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Troubling Transplant Temporality through Crip Technoscience and a Sensory Aesthetics of Time, Machine, and Health

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Abstract

Taking up technologies that act as a "bridge" to transplant, we explore what the lifeworlds of a transplant patient and their loved ones interacting with these technologies tells us about the temporality of transplantation and the imperative of cure. By engaging with clinical literature and practices, transdisciplinary crip technoscience theorizing, and multimodal, multisensory artistic form, we bring together sick and disabled people's expertise and diverse ways of knowing that enable a rich and nuanced exploration of transplant time that complicates biomedical expertise while at the same time recognizes its embrace as one with opportunity and potential for care and collaboration. In troubling transplant

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temporality through crip technoscience and a sensory aesthetics of time, machine, and health, we demonstrate how perspectives often excluded or minimized in acute care offer innovative ways in which to think through the material limitations of taken-for-granted understandings within transplant settings.

Keywords

bridge to transplant, crip technoscience, disability art, sensory aesthetics, ventricular assist device (VAD), extracorporeal membrane oxygenation (ECMO), ableism

Introduction

Worldwide, over 150,000 solid organ transplant operations are carried out on an annual basis (GODT 2022). Country by country, rates of deceased donor organ recovery and living organ donation are outstripped by the numbers of individuals in need of transplant (Lewis et al. 2021). In Canada, for example, more than 4,000 people await transplant each year and 250 to 270 individuals will die on the wait list (CIHI 2023). The discrepancy between those who are in need of transplant and the limited number of organs available for donation results in significant clinical, technological, and research attention given to, and resources focused on, how to best optimize the health of individuals being listed and how to maximize possibilities for timely organ retrieval. Over the past three decades especially, technoscientific innovations in transplant medicine have proliferated in response to these supply-demand challenges, including, for example, how to prolong the viability of organs *ex vivo*, such as through the "heart-in-a-box" technology, which can extend a heart's ischemic time from the traditional four hours to up to twelve hours (Sunjaya and Sunjaya 2019), or the use of *ex vivo* lung perfusion in concert with gene therapies (Gao et al. 2022); how to transplant marginal tissues that would otherwise be unable to thrive in a new bodily ecosystem (Resch et al. 2020); how to fine-tune medical interventions for optimal physiological health even as the reason one barrels toward transplant is the acceleration of end-stage organ failure (Wood-Trageser et al. 2020); or how to expand donor pools through xenotransplantation (Cooper et al. 2018).

Within this focus on the supply-demand dilemma, it is easy to overlook other pressing challenges associated with the complexities of life pre- and post-transplant. What is more, these challenges can be difficult to articulate and address because of the dominant cultural scripts that surround the temporality of transplant. These scripts mark post-transplant life as a kind of "afterward," steeped in imaginaries of cure and of health and vitality restored, even as difficulties exist and persist prominently across transplantation's full temporal span (Heinemann 2020; Wasson 2021). As noted by heart transplant recipient Andrea Barrett, "people feel they cannot share certain facets of transplant life and the harsh realities of transplant medicine because it could potentially reduce the

pool of organ donors" (2023, 38). Barrett links this hesitation to ableism and the socially ubiquitous notion that people are better off dead than disabled. If, as an intervention, transplant itself qualifies recipients as socially undesirable chronically ill disabled people, attaching negative and nuanced narratives to transplantation could further reduce an already scarce supply of donor organs. It is precisely because solid organ transplantation is often considered a pinnacle of achievement in contemporary biomedicine, bringing "second chances" and "rebirth" to individuals facing end-stage organ failure, that other complications and experiences are left unexplored and unspoken. Hope and gratitude are normative affective orientations to transplantation, at times contributing to isolation, guilt, and disillusionment when the optimistic outlooks expected of organ recipients are challenged by difficulties and unmet expectations (Schipper 2014). The field of transplantation, as a field marked by exceptionality and technological prowess as well as a normative optimism attached to cure, has struggled with not only how to understand and represent the quotidian challenges of transplant in ways that are patient-centered, but also how to mobilize insights from patient perspectives to enact changes that can improve post-transplant liveability. It is necessary to address this struggle to mobilize insights from patient perspectives to improve patient agency and thriving both pre- and post-transplant given that so many medical and psychosocial complications are common throughout the experience from threats to survival and traumatic interventions while wait-listed, to postoperative complications and the complexities of long-term adherence to intensive medical regimens and accompanying biomedical surveillance, through to the emotional challenges of survivorship, the sequelae of immune suppression, graft failure, and end-of-life care for transplant patients (Abbey 2011; Colman et al. 2015; Molonado, Sher, and Lokak 2017). While developments in transplant procedures since the 1980s have resulted in a marked increase in one-year survival rates, thereafter the annual mortality rate of 3 to 4 percent has remained constant.[1] The long-term outcomes of organ transplantation, therefore, remain limited largely due to the inability to address the complications of rejection and the damaging effects of immunosuppressant drugs (Claeys and Vermeire 2019; Wilhelm 2015). Given the ubiquity of these medical and psychosocial challenges and poor long-term outcomes, it is imperative to amplify and act on the insights of those with lived experience of transplantation to improve access to healthcare and technologies that enhance quality of life and also to acknowledge the needs, wants, expertise, and contributions of sick and disabled people.

