

Distance and Disruption; the organised disorder of the body in illness

In 2019 I was approved, through ethical processes, to observe a complex spinal surgery performed by the surgeon I am partnering with on the delivery of a collaborative interdisciplinary research project¹. Having spent years researching the medical condition in question in order to understand both its impact on the individual but also on familial units, I thought it necessary to attempt to understand the impact that performing surgical interventions has on the people carrying out the surgery. Scrubbed in, I hovered in the background until the operating theatre was ready and the young patient had been fully prepped for her operation. As a mother myself I was conscious of the young person whose life was currently being controlled by machines and the talents of an anaesthetist, whilst acutely aware of the anxious wait that her parents were going through on the floor below. Her young body was masked to reveal only the area where the operation would take place; doused with iodine her skin took on a look of something less known. With cauterised flesh that didn't bleed, the immediacy of a clear detachment occurred in the setting. Sixteen clinical staff were present for four hours, for fifteen of them their focus was continuously on the surgeon, his instructions, his actions and the activities of copious machines. It might seem strange to suggest that in some ways the patient became almost invisible amongst the chorus of counting swabs, beeping measurements and the overwhelming attention of fifteen people on the dialogue of the person performing the surgery. I wondered what it must feel like under the spotlight of so many for so long in an intensely pressured and precise task and, moreover, to be simultaneously responsible for the life-long mobility of a young teenage girl when one misplaced millimetre might cause immediate paralysis.

What I experienced that day made me question the enduring mind-body dichotomy from an expanded viewpoint, giving rise to questions around whether the objectivity needed to perform such surgeries can be maintained if those in attendance surrender to the lived experience of the individual. If so, what might its impact be on treatment and surgical performance and critical decision-making? In the disorganised, disrupted world of illness does detached organisation become necessary for those who we expected to heal and fix us? I have yet to reach my own conclusions but perhaps, the difficulty that remains around such questions is precisely why the unsettled character of the mind/body dilemma flourishes in our encounters with illness and disease.

Advancement in modern medicine and innovative diagnostic technologies suggests that we are all likely to experience illness or disease at some point in our lives or through the lives of those we care about. Whether that experience becomes life-altering will likely depend on the nature of the

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illness itself and the how it is encountered, coupled with the disruption it brings about both physically and/or mentally. The impact it has on the way we think about who we are in the world and what that world becomes for us as a result is an individual experience, albeit one that frequently parallels the experiences of others. Reflecting on the title of this anthology and the spirit of a broader definition of pattern and chaos contextualised through ill-health, this essay will introduce art, with its potential to draw on creative strategies such as metaphor, and health, which is frequently ordered by science and objectivity. Through identified artworks and the author's own work, this essay attempts to articulate what it means to grasp such experiences amidst and into practice through art made with participants as co-producers rather than art made about patients. The makers of the works herein occupy a complex status, becoming multiple things to many people. In the journey towards final outcomes they act as observers, participants, producers, collaborators, voices, and additionally often become friends. Importantly, in these works the participants align with the artist(s), becoming relational stakeholders whose voice has agency.

Central to the essay is the highly-critiqued Cartesian model of medicine that is based on a mechanistic separation of mind and body. The mind-body problem, as it has come to be known, is presented in the context of two artworks that utilise film as the chosen medium to explore themes including 'waiting' as a factor of illness, the temporal disruption of disease, and death and dying. It seems somewhat obscure to separate the death and dying; Jacques Derrida's (2007) explanation of 'trace' as the idea of an immediate absence of the present, the now as no longer new, suggests that the pressing directness of extant death is so transitory that the authority of dying overcrowds the moment.

Jeffrey Gold, in his discussion paper for the *Journal of the Royal Society of Medicine* (1985), pleaded for the importance of a reconsideration of philosophy in shaping contemporary medicine. Gold largely attributes the problems present in modern medicine to the central concept of Cartesian dualism and the acceptance of body and mind as distinct entities. René Descartes, often attributed with founding a new era for philosophy following the dominance of the church and the epoch of scholasticism, dedicated much of his life to the search for a certainty of knowledge situated through mathematics and physics. He sets out the profound results of his enduring search for certainty in *Mediations on First Philosophy* published in 1641 including Mediation 6, 'Concerning the Existence of Material Things, and the real distinction between the Mind and Body' (1998).

