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EMPIRICAL STUDY/ANALYSIS

Living with Death in Rehabilitation: A Phenomenological Account

Thomas Abrams[1] · **Jenny Setchell**[2,3]

Abstract

This paper uses an ongoing ethnography of childhood rehabilitation to rethink the Heideggerian phenomenology of death. We argue that Heidegger's threefold perishing/death/dying framework offers a fruitful way to chart how young people, their parents, and practitioners address mortality in the routine management of muscular dystrophies. Heidegger's almost exclusive focus on being-towards-death as an individualizing existential structure, rather than the social life with and around death, is at odds with the clinical experience we explore in this paper. After looking to the basic structures of Heidegger's philosophy of death, we point to recent work by Leder, Svenaeus, Aho, and Carel, bringing health and the spaces of healthcare into our purview. Turning to ethnographic data, we argue that a revised phenomenology of death gives a nuanced account of how health care practitioners address death, dying, and perishing, and outline some steps toward a more ontologically sensitive clinical space. These revisions are in line with recent work in disability studies, that see disability as more than a death sentence. We advocate adjusting phenomenological reflections on disability, to be framed as a way of life, rather than as a deficient or especially deadly mode of human existence.

Keywords Rehabilitation · Muscular dystrophy · Death · Disability · Phenomenology · Heidegger

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✉ Thomas Abrams
thomas.abrams@queensu.ca

Jenny Setchell
j.setchell@uq.edu.au

[1] Queen's University, Kingston, ON K7L 3N6, Canada

[2] University of Toronto, Toronto, ON M5G 1V7, Canada

[3] University of Queensland, Brisbane, St. Lucia, QLD 4072, Australia

Introduction

There has been a resurgence in literature on death and dying in phenomenological philosophy. *Being and Time* (*Sein und Zeit*) has a new life in the spaces of health care (Heidegger 1996 [1927]; Aho 2016; Carel 2013, 2016). Three questions come to the forefront: how do we face our mortality in illness? How do we let others do the same? What does phenomenology offer to health care practitioners, who routinely experience death and dying? This paper poses these questions to empirical data, through an ongoing clinical ethnography of youth neuromuscular rehabilitation. In the routine management of muscular dystrophies, death, mortality and narratives about them permeate the clinical space. Phenomenological accounts tend to privilege the orientation to one's own death over the death of others, and the human interpretation of life and death over the perishing, mortified body. While neatly isolated *philosophically*, these three strands—death, dying, and perishing—intertwine in the rehabilitation clinic. We look to three stories about death and dying to show how this is the case, exploring how young people and their parents discuss the shortened life span associated with muscular dystrophies, how the clinical team manages the 'psychosocial' aspects of the death of others, and how clinicians manage death behind the scenes of routine practice. While affirming the importance of past work, we suggest a slight change of course. This maneuver is in line with recent work in phenomenological disability studies, challenging the direct 'disability-means-death' conflation.

Heidegger's Question of Being

Heidegger's *Being and Time* is the central text in the phenomenology of death. While the interpretations of that work differ, the basic frameworks of Heidegger's project are similar. This section provides a short introduction to Heidegger's project in that book before addressing his philosophy of mortality and finitude.

Being and Time presents a fundamental ontology of human existence. It is fundamental because Heidegger interrogates the constitutive structures that make meaningful existence possible (temporality and human finitude among them). It is ontological because it asks about the nature of what is. Our existence is not *in* the world in the same way as the water is *in* the glass, or the dress is *in* the cupboard, but is temporal immersion in a world of significance and meaning, where our lives are disclosed. The structures of human being-in-the-world are different from the presence of objects at hand in the world. This, Heidegger calls the ontological difference, the difference between the fundamental structures of Being and the objective presence of mere things. For our meaningful way of being, Heidegger uses "Dasein".[1]

As being-in-the-world, Dasein is *spatial*, *temporal*, and *social*. Dasein's spatiality is disclosed in our meaningful interactions with things: the wine glass is *used for*

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[1] "There-being" is a frequent translation of Dasein. Sheehan (2001: 194) convincingly argues that "having-to-be-open" better reflects Heidegger's intention.

a toast, the dress is *worn for* the wedding ceremony. Dasein is being-in-the-world; the spatiality of that 'in-the-world' is found in our association with things. "Things at hand are encountered in the world. The being of these beings, handiness, is thus ontologically related to the world and to worldliness. World is always already 'there' in all things at hand" (Heidegger 1996: 77). For things to appear as this or that, they appeal to Dasein's openness for meaning before they display their physical properties. The altar, the high school gym: these are the spaces nearest to the objects, how they first appear as useful for the wedding, and for the class reunion, rather than their mere presence as objectively present entities. Things gather meanings in their places. This nearness is based on their practical utility for the task at hand. This meaning-for-tasks Heidegger calls "care," (*Sorge*) or concern. Together, Dasein's openness for meaning is their focal point.

Just as Dasein is spatial, it is temporal. We are constantly running ahead of ourselves, in care for future tasks, and the skillful re-use of previous acts of concern. In *Being and Time*, this temporality underpins the spatiality of Dasein: "Time is not first coupled with space, but the "space" that is supposedly to be coupled with it is encountered only on the basis of temporality taking care of time." (Heidegger 1996: 383)[2] The meaningful nature of being-in-the-world is disclosed against a historical backdrop of a people, with one's family history (or one's history without). This existential temporality, as a shared background, is contrasted with the structures of "clock time". Dasein's temporality is authentic temporality, not because it exists and clock time does not, but because it is closer to its existential grounding allowing us to unfold as we do *in time*.[3] Clock time presents a constant measure of the "continually enduring succession of pure 'nows'," but it does not address care as our temporal way of being-in-the-world (Heidegger 1996: 376).