Considering these tensions, in this paper, we bring together clinical practices, crip technoscience theorizing, and forms of multimodal and multisensory artistic research-creation to forge new knowledges troubling the temporality of transplantation. Crip technoscience (Fritsch et al. 2019; Hamraie and Fritsch 2019) approaches transplant medicine from the agentive perspective of sick and disabled people, drawing attention to inequities and injustices in healthcare

access and treatments and tracing how ableism and the hegemonic force of the curative imaginary impacts their experiences and quality of life. At the same time, crip technoscience highlights how the creative practices of sick and disabled people navigating transplant contributes to, and can potentially transform, healthcare practices, cultural scripts of transplantation, and offer expertise about what it means to continue living on, and the strategies and ways of being that enable continuance. Through a crip technoscience lens, we mobilize clinical, patient, and artistic research-creation perspectives to improve pre- and post-transplant liveability and contribute to troubling notions of "health" as a temporal destination of transplantation, especially as the "temporal hauntings of before shape the afterward" (Berkhout, Fritsch, and Wong-Mersereau 2023, 2). The contemporary proliferation of transplant technologies offers a rich domain in which to explore how material constraints arise from ableist exclusions within the field of biomedical technoscience. These ableist exclusions intersect with other structural inequities and forms of oppression. It is crucial to recognize and incorporate the expertise of patients, those with lived experience of chronic illness and disability, and the contributions of artistic practices, which can lead to significant positive change.

In what follows, we begin by taking up technologies that act as a "bridge" to transplant, exploring what the lifeworld of a transplant patient utilizing these technologies tells us about the temporality of transplantation and the imperative of cure. Transplant technologies that are referred to as a "bridge" emphasize the capacity for the machinery to enable survival by taking over endogenous organ function until the more definitive intervention of transplantation can take place. We employ crip technoscience to analyze bridge to transplant technologies such as ventricular assist devices (VAD) and extracorporeal membrane oxygenation (ECMO) techniques. These technologies are positioned as a bridge offering passage away from solid organ failure and toward what is purported to be a destination of health post-transplant. Often lost in the orientation to health, cure, and the overcoming of organ failure is the temporal, sensuous, and machinic embodied experiences of living in, with, and through organ failure, chronic illness, and disability, not only as a result of the orientation of bridge to organ transplant process as a kind of overcoming, but also in how post-transplant life is described and hoped for as a "new and improved state" (Standing et al. 2017).

We draw on clinical literature and practices to trouble some of the ways bridge to transplant is frequently positioned through a linear temporality of biomedical cure that orients a person with organ failure to transplant as a destination of health. We juxtapose this positioning to artistic explorations of the lived experience of bridge to transplant and its aftermath, including drawings by visual artist and double lung transplant recipient Dominic Quagliozzi (2023), and Brian and Bibo Keeley's digital short film *Breathe* (2021). We also engage other multimodal artistic works that take up issues surrounding transplantation and

temporality more generally, including Jonathan Kawchuk's soundscape *Boundary Loss* (Kawchuk and Berkhout 2023), and a narrative essay by now deceased heart transplant recipient Amy Silverstein (2023). Combined, these artistic works engage with the sensory aesthetics of time, machine, and health, illuminating aspects of living in, with, and through organ failure in important ways that are obscured not only by the dominant temporality of transplantation but also by the bridge to transplant practices themselves. Convivial with crip technoscience, sensory aesthetics articulate knowledge and experience from a multisensory perspective, incorporating senses like smell, texture, and sound. This approach illuminates and communicates subtle perceptions that challenge conventional biomedical views of the body, which often prioritize uniform understandings of the body that are grounded in a temporality of transplant as a destination of health. We take up crip technoscience and sensory aesthetics to more deeply engage with the embodied insights of sick and disabled people that challenge and complicate entrenched biomedical discourses about solid organ transplantation experiences, premised on the position that not all experience or knowledge is empirically quantifiable or best expressed through words (Culhane 2016; Frankel et al. 2024). In so doing, we take up transplant temporality as "borrowed and looped and experience lived in ways that undercut the seemingly straightforward and linear relationship between transplantation and cure" (Berkhout, Fritsch, and Wong-Mersereau 2023, 2).

In troubling transplant temporality through crip technoscience and a sensory aesthetics of time, machine, and health, we demonstrate how perspectives often excluded or minimized in acute care offer innovative ways in which to think through the material limitations of taken-for-granted understandings within transplant settings. Through this, we forge possibilities for improving the quality of recipients' and families' experiences. By engaging with transdisciplinary crip technoscience theorizing and multimodal, multisensory artistic form, we bring together sick and disabled people's expertise and diverse ways of knowing that enable a rich and nuanced exploration of transplant time that complicates biomedical expertise while at the same time recognizes its embrace as one with opportunity and potential for care and collaboration.

Transplant Machines

The spectrum of transplant-related interventions runs from the spectacular to the mundane: mechanical ventilation, ventricular assist devices, dialysis, cooling machines, portable aspirators (suction machines), nasogastric feeding tubes, shunts, ports, drains and intravenous (IV) lines—the number of ways that someone can be tethered and have usually bodily boundaries of inside/outside blurred is almost endless. Within this list, there are those devices or machines that are purpose driven to improve a critically ill individual's chances of survival long enough to be eligible for a transplant, or while wait-listed to receive a donor organ and create what is often termed a "window" for transplant (Sakpal et al. 2018).