Through his system for constructing knowledge Descartes resolves himself to be merely a 'Thinking Thing' (*res cogitans*), a soul, an immaterial mind distinct from the body (1641:96), having accepted the deceitful nature of empirical knowledge he firmly believed '[...] that one needs to withdraw their minds from the senses as well as from all prejudice' (1641:52). Descartes asserts he

has a distinct idea of a body that he describes as 'very closely joined to me', yet that his essence consists entirely in his being a thinking thing. He further considers that as a thinking thing he is not an 'extended thing' (*res extensa*) (1998:96), a material substance, and is therefore completely independent of anything corporeal, thus:

Accordingly[,] this 'I' - that is, the soul by which I am what I am - is entirely distinct from the body, and indeed easier to know than the body, and would not cease to be everything it is even if the body did not exist.

(Descartes cited in Cottingham 1997:22).

The impact of Descartes' reductionist method is frequently attributed by many from both within the field of philosophy and medicine alike as having given rise to the problematic mechanistic mind and body problem in the condition of illness and/or disease. The logic that Descartes so admired of physics and mathematics, when applied in medicine, envisages illness as organised - yet understanding the impact of disease is seldom ordered. S. Kay Toombs asserts that the Cartesian paradigm of embodiment lacks completion, that a resulting disarray is formed from the failure to consider the whole person; 'In a very explicit way it omits the person to whom the body belongs, the person whose body it is' (1988:201).

The conceptualisation of the biological body in medicine as machine-like is amplified through Descartes' comments on the divisibility of the body into its constituent parts while the mind remains utterly indivisible. Nonetheless, the simplicity of divisible order versus the often-idiopathic character of illness and disease coalesce in troublesome ways for those whose lives encounter the impact of illness either directly or indirectly. According to Descartes (1998: 101), the mind as 'wholly diverse from the body' is part of multiple observations, one being '[...] that my mind is not immediately affected by all the parts of the body, but only by the brain, or perhaps even just one small part of the brain, namely, by that part where the "common" sense is said to reside'. John Cottingham notes that according to Descartes' premise, the 'I', the soul by which I am what I am, could indeed '[...]survive beyond the complete destruction of the body (including, let us be clear, the brain)' (1997:22). This, in turn, gives rise to the idea that failing body parts might simply and inconsequentially be replaced, as in the situation of transplantation, or repaired with little or no impact on self. The criticism surrounding the separation of body and mind in illness is further examined by Toombs who draws attention to the body as object in illness (1993). She highlights that bodily objectification and the experience of the body annexed in its material state can contribute to an experience of the body as separate from self in illness.

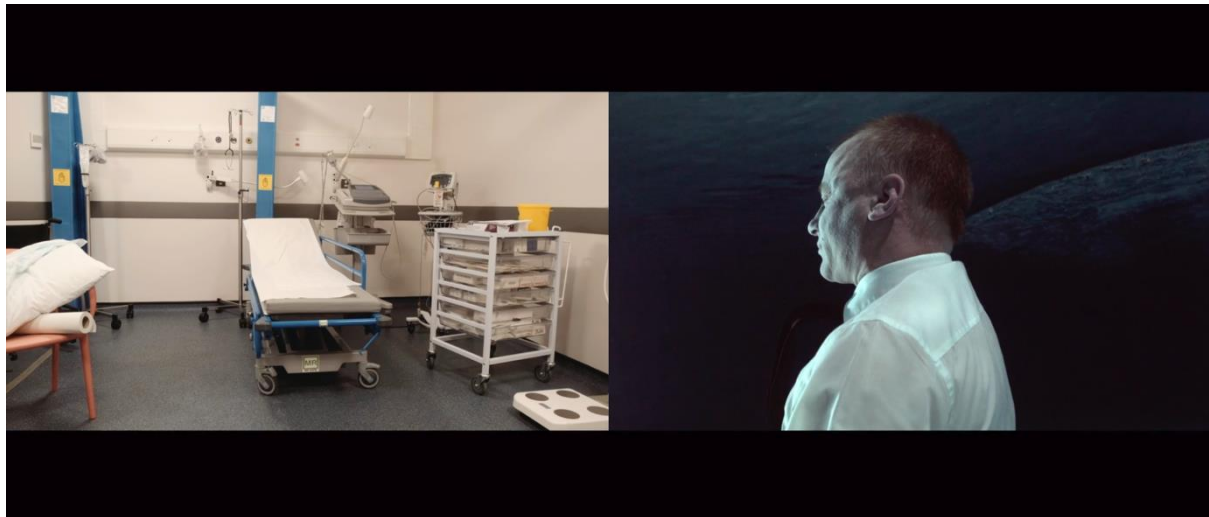


Figure 1. Catherine Baker, *Waiting*, 2019. Artists film still 03:20. © Catherine Baker.

