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Memories of Futures: The Temporalities of Organ Transplantation

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Abstract

This photographic essay explores experiential meanings of haunting in deceased organ transplantation. Where life is often figured as presence and death as absence, this piece delves into how one may be both dead and alive, present and absent. In so doing, it creates space for how death may be vitality and how afterlives continue in the form of collective being. The photographic essay, as a genre, is examined as a turning towards the more-than-one in the self and death as constitutive of life. Photography becomes one way to foreground haunting as both material presence and visual absence. In turn, double exposure opens up the possibility of deceased donor presence and absence in the form of disappearing bodies, body doublings, two beings in and of the self, and ecologies in and of bodies. Haunting – through the technique of double exposure and this uncertain meeting of language and images – creates the possibility of giving visual presence to the dead in the self, to deceased organ donors in transplanted bodies. In so doing, the essay suggests that haunting is integral to the experience of transplantation, to transplant temporalities, where pasts are unknowable and lived, and futures are simultaneously foreclosed and yet to be realized.

Keywords

organ transplantation, photography, disability, illness, temporality, future, haunting

Haunting is when someone, or some thing, is both present and absent, and its realness and existence thereby questionable. The one who witnesses the haunting

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could be believed, pathologized as mad,[1] refuse to acknowledge what has been seen, or live with the disruption that is haunting. Transplantation may be the promise of a future to those of us whose organs are failing or have failed; it is an uncertain future, one marked by old and new illnesses, the temporality of donated organs (e.g., that a donated liver lasts on average thirteen years), and thus a proximity with death as that which is imminent, delayed, and inevitable. For some recipients, there are memories of futures that never were, imagined plains of deceased donor lives, and lives recipients will never live, because of illness, attachments to specific medical teams, and so many more disabled and sick ties that bind us. Hauntings are integral to the transplant experience for some recipients, to many transplant memoirs and to the images included in this essay "precisely because the materiality that is of the other [the donated organ]—but is not the living other—evokes an epistemological and ontological uncertainty about the simultaneity of life and death, presence and absence, and of this time and of belonging to a past (indeed, finished) time" (McCormack 2021b, 72). Following Eve Tuck and C. Ree, I explore how hauntings "[refuse] to stop," are "not what needs to be resolved" (2013, 642), and thus how they are potentially scary invitations to bear witness to what is often unseen, unspoken, unheard, dismissed, refuted as unscientific in the experience of transplantation, illness, and disability.

The words in this essay do not provide answers or interpretation. The essay is a form to "try, test and practice" (Washuta and Warburton 2019, 10), and I use it to explore how to write and visualize histories that are there and yet not always apparent. Thus, "I write from the body" (Whitehead 2022, 74), and my "body leads and there is no choice but to follow" (Huber 2017, 33). Where Joshua Whitehead explores language's relationality to kin and to storytelling as a form of care, I seek to explore the kin we forge through language, photographs, illness, disability, and death. Are our kin those who are already dead but whose organs remain in the bodies of living recipients? Speaking on his story writing and theorizing, Billy-Ray Belcourt states that his "job" is "to report from the scene of an undead past colliding with a still-to-be-determined future" (2020, 12). I take this *almost* literally: photography, for me, turns to the undead past of an unknown donor vitally present in the unpredictable future of a living recipient. Sonya Huber suggests that pain "changes the way I write and the way I think" (2017, 32). I remember times of less pain, but, like Huber, I feel intense pain occupy my bodymind, forcing me to change, to adapt my life to it. I am intrigued by how other recipients speak of a connection to living and deceased donors, and although I have never felt this, I know I am composed of parts from an other, a dead other. Perhaps, like Huber's description of a body in pain, which often transplanted bodies are, "I am two bodies, and one is the history of me" (17). Yet I know and feel I am one body, it is however a body haunted by histories of which I have no knowledge; whether these be those histories of my grandmothers or of an unknown donor, my body tries to remember. Therefore, these photographs and these words bear witness to and are "evidence of absence" (Prosser 2005, 1).

While I, as subject and object of the photographs, may come close to being what Roland Barthes describes as the literal "emanation of the referent" (1981, 80), the use of double exposure speaks to "that rather terrible thing which is there in every photograph: the return of the dead" (9). Is that me, the donor, or something else? Yet my words testify to what you do not see: you cannot (always) know illness, disability, transplantation through the gaze. Knowledge may seem limited to my words, which refract through what is seen as absence, and absence haunts my words, dispersing the body of text, the body as text. Here, "absence has agency, in some guise or form" (Meyer and Woodthorpe 2008, para. 4.2). What kinships are forged through living body parts from dead people? And, what body politics might be imagined when the dead are materially present and absent?

The photos in this essay are taken by me on a Rollieflex 3.5F using 120 color and black and white film. It is material film that interacts with light and the objects and subjects in front of the lens, and is then digitized. All are materially present, there, but in exposing the film multiple times—double exposure—what is seen is an almost present or absent person. This person—me—is always transparent, there and not there. We see through the person, whilst also seeing the person as if the camera captures some aspect of me without defining me in any totalizing form via the parameters of the visual.