One such technology is extracorporeal membrane oxygenation (ECMO), a technique for providing prolonged cardiac and respiratory support by pumping and oxygenating blood outside of an individual's body. ECMO "is routinely offered to patients with a rapidly declining end-stage disease as a bridging strategy to transplantation or, in the case of instability or inadequate graft function, as intra- and/or post-operative support" (Faccioli et al. 2021, 291). Unlike a heart-lung machine, which is used for a number of hours in a surgical context such as coronary bypass, ECMO is designed for longer term use and can be deployed for several days, or even weeks, to enable the survival of individuals with heart and/or lung damage, injury, or rapidly declining end-stage disease (Johns Hopkins Medicine, n.d.).

This technology is characterized as especially advantageous given that the number of patients on transplant wait lists far exceeds the number of available organs and can act as a bridge to transplant (Faccioli et al. 2021). A range of cannulation strategies and implantation techniques exist and are described in the literature as ways to personalize and optimize cardio-respiratory function. ECMO is described as adaptable, with multiple configurations (for instance, it can be used for pure pulmonary support or for combined cardio-pulmonary support in critically ill individuals). Technical advances since the early 2000s have led to improvements in survival following intervention as well as exponential increases in the use of ECMO, particularly prior to lung transplantation (Gulack, Hirji, and Hartwig 2014). That said, there is a paradox at the center of this technology: those who would most benefit from ECMO are the urgent patients with high predicted pre-transplant mortality; these same individuals are often considered *too* critical to be suitable for ECMO as a bridge to transplant (Faccioli et al. 2021). In light of this, various transplant societies have created guidelines that detail liabilities for ECMO, including septic shock, multi-organ dysfunction, obesity, advanced age, or underlying irreversible neurological disease (Faccioli et al. 2021). For example, the International Society of Heart and Lung Transplantation reports that ECMO "support should be recommended in the case of young age, absence of multiorgan dysfunction and good rehabilitation potential" (Faccioli et al. 2021, 293). For as much as there might be a physiological rationalization for such exclusion criteria, they align with (and reinforce) other forms of exclusion in transplantation that have been challenged from equity and justice perspectives, especially in relation to structural factors that influence interpretations of what "good" rehabilitation potential means (Lorusso et al. 2021; Mattar, Chatterjee, and Loor 2019).

Another technology used in heart transplantation is the ventricular assist device (VAD), an increasingly common way to support individuals whose heart failure is worsening despite active medical management and require temporary cardiac support. A short-term VAD is used for those who may be seriously ill in a hospital setting. It supports the heart, either until it recovers, or if the heart is permanently

damaged, the VAD can offer extended life support while other non-cardiac complications—such as renal or respiratory failure—might improve enough for the patient to be listed for an urgent transplant. A long-term VAD is a portable device for non-critical patients, who may have already been listed for a transplant, and who are often able to return home while waiting until a donor organ becomes available. Patients may live with a long-term VAD for several years while waiting for a transplant. VADs are likewise referred to as a bridge to transplant (Sharp 2014). Seen as "durable and reliable" forms of mechanical circulatory support, these technologies are now a standard of care when end-stage organ failure or life-threatening exacerbation of existing heart failure occurs (Holley, Harvey, and John 2014, 1110).

The bridge as metaphor is multi-layered, hailing objects of engineering, components of musical instruments and musical composition, as well as the command center of a ship (Huser, Dockett, and Perry 2016). At another level, the bridge serves as a symbol that denotes the passageway between "the mortal, the transitory, and the immortal," connecting the profane with the sacred (Gordon 2018, 2). Giving access to the supra-sensory, to heaven, the bridge-builder is seen, then, as outwitting gods of death or the devil (Gordon 2018). As Rosemary Gordon has described, the bridge presupposes boundaries and separateness, configured as a "here" and a "there," a "then" and a "now" (2018, 4). As it is employed within the field of transplant technoscience, the symbol of the bridge denotes support as a passage is navigated, as well as expert guidance through that navigation. The movement it reflects is forward, linear—toward a better place, a place of restored health.

The bridge metaphor orients transplant experience, spotlighting certain issues as relevant and attending in particular to the perspective of the transplant team. And while the "crossing" aspect of the bridge metaphor speaks to the liminality and uncertainty of the experience of being wait-listed, in some cases, this liminality refers to people who are often too sick for life yet too well to be prioritized for transplantation (Larson and Curtis 2006); in other instances, people are too sick for life, too sick for transplant. In either case, the metaphor belies the notion of transplantation as a destination.

Sidedness, Linearity, and Loops: Temporalities of Transplant

Embedded in the *sidedness* of the bridge metaphor is an understanding that one reaches an end or target location. ECMO is considered an interim measure that will facilitate an individual's crossing the chasm of organ failure, reaching a destination of restored health in the aftermath. VADs were initially conceived of as a so-called destination intervention as the VAD itself is sufficient to support longevity and quality of life such that it is an alternative to cardiac

transplantation. Indeed, some patients go home with VADs as a permanent transformation of their bodies, and not simply as a bridge in anticipation of a future transplant. However, since the mid-1990s, interventional research has focused on the importance of VADs for supporting post-transplant success, including improved one-year survival (Frazier et al. 1995). With "health" as the destination, the crossing then becomes the work to be done, and the technical prowess of the intervention is the locus for improvements and innovation. The notion of health as a sought-after destination is likewise marked by the simultaneous connotation of ECMO as a *rescue* strategy for post-transplant support when complications arise—intervention remains inevitable and attempts to approximate cure through transplantation continues as an ultimate endpoint (Faccioli et al. 2021). These viewpoints arguably take resources and attention away from what it means to live well in the post-transplantation lifeworld, or what it can mean to not pursue transplant at all. That is, mechanical intervention can act as a bridge to transplantation, but for the patient, the transplantation is never the end destination, even if dominant cultural scripts and the temporality of transplantation orients patients to perceive it as a destination. Instead, it is a vital but single step on the journey to some sense of recovery from organ failure as well as a form of living with altered embodiment.