Finally, Dasein is fundamentally social. We have explored how Dasein's temporality and spatiality are grounded in meaningful relevance, through care. These ways of dwelling are inherited from a shared culture. In the same way that the wedding dress appears *as* a dress for the ceremony, to be passed down through the family, so to do we take on public roles and forms of care. Part of existing in the world is accepting public roles, "as a bride" to maintain the wedding example. To speak about, and engage in discourse about marriage is to participate in a mode of mitsein, being-with.[4] This mode of being 'as anyone else is' Heidegger calls "the they" (often left untranslated as "das Man"). The they, Heidegger maintains, is not a perversion of Dasein, but is rather part of its positive constitution. Part of the being of Dasein is to incorporate other styles of being into itself—but the 'style of being' of public life is one that obscures the ontological structures that make Dasein what

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[2] This wording, at least as translated, is clumsy. Heidegger is arguing that temporality *temporalizes* by continually constituting its past and present in its timely existence. See *Being and Time*, sec. 65.

[3] This interpretation of Heidegger's authenticity, as a "style of being" rather than its content, draws from Guignon (1984). "The distinction between authenticity and inauthenticity seems to hinge not on *what* one is in the sense of specific possibilities one takes up, but rather the *how* one lives." (Guignon 1984: 334).

[4] Again, Sheehan would not agree to such terminology. "Openness to a shared world" is the intended connotation.

it is. It is an obstacle to Dasein's fundamental potentiality for being. "Everyone is the other, and no one is himself" (Heidegger 1996: 120). This fundamentally social nature of Dasein, very often obscuring its own being-in-the-world, is crucial for the Heideggerian phenomenology of death.

Dasein Does not Perish

In *Being and Time*, sec. 49, Heidegger makes a fundamental distinction between the different modalities of death—perishing, death and dying—and the types of analysis which present them: the biological, medical, psychological, and ontological. Heidegger's concern is with the final mode. All living things perish, but only Dasein *dies*.

> Let the term *dying* stand for the way of being in which Da-sein is toward its death. Thus we can say that Da-sein never perishes. Da-sein can only demise as long as it dies. The medical and biological inquiry into demising can attain results which also become significant ontologically if the fundamental orientation is ensured for an existential orientation to death. […] The existential interpretation of death is prior to any biology and ontology of life. (Heidegger 1996: 229)

Perishing relates to what is present in the world, and what is no longer living. It is *ontic*, relating to mere properties of things that exist. Dying, however, relates to the fundamentally temporal way that humans dwell in the world. One never experiences one's death, because it is the collapse of worldly relevance. As such, it is *ontological*, a grounding structure of being-in-the-world.

Heidegger's philosophy of death is *temporal* because Dasein is always a being-toward-death. As in Heidegger's temporality against the measure of clock time, death is not "the end" in terms of an endpoint, at which life ceases.

> The rain stops. It is no longer objectively present. The road stops. […] Finishedness is itself only possible as a determination of something objectively present or at hand. […] *None of these modes of the end are able to characterize death properly as the end of Da-sein.* (Emphasis in original; Heidegger 1996: 227f.)

In being-toward-death, we live toward the collapse of meaningful being-in-the-world. Death is not the final punctuated now, but obliges an orientation to the world.[5] Death is spatial and temporal because it follows a similar constitution as those fundamental structures of Dasein. Dying is not present-at-hand, but ontological. "Being-toward-death is grounded in care" (Heidegger 1996: 239).

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[5] Indifference included as such an orientation, as in the case of publicness, below.

Dying is *social* because its obligatory orientations to the world often recede into everydayness of the one. In publicness, dying becomes something objectively present, that can be managed, ignored, subject to chatter.

> The publicness of being-with-another "knows" death as a constantly occurring event, as a "case of death". Someone or another "dies," be it a neighbor or stranger. People unknown to us "die" daily and hourly. "Death" is encountered as a familiar event occurring within the world. As such, it remains in the inconspicuousness characteristic of everyday encounters. […] *The they does not permit the courage to have* Angst *about death.*" (Italics in original; Heidegger 1996: 235)

Here we return to Heidegger's authenticity, as a mode of being. Death is social because it happens in spaces of mitsein, but it is also always individualizing; we must maintain a mode of attunement to our death—not dying, but death—whether we like it or not. Authenticity or inauthenticity, angst or "untroubled indifference" (Heidegger 1996: 235), mine or theirs—we are obliged to pick a position on death, or have one given to us. But that position must emerge in our worldly *thrown-ness* (*Geworfenheit)*: "Everyday, entangled evasion *of* death is an inauthentic being *toward* it. Inauthenticity has possible authenticity as its basis" (Heidegger 1996: 239).

Heidegger gives us some philosophical tools to explore death. He does not, however, give us any guidance on how we might apply those in the spaces of health care. Aho and Carel will do that in the following section. For now, we should retrace our steps. Dasein reflects our way of being in a world. This is not the Cartesian world of extended substance, but rather immersion in a shared, meaningful existence. Dasein is spatial not because it exists in coordinates, but gathers useful things practically. It is temporal not like the clock, but rather in the way we are heedful of our future, and how we live with our impeding death. It is *social* because one can recede into shared meaning, or orient itself to its ontological basis. Dasein does not perish; it dies. In the way we encounter our everyday being-toward-death, we can adopt a position of authenticity, accepting our existence as careful being in the world, or deny it, following the lead of *das Man*.