Like S. Lochlann Jain, I find myself in an epistemological and experiential "trade-off" (2013, 18) where I have thus far not turned to the personal to portray "a perspective not available in other ways" (20); instead, I have stayed with fiction (films and novels) and memoirs to argue for histories of transplantation that convey how death haunts transplantation and how it is tied to colonial histories of racialized violence (McCormack 2021a, 2021b, 2021c). Death is constitutive of organ transplantation, particularly deceased organ transplantation, and although I would argue that death constitutes life more broadly, here the photographs are traces of how death is a daily, ordinary, lived experience of having the organ from a deceased donor inside one's self. There may be someone else present, or a tiny aspect of that person present (in the form of a donated organ), but they are also absent: there and not there, haunting everyday life. In my experience, this is not an anxiety (Kierans 2005; Shildrick 2015) that some suggest could be treated by bringing psychiatrists and/or psychologists onto transplant teams (although some will undoubtedly find this support helpful), but rather a way of living with death intimately. This intimacy is in the form of the transplant, deceased donors, life-long immunosuppressants that result in further illness and susceptibility to illness, as well as illness that may happen just as it does in a broader population but is at times more difficult or impossible to treat.

Figure 1. Seeing Double. Copyright Donna McCormack.

Figure 2. Others in the Self. Copyright Donna McCormack.

Perhaps there is an other who watches over the self, which may be experienced in transplantation as a presence, not as a dead other coming back to haunt, but the loss, start, persistence, trauma, and end of life in all its lively and deadly forms. Simply put, this is the multiplicity of being—where we come into being through our inter- and intra-action with plants, human animals, nonhuman animals, pollution, water, dead people, lively body parts, and more. I see death as materially present, as creating kin, and pushing us to reconsider how we materialize relationality and responsibility. As Eli Clare suggests, "bodies are never singular, but rather *haunted*, strengthened, underscored by countless other bodies" (2015, 11, emphasis added). We are more than one, even when we may feel whole, where wholeness allows for a belief in linear continuity, in restoration of the body to a pre-transplant life. The disruption of transplanted life is multiple, never-ending as life continues through biotechnological interventions of clinics, theaters, pharmaceutics, re-transplants—an ongoing list that can never be captured as many of us live only through our encounters with transplant teams, gastroenterologists, endocrinologists, oncologists, ear, nose, and throat specialists, gynecologists, nephrologists, urologists, cardiologists, and more. Our bodies are scanned, x-rayed, tested repeatedly week on week, month on month, year on year watching for the smallest changes, subject to pains of tests and of illness, as well as to relief. The more-than-oneness may give a sense of being able to survive such intrusions as the more-than-one be and do together; this multiple is not utopia, just a way of living with death.

Decades later, exceeding any possible expectation of transplanted life, I am still alive, but perhaps all this time has been sickness progressively worsening. At times, it has felt like vitality, like presence; other times it has and currently feels like sickening towards absence whilst still present. Transplantation does not cure, but in some cases it prolongs lives. However, it also creates newly sick bodies: my post-transplant body is a plethora of illnesses, symptoms, and occasionally treatments. How might we nurture our sickening bodies without rendering us absent from society, from social networks? How to be present when we are living with pain, illnesses, and debilitating conditions? In Panteha Abareshi’s (2022) words, “Medical ‘precautions’ for chronic worsening raise challenging questions of quality of life, of pain, of death that is not a vague, distant eventuality—but a daily lived experience breathing hot down the back of the neck. I am sick, I [am] disabled, and I will only get sicker, I will only get more disabled.” I am sick, in some ways more ill than I have ever been, and there is no cure, often no relief. The ableist desire to fix shuts down how organ recipients—and all of us—are radically unfixable. I am here telling this story in images and words not because I need to be seen, but because we refuse to look at how longevity, extension of life may be lived as a daily encounter with death and illness in all its gruesome and sometimes beautiful forms. For me, transplantation comes close to how Leah Lakshmi Piepzna-Samarasinha describes how the past and the dead relate to the possibility of futures: “Being closer to the dead than the living is another kind of crip relationship” (2020, 249). In transplantation, illness and disability are always present, as what makes life possible, as what life itself brings in its persistence. Crip kin and crip relationality are forged through these moments when we are both present and absent, when we witness both life and death, and when we experience bodyminds as healthy, ill and disabled. Transplantation is part of a

Figure 3. Multiple Beings. Copyright Donna McCormack.

Curative imaginary, where normative structures repeat that health is always in reach and that human life is precious and therefore must be extended. Could the turn towards death revitalize transplantation as bearing witness to the visceral experience and structural inequities of organ transplantation? As the planet is destroyed at the hands of humans, as many die daily trying to reach the hostile island of the UK, as Black people are murdered by police officers, as opioids become inaccessible to many in pain from biotechnological interventions, we have to ask: Whose lives are being saved? How might justice be integral to biomedicine? How are socioeconomic inequalities constitutive of healthcare and access to life-extending technologies? Death in life—or what I am calling haunting—is one way to be, do, think, and co-exist where disability and illness are not always overcome, cured, or eradicated.