Contra dominant cultural scripts and temporalities, transplantation is not, in and of itself, a final destination. This is because the afterward of transplantation is a continuity of numerous medical and psychosocial challenges—from transplantation, from bridging technologies themselves, and the interventions that surround these. Improvements to technologies such as ECMO have not altered common complications, including bleeding, infection, and renal failure; less usual are issues such as stroke and limb ischemia, resulting from a restriction in blood supply to the brain or limbs (Faccioli et al. 2021; Gulack, Hirji, and Hartwig 2014). Within the transplantation literature, comparative analyses in primary graft dysfunction focus on the metrics of the technologies used to sustain life and attempt to prevent further end organ damage while "rescue" therapy takes place (whether this is rescue by ECMO or devices such as VAD). And while it is certainly meaningful to examine whether ECMO is superior to VAD, the literature leaves unquestioned the centrality of technological intervention as well as the impact of needing such therapies on those who are struggling in the aftermath of graft failure (see, e.g., Takeda et al. 2017). The bridge metaphor shifts focus away from the challenges and difficulties that are undeniably a part of transplant recipients' lived experience—whether these challenges are embedded in the uncertain liminality of being listed or experienced by those who have "crossed" the bridge.

The complexities of life pre- and post-transplant cannot easily be communicated if the assumption is that the destination has been (or will be) expertly reached, and (potential) transplant recipients are always under scrutiny to demonstrate

their wholehearted commitment to transplant and their capacity to follow the medical obligations generated by transplantation (Barrett 2023; Berkhout et al.2022). The silence that surrounds the complexities of transplant is particularly problematic considering how the field's technological advances (and the expert guidance attached to these) contrast with the lack of advances in the post-transplant lifeworld, including long-term survivability. For example, the drug regimens of transplant recipients typically includes the twice daily use of immunosuppressing drugs such as cyclosporine, first introduced in 1983, or tacrolimus, introduced in the 1990s. Tacrolimus continues to be the standard drug for immunosuppression among new transplant recipients (Chang et al. 2021) and is often paired with other maintenance agents such as mycophenolate mofetil, introduced in the 1990s, and prednisone, a steroid introduced in 1955. These drugs need to be taken at specific times of the day, some with food, some without; tremors are a common side effect after ingesting some, fading as the day continues. Medications heavily regiment the daily lives of recipients in ways that draw continuities with medicalized life pre-transplant rather than marking a "new beginning" (Heinemann 2020). This sentiment is expressed in the work of double lung transplant recipient and visual artist Dominic Quagliozzi. In *Visceral Diary Drawings* (2023), Quagliozzi captures his life on the pre-transplant waiting list with lung failure through to two years post-transplant. One drawing in this series, titled "I Am Support Devices," shows Quagliozzi's barely visible pre-transplant body entangled with devices, wires, tubes, liquids, and oxygen. Another drawing, completed three months post-transplant simply asserts in comic-style bubble lettering, "My immune system is pills." Quagliozzi's art attends to the complexity of an afterward of transplant as a kind of continuity of enmeshments with transplant technologies that radically alter bodies and subjectivities—here, taking the form of an ongoing reliance on pills. Pills that fix certain problems and create others, pills that solve the problems created by the first set, and so on. The avant-garde quality of Quagliozzi's work is, in part, for naming the frustrations that have previously remained unnamed.

To articulate to the difficulties of the post-transplant lifeworld is, in some ways, to undermine the tacit understanding of transplant technologies as cure, and the nebulous concept of health as destination. And while there may be a sense of restored vitality post-transplant, it is also the case that as physical and emotional challenges build and the complexity of post-transplantation medical needs becomes apparent, recipients can easily enter what has been termed "the fall": tormented by the restrictions and responsibilities of caring for their donated organ (Sheikhalipour et al. 2018). In longer-term survivors of transplantation, the post-transplant experience is one where the illness narrative is never finished—not only from memories of past illness, but a present marked by medication side effects and where the intrusion of further illness or graft dysfunction is ever present (Boaz and Morgan 2014). And although survival rates one-year post-transplantation have improved dramatically across most domains of solid organ transplant, recipients

remain at risk for numerous conditions including cancer, infection, metabolic diseases such as diabetes, ulcers and delayed wound healing, high blood pressure, and immunologic graft damage due to the combination of medications that are necessary for immunologic suppression, impacting longer-term survivability (Claeys and Vermeire 2019). As such, there remains a pressing need "for newer drugs that promote immune tolerance without the side effects observed with current immunosuppressive agents" (Claeys and Vermeire 2019, 15).

Laura Heinemann has articulated how the curative possibilities of transplantation are ones that "epitomize the power and promise of biomedicine" (2020, 82). At the same time, as her ethnographic work demonstrates, when one is living with transplant, one is "never quite beyond illness" (83). Two-time heart transplant recipient, Amy Silverstein's (2023) essay likewise offers this perspective, noting how the experience of long-term transplant survivorship is more complicated than messages surrounding transplant, which "tend to follow a familiar narrative of dramatic transformation: the gravely ill patient becomes a thriving, active individual through high-tech medicine and the generosity of organ donors and their families." Silverstein's first donor heart died as a result of insufficient treatment options to offer protection from rejection while her life with her "perfect" and "beautiful" second heart was ultimately cut short due to incurable cancer caused by her drug regimen.