Absence and Homelessness

Leder's *The Absent Body* (1990) employs Heidegger's phenomenology, among motley perspectives, to address the experience of bodily disruption in illness, and, to a lesser extent, disability. Heidegger's analysis of tool-being, as in the daily life of the carpenter, gives us a window to the bodily disruption experienced in sickness and health. As we fall ill, our bodily components arise in mere thingliness rather than lived utility. Leder calls this "dys-appearance," to indicate their absent presence in our corporeal schema. Absent, because they no longer permit action to unfold, and present because this fact is markedly so. One's viscera dys-appear in a stomach ache, just as one's being dys-appears when a physician ignores their reports of unusual symptoms. Leder's analysis of Cartesian philosophy is novel, via the experience of bodily error. Not only does Cartesianism pass over what it means to be a human, embodied and worldly, as Heidegger makes clear in *Being and Time*, but Leder suggests that it is the very structure of bodily dys-appearance that makes Cartesian philosophy so compelling. It is perfectly reasonable to believe that the liberated mind is caged by the body when it emerges obstinately in moments of disruption. Leder's aim is to flesh out the alternative.

Svenaeus' "Illness as unhomelike being in the world" (2011) extends Leder's bodily phenomenology. Illness, Svenaeus argues, has existential implications past those merely biomedical, mental, or somatic. Illness entails a global shift in meaningful attachments. "In illness the body shows up as an alien being (being me, yet not me) and this obstruction attunes the entire being-in-the-world of the ill person in an unhomelike way" (Svenaeus 2011: 337). Illness and disability disentangle our worldly dwelling, but also offer a space whereby we can entangle ourselves anew. As a visitor might 'make oneself at home' in an initially unfamiliar location, unhomelike body-world relations can and often do establish the worldly relevance lost in disrupted existence. Here, however, Svenaeus has very little to say about illness and disability outside of the disruption of homelikeness. We shall return to this point below. For now, and in our search to find a home in the world with, not simply despite, embodied disruption, we turn to the work of Kevin Aho and Havi Carel.

The Will of the Body, the Cry of the Flesh

Aho's "Heidegger, Ontological Death and the Healing Professions" (2016) clarifies Heidegger's position on mortality, temporality and finitude. Renaming the central object of investigation "ontological death" allows him to sidestep many of the misconceptions on Heidegger's position, namely, of death as a mere, objectively present event. Ontological death refers to the collapse in meaningful being-in-the-world represented by both death and anxiety about it, to be addressed by Heidegger's "anticipatory resoluteness". Turning to personal accounts of illness brings forth phenomenology in a new light. They bring Heidegger's account's down to earth, and show the narrowmindedness of the naturalistic model of illness:

> if we look at recurrent themes in illness narratives we see accounts that capture many of the core ideas of 'ontological death'. These accounts help to expand the narrow bio-medical view of suffering as physical pain and discomfort to address the existential and ontological suffering that invariably accompanies world-collapse. (Aho 2016: 60)

Aho turns to Arthur Frank's memoir, *At the Will of the Body* (2002). Experiencing a heart attack and a cancer diagnosis at thirty-nine and forty, respectively, Frank describes a collapse in personal meaning.

> What was it like to be told that I had cancer? The future disappeared. Loved ones became faces I could never see again. I felt I was walking through a nightmare that was unreal but utterly real. This could not be happening to me,

> but it was, and it would continue to happen. My body had become a kind of quicksand, and I was sinking into myself, my disease. (Frank 2002: 27)

Neither the naturalistic disease model, nor his career milestones gave Frank the certainty over his body and future that he once had. Aho reads this as the "Angst about death" heralded in *Being and Time* (Heidegger 1996: 235). Whereas Frank found social histories and objective descriptions of illness akin to Heidegger's "chatter"—ontologically baseless—he found meaning in writing about his illness and finitude, and encouraging others to tell their own illness narratives. "With this community, Frank was able to work through his own 'ontological death,' to give it significance, and, drawing on the context of meaning he was thrown into, create a new identity in its aftermath" (2016: 61). Mitsein overcomes the merely present world, embracing being-toward-death.

Carel, too, provides a philosophical reappraisal of Heidegger's phenomenology, alongside a hermeneutic of her own illness narrative, of lymphangioleiomyomatosis (LAM). With Carel's diagnosis of this rare lung disease, at age thirty-five, she was given 10 years to live. The biographic component of Carel's work is most prominent in *Illness*, but the "cry of the flesh" can be heard throughout her post-LAM work.[6] The personal and the philosophical are not so easily divided. In *Illness*, we read a description of ontological collapse following her diagnosis.

> All the usual rules that governed my life—that trying hard yields results, that looking after yourself pays off, that practice makes perfect—seemed inoperative here. […] The inevitability of decline was the only rule governing my life. Being good failed, so I turned to denial. (Carel 2013: 74f.)

The similarities with Frank continue: Carel's passage from despair to anticipatory resoluteness involved both a personal hermeneutic guiding her academic work, and an interpersonal response.

Professionally, Carel turned to the philosophical void surrounding illness. Yes, illness has been written about before, but the phenomenological literature seemed stunted; 'the ill' (often treated singularly) barely had a say.[7] This wouldn't do. Outside the more autobiographical book, her *Phenomenology of Illness* (2016) explores the Heideggerian phenomenology of death, and the gaps therein. "Heidegger does not discuss the possibility of an authentic experience of the death of another. This lacuna creates what is in my view an unjustified identification of individuation and authenticity, and can be overcome" (2016: 153). Closing the gap between authenticity and inauthenticity is a first step in this regard. The difference is not between a genuine death and a fake one, but a fluid spectrum of responses to anxiety (2016: 159f.). Emphasizing Dasein's temporal nature *alongside* Angst about death is another. We cannot only regard death as the end of possibility-to-be, but also a necessarily temporal structure, a part of care and thrown projection, against which one might orient themselves authentically or otherwise. This offers an *ontological*

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[6] The phrase is drawn from Epicurus, and the subtitle of the 2013 book.