The artworks presented herein attempt to explicate the profound sense of loss experienced by the alienated self in illness (as in Fig. 1, for example) or perhaps what Maurice Merleau-Ponty might refer to as the *ambiguity* of the body, the difference between the lived body and the biological body that is revealed through illness (cited in Carel 2013:30). Paraphrasing Havi Carel, (2013), the healthy body is both the biological body and the body as experienced in complete harmonious alignment. Thus, the constant awareness of the body that asserts itself in illness and disease recedes in the healthy body; it functions and by default it is not present despite not having gone away. Carel explains that 'while digestion, fluid balance, and muscular performance are going well, we do not experience them consciously', (2013:31), imperceptibly they enable us to go about our daily activities without a single thought. However, illness acts to disrupt the balance, bringing confusion with it and unsettling the everyday taken-for-grantedness of the body as experienced in health. The harmonious pattern of everyday life ceases and with it comes a shattering of Merleau-Ponty's phenomenological description of the body, that speaks of the unified and complete body '[...] I am not in front of my body, I am in it, or rather I am it' (cited in Carel 2013:35).

In Steven Eastwood's essay (Eastwood, 2016) *The Interval and the Instant: Inscripting death and dying*, the complex relationship between ethics and aesthetics in film are explored. Far removed from the fiction of cinema and notions of a good death, whatever that might be, Eastwood's work reveals dying as a lived experience of the deteriorating body. Framed in the context of palliative care and end-of-life, the multiscreen installation *The Interval and the Instant* launched at Fabbrica in 2017 (Fig. 2), with the sister artwork, a feature length film titled *ISLAND* (released in 2018). The works raise questions surrounding the absence, in western society, of accurate depictions of death and dying when, much like illness, dying is omnipresent. Eastwood states that the somehow unacceptable vision of dying has resulted in minimal filmmaking approaches that respond to the shared potentiality that

exists between the filmmaker and the dying person. He points out that '[a]s a consequence, there is very little filmmaking done with the consent and collaboration of the dying person and there are few moving images of the very end of life (Eastwood, 2016).



Figure 2. Steven Eastwood, *The Interval and the Instant*, 2017. © Steven Eastwood, courtesy the artist

In the same way that modern medicine has contributed to an increased awareness of illness as an everyday presence, death persists as the one true constant, yet remains unwillingly acknowledged. As presented in the opening paragraph of this essay, under challenging clinical settings a 'distancing' was observed that enabled those at the so-called front-line to continue to operate in the best interests of the patient. Similarly, Eastwood's work provides a profound insight into the private world of disease and illness and one that I suspect challenged audiences, albeit not unanticipated (as in Fig. 3).

Whilst Toombs and Carel advocate a phenomenological consideration of the person whose body is in illness; Eastwood likewise promotes the voice and agency of the patient; his approach involves them as both subject and co-producer. This could be considered as in opposition to those who might seek to encourage seclusion at such times, shielding the wider connected community from the harsh reality of death in terminal illness. Eastwood points out that the well-meaning situation of palliative care in terminal illness '[...] may occlude the validity of the dying person's need to speak and participate in the creation of an image of their dying (2016:29)'.



Figure 3. Steven Eastwood, *The Interval and the Instant*, 2017. © Steven Eastwood, courtesy the artist

While terminal illness, as presented in Eastwood's work, brings the temporality of death to the fore, I am struck by the parallels that exist between his role as filmmaker and that of the clinical ethicist. In communicating disease that is incompatible with life to an extended community that includes family members, physicians, and audiences alike, it seems like an important meeting-point reveals itself amidst the possibility for confusion that lurks beneath the surface. Through my own work in both clinical and non-clinical settings I have witnessed and shared the intimate experience of being 'towards death' and the ensuing existential trauma that loops endlessly for the individual. Patients with life-limiting conditions are often invited to take part in surveys that attempt to measure their wellbeing as a process of data collection that has nothing to do with the clinical outcome. Overlooked in such studies is the experience of waiting in illness and the conditions under which the waiting takes place (Cohen et al 1996:580). If we scrutinise waiting as experienced it varies considerably in response to who waits and with what illness, disease or sickness. For my film *Waiting*, (Fig. 4), which shows patients and those they share their lives with as they wait underwater on a single breath, my research revealed somewhat expected commonalities that align with the mind-body problem whereby the patients described themselves as data, as incessantly measured, encountered as their condition and not for who they are. The simple act of holding one's breath proved a powerful metaphor for the participants who co-produced *Waiting*. Despite what might be considered a move

towards a pervasive narrative, the inclusion of water as both a life-sustaining but threatening material attempted to intensify the involuntary nature of breathing for the audience.