The intensive self-monitoring required to maintain one's transplanted organ also places a psychological toll on recipients, their loved ones, and caregivers, and the medical events leading to critical illness and pre-transplant organ failure can also have persistent emotional impacts lasting well beyond the surgical healing process (Lai, Ufere, and Bucuvalas 2020). In the weeks leading up to her death, Silverstein writes in the *New York Times*,

> The side effects of transplant immunosuppression can be sickening day to day, as my small posse of stalwart organ recipient girlfriends knows well; we talk about the vomit bags stashed in our purses, the antacid tablets we tuck into our front pockets for quick-nibble access at a cocktail party or when giving a presentation at work. We've encouraged one another to be inventive and keep finding little fixes or at least ameliorations.
>
> Yet over time, each of us tolerate significant challenges and damage, the kind that prompt us to call late at night in tears, reeling from the intractable infections that land us in emergency rooms and hospital beds, the biopsies that pluck pieces of our donor organs leaving us scarred and shaken, the skin cancers that blossom rapidly beside an eyelid or ear. We've learned that there can be no clearing every single cancer cell with a suppressed immune system; we will get cut again, and again, and again.

In addition to these stressors, many transplant recipients report a sense of indebtedness to their clinical team and donor that complicates negative emotional responses and experiences of stress resulting from complex medication regimens with numerous side effects (Tong et al. 2011). But because transplantation is often conceptualized as a "new beginning," a "second chance," and the "gift of life" (Siminoff and Chillag 1999; Stubber and Kirkman 2020), a curative imaginary frames transplant medicine. This frame is practically "a genre" (Heinemann 2020, 83) and can prevent a robust engagement with the challenges of survivorship, including how to live well with chronic illness and disability. As Heinemann puts it, "While illness might be periodically obscured in the tangle, it is never truly severed from the experience of living with transplant" (83). Silverstein (2023) notes that this "narrative discourages transplant recipients from talking freely about the real problems we face and the compromising and life-threatening side effects of the medicines we must take."

Kidney transplant recipients are, for instance, less likely to meet clinical targets for anemia, blood pressure, and blood sugar control compared to non-transplanted individuals with chronic renal disease, a finding thought to relate to the challenges of adherence to medications and clinical regimens (Bissonnette et al. 2013). As compared to non-transplanted counterparts, transplant recipients are also less likely to have important discussions regarding goals of care and palliation should their disease progress (Berkhout et al. 2022). In the case of heart transplant, the newly transplanted organ does not offer the same characteristics as a non-transplanted heart. That is, while a successful heart transplant can offer an immeasurable improvement in quality of life (given that end-stage heart failure offers no viable alternative), a transplanted heart retains limited functionality compared to that of a non-transplanted heart. The donor heart is completely denervated in the process of transplantation, with the loss of sympathetic and parasympathetic regulation. Although some reinnervation can take place over several years, the denervation results in a higher resting heart rate (c. 90 beats per minute) as well as an impaired cardiac response to the demands of physical exercise (Grupper, Gewirtz, and Kushwaha 2018). Although levels of fatigue in heart transplant recipients are reportedly moderate overall, in some cases it has significant impacts on the ability of a recipient to participate in life activities, as for example, there are higher levels of fatigue reported among younger heart transplant recipients, whose expectations of health post-transplant and quality of life may be higher (Almgren et al. 2021).

Discussing such factors and experiences can enable transplant recipients to have a sense of agency regarding their goals and quality of life in light of the very real complications that exist for them. Primary graft dysfunction is one such major complication whereby intervention can beget further intervention, including "rescue" ECMO, *ex vivo* lung perfusion, the implantation of VADs in the case of

heart failure, as well as dialysis. For some, these are interventions that are embraced to allow them to extend their lives. For others, returning to interventions following primary graft dysfunction such as dialysis reinscribes feelings of loss, grief, failure, guilt, anger, and depression (Gill and Lowes 2014). It is imperative to question and unpack the extent to which imagined futures shaped by a curative biomedical frame contributes to these challenges. For as Heinemann asks, "How do we understand the relationship between biomedicine and the everyday when there is no 'after' to illness?" (2020, 83).

Sensory Aesthetics of Time, Machine, and Health

Our crip technoscience lens brings us in contact with a need to appreciate the embodied, sensory, and affective aspects of transplant technoscience—what the lifeworld of a patient-machine-recipient-health system assemblage might tell us about transplant temporality and the imperative of cure. To explore how crip technoscience troubles transplant temporality and the imperative of cure more deeply, we turn to recent multimodal and multisensory artistic engagements with critical illness and technologies in relation to transplantation. We take up artistic work that considers the technologies active in bridging to transplant as well as medical practices and temporalities at play more generally in both pre- and post-transplantation.

