can be incorporated into crip ways of moving through time, into messy lived realities and unreliable ways of moving with and through time. Crip time must include times of crip self-care, even if those times might not look like care at first glance.

Ethics and Consent

Ethical approval for the project was granted by Edge Hill University Ethics Board, April 2014. All participants here are represented by pseudonyms, and all efforts have been made to ensure their anonymity; all details regarding participants' identities have been approved by them prior to the project completion.

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Competing Interests

The author has no competing interests to declare.

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