[7] Toombs (1995) is an important exception here, as Carel indicates.

opportunity to embrace and discuss our shared finitude. “Authenticity becomes a genuine engagement with the everyday world, not its erasure” (2016: 177).

Like Frank, Carel took up illness’ ontological opportunity in collective action. This entailed both patient activism, and a phenomenological teaching and research agenda directed at newfound dialogue between practitioners and patients. “Doing this is another triumph over my situation, another way of saying no to despair” (Carel 2013: 156). This is not to displace the authentic, ontological depths of despair, but to demonstrate the plurality of authentic responses to illness, individual and collective. Solitary despair is not the only game in town. In collective historicity, we can care for one another in ontologically robust ways.[8]

Together, Aho and Carel’s work does more than simply apply Heidegger’s phenomenology. They fill some of the gaps in his account. First, in line with the main thesis of this paper, it serves to take a more communal approach to death. In Heidegger’s account, others are more than present objects surrounding Dasein. But not *much* more. It would be wrong to equate authenticity with self and inauthenticity with other, but Heidegger does not provide much in the way of proof that such an equation is inaccurate. We find it in subsequent work. Secondly, Heidegger’s account is abstract. His work does present an alternative to inauthentic being-toward-death, so-called “anticipatory resoluteness” to the “call of conscience”[9]—but this says little more, practically, than lauding ‘the courage to be anxious’. An autobiography grounds this abstraction in a life. Thirdly, Aho and Carel demonstrate that the clear-cut division between death, dying, and perishing might serve abstract fundamental ontology well, but to follow illness as it is lived, authentically or not, requires a much messier approach. Finally, Heidegger’s brooding seriousness and condescending talk of public chatter is rather bleak. In contrast to this dour emotional climate—fear, anxiety, boredom, and the like—Aho and Carel give us a glimmer of hope.

An ontologically robust phenomenology of death, alongside Leder and Svenaeus’ philosophies of health and disability, leads well to an empirical exploration of death and disability in the clinical space. In both arguments, disability, health care and death are explored phenomenologically at the inter-individual level. Being disabled, being ill, and making sense of one’s finitude takes place in concert with others. While Heidegger’s emphasis is on the fundamental ontological aspects of death, always ultimately mine, the subsequent literature has emphasized the collective spaces where meaning is distributed, in health, death or otherwise. This is for good reason. One cannot live an entire life exploring Dasein, or an entire life obscuring it. In the clinical space, we will see both sides of the ontological divide, Being as Dasein and being as mere presence, in frequent tension. With this, we turn to the clinical space.

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[8] We intentionally use care, in reference to both the lay and Heideggerian senses.

[9] See especially *Being and Time*, sec. 60.

Mortality and Rehabilitation

The empirical component of this paper draws from an ongoing, interdisciplinary qualitative research project, composed of both (a) an ethnography of a neuromuscular clinic for young people diagnosed with Duchenne muscular dystrophy (DMD); and, (b) roundtable discussions aimed at promoting critical reflexivity with the clinic's health practitioners, (Setchell et al. 2018). At the time of writing the study had been running for 18 months at a single site and had just commenced at a similar second clinic in a different city. Institutional ethics approval was obtained at both sites.

The ethnography involved observing the four-monthly clinic visits of young people with DMD and their families in the clinic. (hereafter 'observations'). During these observations the young people were seen by a range of six to eight practitioners over the course of 3–4 h. The main data source was the ethnographer's detailed field notes. At the time of writing, six roundtable discussions (hereafter 'dialogues') had been held. These 2-h dialogues involved the researchers introducing elements of social theory and philosophy through various exercises to engage the clinicians in a reflexive critical examination of their individual and shared practices (Setchell et al. 2018).[10] The following discussion includes excerpts from these data. All names are pseudonyms.

In the rehabilitation clinic, death is at once everywhere and nowhere. Death is everywhere because people diagnosed with DMD have a shorter than typical life span, with many dying in their 20s or early 30s, although some have lived longer. While all lives are uncertain, the changing landscape of DMD management and unclear/changing life expectancy mean that people with the condition live with more uncertainty of life trajectory than their 'healthy' peers and many other disabled youth (Passamano et al. 2012).[11] Much of the treatment, monitoring, and intervention is intended to preserve physical muscle strength and functional abilities, and to ward off perishing from cardiac and respiratory symptoms for as long as possible. As the young people are monitored at the clinic from early childhood to age 20, it is likely they will have a family friend or loved one die during this time. Death is present as more than just perishing, too. The study revealed that death is routinely present in the clinical space, and discussions about "doom and gloom," as a parent put it, are inevitable. Unacknowledged, maybe, but inevitable nonetheless.

And yet death was also nowhere. Deaths associated with these neuromuscular disorders are unlikely to take place during the typical patient's treatment. Throughout our observations, dying was a shadow trailing bodies and practices, rather than a mentionable object unto itself. While declining lung and heart function are the likely causes of death (Moxley et al. 2010)—this was only rarely stated, and even then, often under one's breath, in muted voices, or while looking at the floor. Questions about mortality were almost always submerged under another practical field (innocuous sounding 'disease progression,' 'psycho-social needs,' 'mental health,' 'quality

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[10] This is similar to the phenomenological workshop described by Carel (2012), though practitioners made up our target group, rather than clinical subjects.

[11] DMD is an X-linked disease, present almost exclusively in male births (Bushby et al. 2010: 77).

of life,' and so on). In these ways, an existential engagement with death was avoided. Not only by practitioners, of course; on other occasions, parents and patients participated, too. Such is the clinical life-as-usual: death everywhere, but nowhere, what Foucault calls "the visible invisible" in the modern "clinical gaze" (1973, chap. 9).