Artists and co-authors Brian and Bibo Keeley have worked in various media to explore their respective and mutual perspectives on Brian's experience of an unexpected heart attack while vacationing in a remote area of Scotland in 2013, and the subsequent events that have shaped their lives since then. After 101 days in critical care, supported by Bibo, countless clinical staff, as well as numerous machines, tubes, pumps and wires, Brian received a heart transplant. Following an in-hospital cardiac arrest, he had an extended administration of AutoPulse, a machine that delivers automated cardiopulmonary resuscitation (CPR). He then spent a period of time on ECMO during his early critical care. There followed more than three months on a "short-term" VAD until his eventual transplant. His life support systems also included a dialysis machine, a ventilator, and a nasal-gastric feeding tube. In order to achieve the ultimate goal of transplantation, several chasms had to be bridged. Only when his kidney and respiratory functions showed some improvement was he considered a candidate for an urgent transplant, which took place just a few weeks after being listed. While much of Bibo and Brian's individual and collaborative artistic works explore the physicality, trauma, sensory, and emotional vortex of that time, we look in particular to their artistic digital short film *Breathe* (2021) to think about the juxtaposition of artistic engagement with lived experience of transplant, versus the image of the bridge as the conventional metaphor that dominates the field of transplantation technologies.

Breathe opens with the subtle movement of fluid within the letters of the word "Breathe," shifting into an image of a beating heart rendered through functional

magnetic resonance imaging (fMRI). The beating heart transitions to a seascape, from which a screaming face, submerged in the water emerges. The rhythmic beeping of a telemetry monitor sonically marks the next shift, to an fMRI body superimposed on close-up shots of insects engaging with plants. At various points, the sway of wildflowers coordinates with the pulsations of the fMRI. A sonic return to a beating heart is overlayed with a whispered voice, "Open your eyes. Take my hand. Can you hear me?" The scene becomes simultaneously soothing and monstrous, as hands wrap around the trunk of a tree, eyes within the tree's knots. Shifting between the linearity of the tree and hands touching the linearity of a surgical incision, we then hear the whoosh of a heart doppler along with a different whoosh of breath—the slow internalized breathing from inside one's own head. The forest becomes a nightmarish dreamscape, trapping an individual wearing a hospital gown in a waking coma-like state. The sound of the heartbeat merges into the faster rhythms of erratic drumming and through flames we start to see a masked creature, various skulls, and then a half-human, half-bird figure draped in a shroud of white torn cloth, which dances a grotesque slow-motion dance in a verdant forest. Huge undulating earthworms intersect and engulf the figure like tentacles. Finally, a face drifts slowly underwater, with eyes open, blending with the sand and the seaweed, as a woman's voice sings "in Zeit und Ewigkeit," or, "in time and eternity."

Reading *Breathe* against the literature where we see the bridge metaphor, it becomes clear that perspective matters. The bridge metaphor, invoking a linearity of crossing and the expertise and command of captain/architects, fails to capture essential aspects of the sensory and affective qualities of actually being a living, breathing, bleeding, shitting, and agentive person that—to stay alive another day—is imbricated with a mass of machinery and experiencing side effects of various medications. *Breathe* expresses a non-linear experience, where hope and angst co-exist in an ever-present way, where memories merge with imagined realities, and where death and loss are the ultimate threat of critical illness, as well as of the subsequent non-critical, yet relentless, chronic health condition. The dual perspective of the artist couple's trauma merges into one shared visual and aural assemblage that is rooted in the embodied experience of critical illness and heart transplantation, where medical technologies are a part of, and witness to, the compassion, co-suffering, helplessness, isolation, and a sense of eroded confidence in life. If, metaphorically, bridges are technological feats that escape the clutches of death and the devil (Gordon 2018), *Breathe* offers a sensorial feast that enunciates counter-logics of the conventional views of transplant technologies, situating these within the artists' respective and shared lived experience.

The immersive, suffocating fever dream provides a vastly different sensory landscape for viewers than what we might take from the imagery of the bridge. *Breathe* offers messiness, repetition, and loops, as well as blurred boundaries of

self/other and human/machine, contra the linearity, precision, and cleanliness of conventional and normative images of a bridge. What becomes palpable when reading these against each other is the way that transplant technologies are part of a doubling back: the machines have a central, crucial, agentic role in the drama of transplant, bridging to surgery. At the same time, these technologies are typically discounted as relevant affective actors in the situation—machines are not considered in the sensory or affective milieu that shapes the transplant experience. Technological objects—machines and monitors—become so commonplace to those doing the work of caring for the transplanted patient that their role (and their din) become backgrounded. In our own fieldwork, these machines were only occasionally noted by healthcare providers routinely working with patients for hours on end: personal support workers, constant observers, care aids, and some nurses at the bedside. This sensory story and its impact on lived experience is obscured by the metaphor of the bridge.

And yet, as *Breathe* so clearly demonstrates through visual image and movement, these sensory experiences are crucial to understand, both from the perspectives of those receiving care and their families and loved ones. In the microcosm of the critical care setting, the incessant sensory experiences can be terrifying and overwhelming during a period of time when people may be at their most vulnerable. The constant alarms and beeps intended to alert staff are more intense for the patient whose ears are at much closer proximity to the machines emitting the sounds. These machines and monitors, with their cacophony of pumps, fans, and humming, are also typically placed behind and out of the patient's field of vision, potentially adding to the unnerving experience of the unknown, unpredictable, and incomprehensible. Harsh hospital lighting, which is beyond the control of the patient, and depressingly functional ceilings may for prolonged periods be the dominant stimuli from the perspective of someone in an intensive care bed. Neither aesthetics nor sympathetic aural considerations are typically engaged as an important part of the patient experience. Just as the visuals and movements of film can both express a sensory and affective landscape that is otherwise left untouched, unexplored, and unacknowledged in the dominant conceptualizations of transplant technologies, the sonic experience of transplantation also blurs the bifurcations of familiar/strange, insider/outsider, and self/other aspects of this medical field.