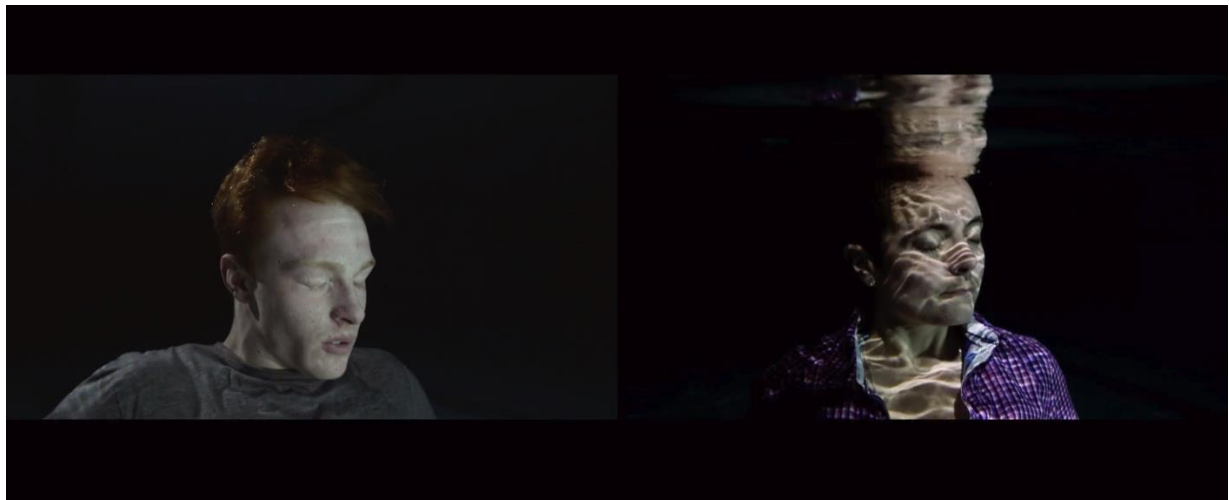


Figure 4. Catherine Baker, *Waiting*, 2019. Artists film still 10:20. © Catherine Baker.

The accompanying sound, composed from recordings of Magnetic Resonance Imaging sequences, echoes the process towards the search for a verdict, whilst scenes of empty, impersonal clinical spaces (as in Fig. 1) focus and tell again the repetitive narrative bleep of medical settings and clinical diagnosis. In *Waiting*, the people we see on screen hold onto breath, each other and life as it slips away with surprising speed or is wished away in the hope that certain conditions will reveal their full impact more quickly (Fig. 5). The unknowns of illness wreak havoc in the temporal experience of being, time can appear to run fast yet pass slowly when waiting for results or the right time to tell others.

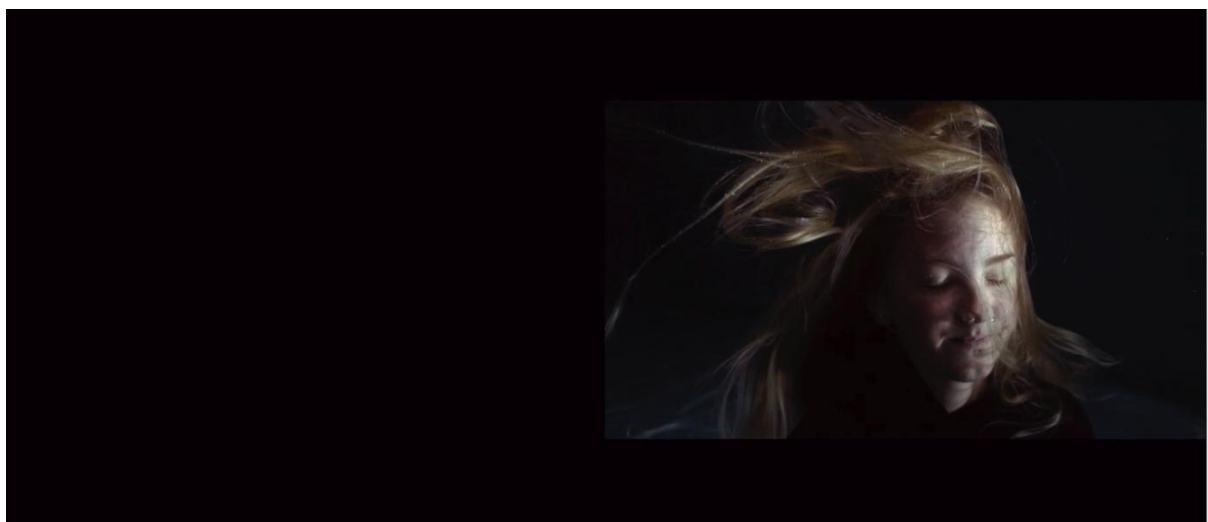


Figure 5. Catherine Baker, *Waiting*, 2019. Artists film still, 08:53. © Catherine Baker