What we want to do here is outline clinical moments when the messiness of death was too big to be swept away. Our intention is not, and this cannot be stated enough, to judge patients, their parents, or practitioners for dealing with death authentically or not, as if it can be 'done' in a right or wrong way. Nor do we *only* want to emphasize the world-shattering nature of DMD. Our purpose is to show those moments when death emerges in clinical life, acknowledged or not, to work toward a clinical gaze that doesn't avert its eyes so quickly when it does.

"I Already Know What's Gonna Happen"

Kyle (aged 11) was observed during his clinic visits three times throughout the study period. His parents were "having trouble with the diagnosis", as a practitioner put it in one of the morning meetings.[12] Kyle's muscular strength had undergone a recent noticeable decline. Prior to the first meeting we observed, Kyle's mother expressed her desire to 'keep things together'. Psychological needs had been outsourced from the clinic; "we have our own people," as she put it.

> Mom said that they each go to counselling individually, in addition to attending family counselling. She said that just coming to the facility [was …] very overwhelming for them (with the amount of information they have to take in) that she would rather not break down in front of her son. […] I was told by another research coordinator that mom continues to have trouble with the diagnosis and sometimes does get emotional in the room and as such, declines seeing the social worker.

Kyle did not match his mother's silence. With each of the three observed clinical visits, Kyle came armed with a barrage of questions, relating to his condition, its trajectory, and ultimately his death. Kyle said, referring to his questions, "They're kinda personal. And I already know what's gonna happen". Unlike Frank and Carel's ontological death, Kyle's personal crisis was one of information. He was looking for answers.

> Mom said that one night before they went to bed, Kyle had questions about what will happen to him in the future. She and dad then sat up with him to answer his questions. Mom said that she explained, in general terms, that they don't know when they will all die. Kyle responded to say that he knew that, but he wanted to know more specifically what would happen to him. Once they provided him with some answers to their best ability (right before they went to sleep), he was satisfied and went to bed. Mom said that the next morning, she

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[12] All quoted material is from ethnographic notes or dialogue transcripts, unless stated otherwise.

> asked him if he was okay with their conversation from the previous night. He said he was fine with everything they discussed and carried on. Mom said that she was very worried about it but he was not. Mom said that once they answer his questions, he's done and ready to carry on to the next thing, "He doesn't carry on and think about it".

Existential analysis might read Kyle's questions as interrogations into perishing, and not death. This would be an error, we think, because of the intimate relationship between the two. It highlights, in part, the presumption that all individuals equally 'take stock' of their lives in the same way. The clinicians and his parents formed the infrastructure that Kyle used to understand the objective limits on his existence, which he could *then* assess existentially.

Kyle's matter-of-fact tone continued throughout our observations. In the usual consultation with the clinic's pediatrician (Dr. Lane) Kyle's questions continued. Until this point, the topic of discussion had been bone-health management.

> Kyle looked up from his iPad and said curiously, "I thought my *muscles* get weaker?" Dr. Lane turned to Kyle and said he was correct. She explained what happened to his muscles and his bones. Dr. Lane's explanation was clear and very simple but not at all dumbed down. […] Dr. Lane then paused and said that the magic age of 18 is when things change. […] As soon as she said that, Kyle looked up and very matter-of-factly said, "For some reason, I don't think I'll turn 18". Mom immediately got teary eyed and dad's face became very red. [… It] took Dr. Lane a second to figure out how to respond. She said, "I think you will". Kyle asked curiously, "Really?" Dr. Lane said, gently, "Yeah". Dr. Lane paused again and then asked, "Do you want to talk about it?" Kyle said, "I just cry and talk about it randomly and then I stop." […] There was a long pause which was broken by Kyle who said with a little sarcasm, "It's really quiet!" Dr. Lane smiled and mom said, "Yes" with watery eyes. Kyle went back to his iPad, sort of signaling that he didn't want to continue the conversation further.

Kyle's orientation to his death was supported by both his parents, the clinical team, and his (and his family's) counsellors. Kyle's curiosity was a work in progress, in the kinds of questions he asked, and in the family's response to them. He "knew what was going to happen" – perhaps in part due to the answers provided to his questions - yet his ongoing return to the topic suggested some of this existential questioning continued unresolved. Kyle's parents suggested the concept of the afterlife; "but Kyle, who has a very scientific mind, "debunked heaven". Mom said [it] didn't make sense for his mind". Here, mitsein is not simply an impersonal herd, "they." falsely promising immortality to conformers. With some work, it gave Kyle some of the ontological infrastructure used to stake a claim on his mortality.

The dynamics of Kyle's ontological exploration pose some questions not so easily answered by Heidegger's threefold relation to death. In *Sein und Zeit*, the Dasein/mitdasein distinction is a simple binary—our death is a grounding ontological structure, whereas that of others is not. But what of the mother, who has to make sense of the fact that her child will likely perish before she does? And what of the growing child, still developing his state of thrownness, asking questions (though perhaps not receiving all of the answers) on his existential state? Neither case seems to reflect the existence of Heidegger's prototypical black forest carpenter. Rather than simply an inauthentic passing over of the conditions of worldly existence, we would rather treat Kyle's ontological questioning as a space of truthful disclosedness, of what Heidegger calls *aletheia*. Simply put, Kyle is making sense of his own mortality in the midst of others, and choosing a style of being accordingly. Here neuromuscular disease is not solely world shattering, but cause for existential exploration. In this example at least, the clinician supports this journey: "Do you want to talk about it?"

Dealing with Death Differently

Our research demonstrated there was not solely one way to address mortality. Hayden (aged 8) was observed three times throughout the study. On his third clinical visit, the family had recently experienced a death in the family: Hayden's grandfather. In a conversation with Dr. Lane, Dad indicated that Hayden "hadn't talked about it".