In some ways being a three-decade transplant recipient comes close to the way Audre Lorde describes her experience of breast cancer, even whilst our identities and privileges are different. In her words: "I am writing across a gap so filled with death—real death, the fact of it—that it is hard to believe I am still so very much alive" (1980, 54). The photographs included here materialize the intersection of presence and absence, as well as interrogating the assumed connection between life as presence and death as absence. Jeremy F. Walton and Çiçek İlengiz argue there is an "uncanny mingling of past and present in afterlives" (2022, 348) and thereby that "taking materiality and objects seriously demands a refusal to reduce them to their affective entailments for subjects" (350). These photographs explore how material from the dead may be animated inside a living being, how matter may be irreducible to either subject or object, and thereby put into question the certainty of these onto-epistemologies. Ruha Benjamin (2018) engages with "afterlives" to speak about how Black people murdered through police brutality have formed the basis of a collective politics of resistance, kin-making, and building alternative presents and futures. She states, "Kinship with the dead has its own demands and effects" (2018, 50). There is no equivalence between Benjamin's argument and the photographs here, but instead I evoke "afterlives" as a way of exploring this kinship with the dead in the context of illness and disability, as well as linking Benjamin's arguments to further contexts where the dead remain animated, both literally and metaphorically. Transplantation, as Benjamin (50) suggests, building on Anne Pollock's work (2015), is always submerged in these questions of racial justice, disability justice, and global inequalities.[2]

I look back on their future that was never to be, on the deceased donor who makes my daily life possible, not as an idyllic cure, but as decades of illnesses, worsening symptoms, and disability joy.[3] I contemplate Jay Prosser's statement: "photography captures a reality that we would otherwise not see, that we would choose *not* to see" (2005, 1). Will absence—as viscerally present, deadly absence and double exposure—do work in the medium of the visible to be present? A viral pandemic that is SARS-CoV-2 is yet another layer to life when immunocompromised, transplanted, and in community with others. Masks, clean air, vaccines—when accessible—are some of the ways in which we might care not just for our own selves but also each other. Belcourt states, care "is to participate in a process of self-making that exceeds the individual" (2020, 92). Given transplantation is to be dependent on a donated organ for life, then self-making is always already a process of caring for an other, a dead other, and may thereby also be how we care for other others. Assuming we know what immunocompromised, transplanted, sick, disabled, Mad people (particularly those whose mental health is seriously impacted by transplantation) look like or what we might need fails to realize that we are always amongst you, haunting the imagined normality of healthiness. You might not see me as sick, but that gaze, your gaze, does not define my reality. Even when we do not declare our status, we are still there. As Tuck and Ree argue, "Erasure and defacement concoct ghosts; I don't want to haunt you, but I will" (2013, 643). As we get sicker and more disabled we do not vanish, even when confined to our homes. There is a wish to haunt.

Figure 4. Still Vital. Copyright Donna McCormack.

I have memories of futures of living with the organ of a deceased donor, wondering what deceased people's lives were, not just the donors, but those who die daily fleeing conflict, at the hands of police, through medical neglect. Post-transplant life is not detached from the very power dynamics of existence that make such interventions potentially impossible or realizable. Transplantation is haunted by questions of inequality even if the practice may not always address who accesses healthcare, who donates, how waiting lists work, medical racism and sexism, homo- and transphobia, and so many more intersecting vectors of inequality, prejudice, and exclusion. My own research seeks to think transplantation with colonialism and queer, as a desire to engage with its constitutive structures where biomedical and biotechnological experiments and treatments require disposable and recyclable bodies and parts.

My photography opens up questions of what it means to be present as a sick and disabled person, a dead donor, a living recipient, in a global pandemic, and how we materialize the injustices of health, illness, particularly transplantation. The materiality of a 120 film, of being present and yet not fully materialized in these images, is one way of thinking and doing transplantation. Seeing partially and multiply may evoke the kin who are dead, whose parts are there even if not visible. Sickness and death may not be readily readable and yet their presence is felt, lived, and there. "Memories of Futures" is a question of witnessing what happens in transplantation that is rarely spoken about, acknowledged or is even dismissed; it is a way of remembering that other disabled and sick(er) lives are possible; and it is a desire to haunt to mobilize collective care.

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Notes

[1] For more on the politics of the term *mad*, see Shayda Kafai's *Crip Kinship*, particularly note 2 (2021, 183) for detail regarding when the term might be capitalized. I do not capitalize it here to emphasize that this is an imposed diagnosis rather than a chosen identity or emerging from activism, but I do capitalize it later in the essay when I refer to those of us who may identify in this way. See also Therí Alyce Pickens's *Black Madness :: Mad Blackness* (2019).

[2] There are many who explore racial inequalities, particularly in the context of global injustice, in relation to transplantation. See, for example, McCormack (2021a, 2021c).

[3] The first clause in this sentence is a reworking of Claire Sylvia's way of describing her connection to her donor: "I felt his future that was never to be" (1997, 160). For an analysis of this text, see McCormack (2021b).

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