This is also apparent in the soundscape *Boundary Loss,* by Jonathan Kawchuk. In an interview with the artist accompanying the recording, Kawchuk and Berkhout (2023) explore the sonic qualities of transplant spaces. Kawchuk's soundscape developed from field recordings in a Canadian hospital, capturing acute care areas of transplant such as the transplant ward and intensive care unit (ICU) but also the mundane, quotidian spaces of transplant such as the hallway, the elevator bank, and the atrium where patients and families might meet if someone is well enough to move from their hospital bed. The soundscape enables listeners to become

attuned to the frictions between absence and presence in transplantation: sensory experiences that are simultaneously dulled and sonically overwhelming within a single acute care transplant setting. The sound experience, as described by Kawchuk, is "actively brutal, it's mundane" (Kawchuk and Berkhout 2023, 117). The sonic environment is, he notes, "stark, sterile. The sound experience in the hospital isn't going to reveal a truth that is easier to handle than that, because it's not easy to handle. The essence of the thing is difficult" (117). "The soundscape doesn't give you a sense of what is living," Kawchuk continues, nor "a sense of time. There's a stasis that is sonically present. Everything is regulated, monitored, static. It felt like I wouldn't know what time of day it was" (119). Brian comments on this unsettled sense of time, directly after his heart transplant, when he was still affected by anaesthetics and powerful painkillers:

> The clock on the wall says that an hour has passed since I last checked, but I am confused because the same procedure is repeating. The same nurse who came in an hour ago does so again and asks me the same questions. Other members of staff come in and repeat what has been done already, and in exactly the same order. I tell them all to stop because this has already happened, but they don't believe me. Then I notice that I know what they are going to say next, because they said the same thing previously. I continually protest that they are wasting time because I want to move forward. I feel overwhelmed by everyone in my room moving around and repeating things. I feel they are not helping me to move out of this continuous present. I point to the clock to prove that time is passing, and we are still repeating the same routines. A nurse comes in and says the same thing to me for a third time. I sink back into my pillow, knowing that I will have to lie here and watch another hour of the same repeated activity. (Keeley and Keeley 2023, 16)

Kawchuk's soundscape captures "something about disorientation, feeling both overwhelming and underwhelming" (Berkhout and Kawchuk 2023, 119). For example, in asking permission to enter a care space with various microphones, recording equipment and transducers, Kawchuk confronted the ways that patients, like Brian, have already become conditioned to intrusions, many of which include unknown machines and technologies and where the purpose of the interaction may be incomprehensible or bizarre. Kawchuk reflects,

> The hospital can be a magic place where magic happens, or it can have so much mistrust and pain. It was surprising to go into everyone's room. I was thinking, "Why is he letting me do [this recording]?" But what's happening to him is, so many people are already doing weird stuff anyway, so it's like, "Sure. Do whatever measurements you want." If you have only a tiny bit of energy for self-

> advocacy, where do you aim? How you figure out what you push at is very hard, I think. (118)

Perhaps critically ill patients become conditioned to receiving little or no explanation of the technologies and procedures that are being delivered to/used on them such that a request to record the sounds of machines in their rooms was just one of many hundreds of interactions in the acute phase of transplantation that are without sense or meaning to individuals. ICU patients have no privacy and often receive no advance notification of the multitude of daily interventions by staff. The physical passivity and de-personalization that is observed from the outside may also assume some lack of capacity or interest in understanding the technologies and the clinical interactions. Or it may be that vulnerable patients are not routinely afforded the opportunities, or that they do not have the confidence to engage with staff about the complex systems involved in their care.

In Brian and Bibo's experience, there was no routine explanation of the sounds and technologies surrounding Brian's hospital bed and body. Bibo would photograph everything out of Brian's line of sight, and she asked questions of the staff that Brian was not able to articulate. Their creative process was adapted into the service of managing an ongoing tension that surrounds the "good" transplant patient: one who adeptly alternates between being a docile, passive patient (particularly during the wait-listing and surgical periods) and being activated, motivated, and self-managing in the right kinds of ways. It can be a very quick pivot (Wong-Mersereau et al. 2023). This kind of inhabiting—of a complex and contradictory transplant subjectivity—is left unspoken within the imagery of the bridge but the sense of this inhabiting emerges from the affective space that forms within creative practices. They contribute to a sensory aesthetic of transplantation that eschews what Susan Squier (2007) refers to as the "epistemic narrowing" of biomedical information, opening up new ways to imagine and engage with transplant's multiplicities.[2]

Unsettling the Curative Imaginary

Better technologies and better treatments are often taken to be the answer to the problem of illness, disease, and disability. Better technology and treatments are framed as a way of overcoming and curing illness, disease, and disability. But these approaches are also responsible for long histories of institutionalization, eugenics, sterilization, lobotomies, and other violent interventions that have led sick, mad, and disabled people to have an "ambivalent relationship to technology" (Kafer 2013, 119), medicalization, and cure (Clare 2017). At times, healthcare providers working in transplantation themselves offer critiques of device-centered (rather than patient-centered) care (Sharp 2014; Wong-Mersereau et al. 2023). A nascent literature on the notion of survivorship in liver transplant also points to a growing recognition of the need to attend to extended temporalities in transplantation (Lai, Ufere, and Bucuvalas 2020). Crip

technoscience approaches to the innovations and interventions of transplant medicine require both disability world building and ableist world dismantling. This means calling attention to the complexity of non-compliance with the curative imaginary of biomedicine, what it means to continue living on, and the strategies and ways of being that enable continuance.