> Dr. Lane paused and then asked Hayden, with a softer tone, "Hayden, did you get to see your grandfather sometimes?" Hayden looked up and slowly nodded. Dr. Lane said if he wanted to, he could talk about anything he wanted to with her or with Julie [the social worker]. Dr. Lane reiterated to Dad too that they were all here for them. She then smiled and said they could have cancelled the appointment and rescheduled for when it was convenient to them. Dad said no, adding that there wasn't much for him to do at home, since his wife and mother-in-law were taking care of things. He said it would have weighed on them to miss the appointment. […] Dr. Lane then said, "Let us know how we can help with Hayden or the family. It's important." Dad said, "That's why I brought it up." Dad began to explain how each member of the family was dealing with it. His wife was obviously upset but flew into 'work mode' to help get things sorted out; his daughter cried and talked about it. Hayden had not showed much emotion though he did say he understood what happened and he was sad. They've been watching both the kids since they found out and are a little worried about Hayden.

Dr. Lane, returning to the ante-room just over an hour later, addressed the other practitioners, explaining that there had been an unexpected death in this family, "and Hayden had not said much about it". "I noticed [wrote the ethnographer] that other people in the room had stopped and were listening to the discussion, all very worried". Julie, the social worker, saw the family again, in the last visit before they the clinic: "the team was there for them whatever they needed". Though the clinical team clearly demonstrated worry on the part of the family, the tone of the conversation remained pragmatic. What can we do that you won't have to? How much clock time do you or your son need to 'process' death? In this way, the team matched Hayden's mom's method. They were in 'work mode,' addressing a recent death in a professional manner.

Hayden's visit contrasts greatly with that of another family, Kamil's (age 14). Kamil came to the appointment with his visibly ill grandmother. When [the observer] initially contacted the family for consent, she noted Kamil's uncle had unexpectedly died in his sleep a month earlier. Two other family members had passed away as well, his mother and another uncle, years earlier. Kamil lived with his grandparents, who had fought for custody of Kamil, believing his father would not be able to care for him. Kamil's grandmother had encouraged him to speak about his uncle's recent death alone with Julie, the social worker. When asked if it was useful to them, "Grandmother looked up and said with a huge smile, "Very helpful". It was evident that they come in to the clinic, on occasion, just to see the social worker, and that what is discussed remains between Kamil and Julie. ""That's what I tell you, right?" Grandmother said to Kamil, "I want you to tell her whatever you want". Kamil nodded. […] She said it was important to talk about these things". Throughout the visit, Kamil's grandmother showed more and more signs of illness. Despite this, she insisted to stay until the end. She repeated frequently that Kamil was a good child, that she would do anything for him. While Kamil was weighed by the nurse (Evelyn) his grandmother hinted at what their home life was like, "taking care of herself and her husband, both of whom were not in the best of health, three grandchildren (one of which was Kamil) and a son. This was a busy household.".

Kamil left the room for routine respiratory tests. At this point, only grandmother, and the ethnographer remained, with the social worker on the way.

> She then began to talk about her son who had just passed away. She began to talk about what had happened that evening—how they had dinner together and he had helped to put Kamil to bed. She said that when she woke up in the middle of the night to check on Kamil, she had noticed her son's light and checked on him. This was when she found him. Her eyes welled up as she spoke. I was ready to tear up too. I sat and listened to grandmother and did not write anything. […] I felt as though she needed to get it out, but not in front of Kamil.

After 10 min, Julie arrived at the door, 3:15 pm. Subsequent discussions between grandmother and Julie addressed the nature of home life, and the possibility of a short hospital stay for her grandson, so she might attend to her own health. This, she opposed explicitly. With Kamil returning to the room, it was evident that each of the practitioners were increasingly concerned about the length of the visit, but grandmother was resolute to stay. Kamil came first, always.

By 4:07 pm, grandmother's condition had significantly deteriorated. Dr. Lane and the respiratory therapist, Nina, were in the room. Noting grandmother's state, and in a calm voice, Dr. Lane asked Nina to fetch the blood pressure machine. She nodded, leaving the room immediately after.

> Dr. Lane then gently asked how grandmother was doing. Grandmother hung her head and began talking about her son passing away and the heartache she was experiencing. Grandmother began to cry. Dr. Lane [fetched] a box of tissues and sat down beside grandmother, gently placing her arm around her. Grandmother was crying heavily. She talked about how she couldn't stop seeing her son at night, or any time she closed her eyes. She felt physical pain

> from all of this and did not know what to do. Dr. Lane let grandmother talk and cry and did not interrupt her, [herself] looking like she was holding back tears. I looked over at Kamil and he looked sadly at the floor.

Kamil and his grandmother remained for another 25 min, finishing the appointment. Evelyn, the nurse entered the room with the blood pressure machine, checked and rechecked grandmother's blood pressure. It was too high. Calmly, Dr. Lane suggested she go directly to the hospital, that she would write the number down, to provide once she was admitted. Grandmother declined; she was tired, wanted to go to bed, and would see her doctor tomorrow. "Dr. Lane did not look convinced". She could insist, but not force her to go.

Kamil's was an emotionally difficult appointment to observe. Though, toward the end, it seemed more like grandmother's appointment. So too was the follow-up: after the appointment, Dr. Lane contacted grandmother, asking if she could speak with her doctor directly. She agreed. Grandmother had elected to go home to bed, rather than the hospital after Kamil's appointment. Dr. Lane emailed the ethnographer directly the following day, "asking how I was after the appointment. The team had found the appointment very difficult to handle, and they had each other to lean on that evening and the next morning. […] I did get teary eyed driving home as I replayed parts of the appointment in my mind. This family had experienced a lot of tragedy and the team was very worried about them all".