When seen through the lens of the artworks herein and in the broader context of contemporary medicine, the mechanistic, orderly separation of mind and body as presented through Descartes' philosophical meditations is clearly inadequate in reflecting the complexity of experience. However, this essay hopes to have articulated that within the problematic inferences of critical illness whereby people, both patient and physician find themselves 'not on the same page', a broader consideration of moral distress is necessary. Maybe repeatedly bearing witness to trauma goes some way towards explaining why the mind/body dilemma has endured in the context of the disrupted body and those who seek to treat and/or comfort. Dr Alyssa Burgart, paediatric anaesthesiologist and bioethicist, in conversation with Professor Ian Sabroe (2021) describes how 'It is traumatic to be a clinician, we are sitting in people's pain and suffering.'

What is clear is that adapting to or conceptualizing uncertainty seems significantly more critical than searching for the certainty that Descartes pursued. The patterns that emerge and repeat in the context of disease expose the chaos of temporality and illness, revealing that which was perhaps there all along, the difficult problem of our awareness of time. When data and measurement fall flat and the limitations of language are exacerbated, artistic strategies employing creative metaphors that attempt to enhance our understanding of the intangible and the invisible have the capacity to bring about the creation of a meaningful dialogue attending to the mind/body issue for clinician, individual and future audience.

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References:

Carel, Havi ([2008] 2013), *Illness: The Cry of the Flesh*, London and New York: Routledge.

Conversations about Arts, Humanities and Health (2021), 'Episode 6 In Conversation with Prof David Magnus and Dr Alyssa Burgart', UK, 30 April, <https://anchor.fm/convoartshealth/episodes/Episode-6---In-Conversation-with-Prof-David-Magnus-and-Dr-Alyssa-Burgart-e15qgfl>. Accessed 12 August 2021.

Cottingham, John (1997), *Descartes: Descartes' Philosophy of Mind*, London: Phoenix Books (Orion Publishing).

Derrida, Jacques (2007), 'Derrida: "What Comes Before The Question?"', YouTube, Dec 2007, <https://www.youtube.com/watch?v=Z2bPTs8fspk>. Accessed 04 March 2021.

Descartes, René (1998), *Discourse on Method (1637) and Meditations on First Philosophy (1641)*, (Fourth edition, trans. Donald A. Cress), Indianapolis, IN: Hackett Publishing Company, Inc.

Eastwood, Steven (2016), 'The interval and the instant: Inscribing death and dying', *Moving Image Review & Art Journal* · Volume 5 · Numbers 1 & 2, pp. 26-42.

Eastwood, Steven (2017), *The interval and the instant* Steven Eastwood, November 2017
<https://www.fabrica.org.uk/the-interval-and-the-instant>. Accessed 13 April 2021.

Gold, Jeffrey (1985), Cartesian dualism and the current crisis in medicine - a plea for a philosophical approach: discussion paper, *Journal of the Royal Society of Medicine*, vol. 78. pp. 663-666.

Merleau-Ponty, Maurice ([1945] 1962), *Phenomenology of Perception*, (trans. C. Smith), Routledge.
Cited in Carel, H ([2008] 2013), *Illness: The Cry of the Flesh*, London and New York: Routledge.

Mulhall, Stephen ([1996] 2005), *Heidegger and Being and Time*, London and New York: Routledge.

S. Robin Cohen, Balfour M. Mount, Jon J.N. Tomas and Lauren F. Mount (1996), 'Existential Well-Being Is an Important Determinant of Quality of Life: Evidence from the McGill Quality of Life Questionnaire', *Cancer*, 77: pp. 576–586.

Toombs, S. Kay (1993), *The Meaning of Illness: A Phenomenological Account of the Different Perspectives of Physician and Patient*, vol. 42, Dordrecht: Kluwer Academic Publishers.

Toombs, S. Kay (1998), 'Illness and the paradigm of the lived body', *Theoretical Medicine* 1998 Jun;9(2):201-26.