One important point to be made at this juncture is that while biomedical approaches frequently view patients as autonomous individuals, those living with transplant rather need to be understood as living in relation with others. They care for living others, for example, and enter into caring relations with the donated organ and its relation to the deceased or living donor. Relationality is an important consideration because transplantation is not simply about extending the life of an individual but also can restore the "possibility of engagement with the day-to-day contexts of kinship, friendship, leisure, and occupation" (Heinemann 2020, 83). As Heinemann notes, some transplant patients may not have any interest in pursuing an intensification of medicalization for their own selves as "everyday *living*, rather than life itself, becomes the stake" (83).[3] Paying greater attention to relational context also means being attentive to the temporalities of transplantation: "Transplant recipients and clinicians alike point out that the procedure trades one set of problems for another: the difficulties of [pre-transplant] dialysis [for kidney patients] for the side effects of immunosuppressants [post-transplant]; the fears of organ failure for the fears of organ rejection…immunosuppressant medications can increase risks of cancer, osteoporosis, high blood pressure, diabetes, and other complications" (83–84). Solid organ transplant recipients are at risk of various forms of longer-term organ damage (their own endogenous organs and their new graft) from the very same medications that help to ensure their more immediate survival. The lived reality of transplantation "reveals that normalcy is elusive," marking life as "tethered to the chronicities…of enduring medical intervention and monitoring" (84). Despite the impossibility of the restoration of a prior, self-same "healthy" embodiment, transplantation, as conceptualized in Western biomedicine, attempts to enact temporally normative forms of biocontinuity and linear life extension through notions of scientific progress while simultaneously being replete with disruption, non-linearity, and hauntings. These temporal frictions capture, for many recipients, the presence of the absent other (the organ donor) and the intersections of histories of dead and living (McCormack 2021; McCormack et al. 2023; Wasson 2021).[4]

Our engagement with multimodal and multisensory artistic research-creation attends to the sensory aesthetic aspects of time, machine, and health that demarcate acute illness experiences in the transplant context, displacing certain valorized understandings of the body that are based in a temporality of transplantation as a destination of health. When transplantation technologies are configured through the imagery of the bridge—always in offer of a destination in

which illness and disability serves as the agreed-upon limit of our projected futures (Kafer 2013)—the skills and resources for living well with disability and illness may not be cultivated or recognized. How to live in the visceral present (Clare 2017), how to be with oneself and with each other in the meantime, how to embrace healing that is "neither a departure nor a destination, neither overcoming nor tragic" (Sandahl 2019, 130). These are questions prompted by our critical engagement with the bridge. Even if unintended, dominant transplant temporality binds to the past and glorifies the future, producing detrimental impacts on those whose lives cannot so simply be considered to be in a new or improved state post-transplant.

Instead, we have opted to engage crip technoscience and sensory aesthetics that seeks to transform the ableist curative imaginary that drives so much of the rehabilitative sciences and medicine. We do so to unsettle progression and reconfigure time through loops, repetition, speeding up and slowing down; it is a relational orientation that disrupts the myth of autonomous, self-sufficient personhood as a pinnacle of achievement (White 2017). We reimagine spectacle and speculativeness in order to access sick and disabled futures and non-normative embodiments that politicize the relationships between sick and disabled people and medicine, technology, and design. We do so not as an esoteric commentary, but to improve access to healthcare and technologies that enhance quality of life and also to acknowledge the needs, wants, expertise, and contributions of sick and disabled people and disabled communities. If any aesthetic act is a political act, when it affects and effects a reordering of the world (Rice et al. 2017), the sensory aesthetics of crip technoscience is one that can reorient transplant spacetime, opening a multiplicity of possibilities for sick and disabled futures.

Notes

[1] Between 1982 and 2001, global figures showed that the 50 percent survival rates of heart transplant recipients—who survived the first year—was 11.8 years (Hertz et al. 2002). As recently as 2018, a US study showed that the 50 percent survival rate for heart transplant recipients was 12 years (Hsich et al. 2020).

[2] The epistemic narrowness we are considering here, structured by biomedical ways of knowing, likewise extends to a narrowness of how temporality is conceived. As one reviewer helpfully identified, temporality itself cannot be universalized—understandings of time (particularly in relation to life and death) are shaped by cosmologies, cultural beliefs, and spiritual practices that are themselves far more diverse than the linearity presumed in a westernized biomedical context.

[3] Within her ethnographic work, Heinemann articulates, for instance, how some individuals within her field site "turn toward transplant out of a sense of obligation

to children or grandchildren, aging or infirm parents, or others who rely on them and suffer the ripple effects of their life-threatening illness" (2020, 83).

[4] There is a rich literature on absence/presence, which is out of the scope of this piece to engage with. For additional sources in anthropology and material culture, see Bille, Hastrup, and Soerensen (2011).

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Brian Keeley is an artist based in Scotland whose collaborative practice with Bibo Keeley is rooted in their shared experience of living post-heart transplant. Brian graduated with an MA from The Glasgow School of Art in the 1980s and is currently a doctoral candidate in the Department of Film & Visual Culture at the University of Aberdeen.

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