Hayden and Kamil's stories are more than simply incidental moments when the words 'death' and 'dying' were voiced in the clinical space. In each appointment, we find explicit orientations toward death. While the *content* of those orientations certainly differ, it is nonetheless possible to map them within the typology provided in *Being and Time*. Hayden's mother's "work mode" around his grandfather's death, reflects, for example, Heidegger's inauthentic "constant tranquilization about death" found in *Being and Time* (sec. 50). So too with the trope, "let us know if there's anything we can do". Even the clinicians' conversations following Kamil's appointment. Idle chatter, inauthenticity (*uneigentlich*), the they-self throughout—at least to Heidegger. Kyle's stoic acceptance, and Kamil's grandmother's anxiety, however, would be read as authentic, through and through. Each accepts the inevitability of death, and stakes a claim on one's remaining life, even if it upsets the social order surrounding them. The point, then, is that these multiple orientations to death *can* follow the pathways laid before us in *Being and Time*. Whether or not this typology is analytically useful is another matter (one discussed below).

By empirically exploring the ways that death came up (or did not) in the two incidents involving Kamil and Hayden, we see there is not one story of disability and death, or one way of dealing with disability or death, or even one side of the ontological divide implicated. Kamil's grandmother's incident at once displays ontological exploration of finitude, and objectively present symptoms of deteriorating health. Kamil's grandmother was worried not only for her being-toward-death, but for the conditions of her grandson's existence afterwards, should her health worsen. Whereas *Being and Time*'s Dasein only owns its own death, Kamil's co-presence and co-existence colours this entire event. Hayden's withdrawal can be coded as a space of co-presence as well, where his reluctance to make meaning with others becomes the object of concern. Das Man, in this instance, does not ask Hayden to tranquilize his feelings on death—in fact, the opposite is the case. In both examples, a clear-cut distinction between being and Beings, and one's own death versus that of others, fails to capture the dynamics at play. An entangled phenomenology of death, following death, disability, and mitdasein in situ is required. In the following section, we apply such a phenomenology to discourse amongst the health care practitioners themselves.

Practitioner Dialogues on Death

To this point we have focused on the emergence of death in clinical practice. As mentioned, part of our study included dialogues between our research team and the observed practitioners. Here, too, death was absent and yet present. Here we quote a dialogue with practitioners following the initial study period. The dialogue had not gone very well. The clinical team was resistant to addressing the particular practices highlighted by the researchers. "It's rude to talk about other people, I feel like we are criticizing other people," said one member. The room overwhelmingly agreed. This mood was not conducive to the type of discussion we wanted, for practitioners to reflect on their assumptions about what constituted good care. Guards had gone up.

Orientations to death were one such area where the practitioners were resistant to engage in critique. Parents' decisions regarding their children's treatment was another. The research team had posed a question, about the role of practitioners in educating parents, before making an informed choice. The initial object of discussion was the use of a walker versus power wheelchair, in a school setting. The question was asked: does the way that questions are posed to parents give them an actual choice in the matter? Dr. Lane replied that it is contextual. Perhaps in the choice between a power chair or walker in school, but preventative measures are different: "like when I think from a medical standpoint I recommend the flu shot. Why? Because then you'll get the flu and die. […] I think it would be interesting to think of what is the better way of having that conversation".

> Karen (Respiratory Therapist): This is a conversation that we have to have often, especially when kids get older. We give families documented information about breathing overnight and we tell them your child is not breathing this many times in one hour every hour that they are asleep. […] And eventually it gets to the point where we have to say, "If this goes untreated, this will be their cause of death". Given that the family has the right to choose, but we get to the point sometimes where we don't accept that because it is dangerous for the child.
>
> [Researcher]: So you force them to do it?
>
> Dr. Lane: It depends on their age.
>
> Karen: Most of the time, yes. If parents are the reason that the child is going untreated, then yeah we have to call [protective services] […] because this

> child is at major risk by not being treated. [We] try to negotiate with families and […] suggest that this is why we are recommending this, but we get to the point where it is *very* frustrating because they just want to do their thing and it becomes a danger to the child. […]
>
> Julie (Social Worker): But a lot of families you wonder if they are not hearing it or they are not ready to hear it. They don't want to think about the fact that this could be causing [their child's death].
>
> Karen: Oh yeah, we've gotten to that place only once or twice since I've been here and it does come to that sometimes and especially with breathing, it's tough. It's a tough conversation to have.
>
> Julie: But regarding your question "Are they are making an informed decision?" I don't like using the word denial – but [it's like the parents are saying] "we're not gonna go there because my child looks fine right now, so why are you going to tell me that they are going to die"?

The dialogue was not a failure. The question got an answer, but not without a certain friction. In that answer, death was treated as a present object, like any other, to be managed. This is, we believe, the "natural attitude" toward death in the clinical space (Schütz 1945: 533). Health care is, for the most part, prolonging life. When death is the anticipated result of parental neglect, the authorities are called. When death is the likely outcome of disease, people receive palliative care. In both cases, it is a problem in the need of a solution. To the Heidegger of *Being and Time*, this is mere chatter about death, passing over its founding existential role. We do not want to contest this form of pragmatism, addressing death in terms of things, as objective perishing. Ours is not a categorical case for demise over life. But prolonging life need not, we argue, come at the expense of affirming life. By looking to moments where clinicians, too, have existential agency (as in Kamil's clinical visit) we can demonstrate the very real impact that clinical practices have as we live with death. Clinicians can and do provide the existential infrastructure necessary for the various relations to death and dying to unfold. Despite moments of friction, practitioner reflexivity can surely guide this process.

Discussion, with or Without Heidegger

Taken together, we believe this empirical material is at once cause to entertain and ultimately revisit the Heideggerian phenomenology of death, as Carel and Aho do above. First, to entertain. There were numerous instances where death was swept under the rug in a routine manner, whereby the publicness of "the they-self" addresses death only as an object to be managed and avoided, and this management obscures the acknowledgement of our own finitude. "Let us know if there's anything we can do" is the characteristic statement. No, Heidegger would object, there's nothing any one of us can do. We're all going to die. The moment we stop asking these kinds of mundane questions is the moment we can start addressing our own mortal anxiety, and prepare ourselves for the kinds of “ontological death” that Carel and Frank, and Kyle encountered. This inauthentic attitude is a barrier to existential exploration and, ultimately, existential affirmation.

Death, as an object to be managed and avoided, was the basis for the clinical friction described in the difficult practitioner dialogue as well. Clinical practices and clinical sciences are ontic in the fact that they *must* treat death in an ontic, existentially void, manner. The contemporary medical model of disease is one that is based on an objectively present formulation of death. Its purview is biological, not existential. And for good reason: preserving life means bracketing ontological questions about death in order to get things done. To put it bluntly, a practitioner mired in existential angst is not the first choice for parents worried about their child’s ability to breathe. This, too, supports Heidegger’s outlook in *Being and Time*, dividing the philosophical exploration of death from its management in biology, psychology, and the childhood rehabilitation clinic.

Though it may support Heidegger’s thought in some ways, our study asks us to revisit his fundamental ontology in many more. We do not fully accept the tacit position that the medical clinic must entirely bracket ontological questions about anxiety and finitude. As Carel outlines in *The Phenomenology of Illness* (2016), authenticity and inauthenticity reside on a spectrum, feeding into one another. Dasein’s tendency to publicness regarding death is one endpoint, resoluteness toward it is another. While the clinical gaze did not perceive death as an existential opportunity in every instance, it did after Kamil’s visit, when the practitioner team met to discuss ontological anxiety. In assembling around finitude as a clinical team, existential infrastructure was put in place for the next encounter. Death *can* be managed with an ontological sensitivity surrounding it, and this sensitivity is put to work in *mitsein*, being-with-others. This is Frank’s wounded storytelling, and Carel’s LAM patient activism.

This is cause to revisit two foundational pillars of Heidegger’s philosophy of death, first, the threefold perishing-death-dying framework, and second, the place *mitsein* plays within that framework. Heidegger’s threefold division between perishing, death, and dying works when outlining the individualizing nature of death, something we are always anticipating but will never reach, in contrast with the collective experience around a death. But how well attuned is it to the clinical space? While philosophers can spend their time making neat and tidy analytical divisions between ontic perishing and ontological death, practitioners cannot. They need to come up with an answer to questions about death and demise when asked, and to answer those questions in compassionate ways. At least, that is the hope. This may mean allowing a patient to stay silent about a death in their midst, like Hayden. It may mean a calm and clear answer to the “kinda personal” questions about finitude posed by Kyle, like Dr. Lane gave above. Or encouraging talk, like Kamil’s. Each of these is a different position on the authenticity-inauthenticity spectrum, and the reality of clinical life demands none are discarded a priori, regardless of what Heidegger might say. To treat dying as a mode of perishing is one human strategy to deal with death, as is existential realignment following ontological anxiety. An entangled philosophy of death, a philosophy of death *and* dying *and* perishing, must address both equally.

Finally, mitdasein. As we outlined in the first section of this paper, Dasein is always already a social being, living in a world of shared relevance and meaning. In and through this shared meaning we can assume a stance of publicness, doing as "one" does, or a state of authentic being, in line with the structures that make our existence what it is (being-towards-death being one of them). This does not necessarily *shun* publicness, since it is a mode of being-in-the-world, but it presents the opportunity to do so, one Heidegger took frequently.[13] While being-with-another is an essential component to openness to the shared world, it is sociologically underdeveloped. Heidegger does not ask questions about power and authority in the modern world. Nor, considering later writings, does he entertain how Dasein's being-with-another might serve as the basis to gain a free relation to technology, to overcome the calculative instrumentalism dominating modern life. Mitsein is just a homogeneous structure *acting on* us. Heidegger does not give much hope, like Aho and Carel do, that we might shape the spaces of mitsein to encourage various forms of ontological exploration. As we continue our study, we want to promote dialogue within the clinical space that makes this possible.

More than simply a footnote in the Heideggerian literature on death and dying, we would like to propose that our findings tell a story about disability, too. While *Being and Time* presents a structural description of human existence and its finitude, it does not tell us anything about disability. We would like to press Heidegger here, toward death and specifically disabled existence—somewhere he would surely not want to go. Our object of critique is what Reynolds (2017) calls the "ableist conflation," formulated as follows:

1. Disability is a lack or deprivation.
2. Deprivation of potential goods is a harm.
3. Harm causes or is a form of pain and suffering.
4. Given 1–3, disability is coextensive with (weak version) or causes (strong version), pain and suffering.

To point 4, we would add the dominant, Western belief that disability simply equals death. If, following Titchkosky (2007: 111) the point of disability studies is "undoing disability's deadly status," we suggest an entangled phenomenology of death is in the service of that goal, and that discipline. By moving from merely present, inevitable and existentially void understanding of death, to an entangled, co-constituted, and phenomenologically rich account of human finitude, we might begin to fully live with death in rehabilitation. We also advance the phenomenology of illness and disability past dominant narratives *only* of world shattering to world-dwelling. These lives, as they are lived, may be shorter than a typical lifespan, and there may be moments, brief or otherwise, where tragedy comes to the fore, where we are made to feel unhomelike, or disability does indeed cause death. However, as Titchkosky, Reynolds and the contents of this study attest, this is not the entirety of disability. An open dialogue on death means disability can be treated as a mode of

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[13] See, for instance, "Why do I stay in the Provinces?" (Heidegger 1981).

Dasein, death and all, and not simply a thing with an early expiry date. This is the point of our greater project, and this paper.

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