Ars Medica
A Journal of Medicine, The Arts, and Humanities

Volume 17
Issue 2
2023

Fragments of Futurity, Reflections on Transplant Sustainability / Transplant Tarot Triptych: Cards and Descriptions

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Fragments of Futurity, Reflections on Transplant Sustainability

I have survived over twenty years since my heart transplant. Most heart transplant recipients cannot say this. This truth is never far from my mind. When making life decisions, when deciding how to spend my time, even further compressed by chronic illness and a high need for rest—more and more, as time passes and I become host to an ever-shrinking numerical statistic in terms of longevity, and I witness the increasing global crises as an immunosuppressed person—the question of long-term sustainability of transplantation for my body, for all human bodies, becomes an ever-louder scream reverberating in my mind.

Sustainability as a concept evokes the environment: our planet, our home, our natural world. However, this is only one dimension. Sustainability encompasses all dimensions of existence, and their capacity to keep on keeping on. I have begun and had to pause many a research project on transplantation: my ill health has gotten in the way. Below are some fragments of future research areas I hope I develop the health to conduct. Or that someone, somewhere, will be able to undertake.

When considering calculating a mathematical formula of the overall, interconnected global benefits and harms that the advanced technology of transplant medicine brings the world, we do not know yet which way the scales of justice will weigh in. We have to sit with the weight of uncertainty, with curiosity and hope, until more extensive research has been conducted.

Environmental sustainability

Another twelve hours, another set of medicines. This has been my last twenty years, and, I must hope, my next twenty, for I am not even 30 years old yet. I often procrastinate taking them for a few moments. In these moments, fiddling with the empty blister pack shells ubiquitously used as pill packaging in much of Europe and many places around the world, I often flit between thoughts connected to them.

Today's thoughts: blister packs are not typically recyclable. They go to landfill. My country, like all "developed" countries, pays "developing" countries to take our landfill. However, developing countries don't have the infrastructure to dispose of the waste safely. Environmental pollution harms health. This waste, including my pill packaging, is harming, even killing, people elsewhere. I put the empty blister packs down. Others are paying a heavy price for my staying alive. The pills are already out their packaging: it's time to do my daily duty.

Unfortunately, the very medicine that has the lofty goal of remedying pain, suffering, and otherwise fatal bodily damage, is contained within a

shell which, once discarded, gives rise to the very diseases that the medicines aspire to cure. This chain of interconnections between pill packaging and global health trade-offs, spans vast distances. The implications from cause to effect are not immediately noticeable. Once noticed, however, they cannot be forgotten: the very medicines that make possible the transmutation of organ failure, in organ transplant recipients, are also creating organ failure elsewhere. The spectacle of progress and advancement is revealed as a reality of exchanging one problem for another: the cycle of life's maladies, even with technological intervention, seems to continue, on and on, as an infinite unsolvable problem.

Currently, organ transplantation depends upon the health harms its pollution causes to exist. Transplantation, including materials associated with surgery and life support machinery, also depends on broader contributions to environmental pollution and climate warming. Yes, my life was saved. Millions of people have had their lives and loves saved by transplants. But if the cost, at least in part, is making the world more unsafe, if it has meant harming the planet and its other inhabitants, then its environmental sustainability is in question.

Ironically, the pollution the transplant field engenders is making the world more inhospitable to transplant recipients, who are more vulnerable to the impact of increasing temperatures than most and will be the first to be impacted as the climate crisis escalates.

Physical sustainability

After winning the medical lottery by being allocated a transplanted organ, a patient's failing organ is replaced with a functional one, at a cost. The bodily cost is the sacrifice of the normative functioning of one's immune system. In technical terms, the immune system of transplant recipients is disabled by immunosuppressants. This disabled immune system means an altered reality for the transplant recipient: they, we, I, have been disabled.

Transplant medicine creates disabled people. It is a controversial statement, but one which needs wider consideration. A caveat: we transplant recipients were already at the stage of disability when we needed an organ transplant. It is not transplantation that transforms someone from able-bodied to disabled, but rather it performs the magic of ending one kind of disability by enacting another kind of disability. The law of substitution is in play: an organ is substituted, at expense of an immune system, which then will need substitutive intervention at a later date, be it through increased vaccination, monoclonal antibody infusions (immune cell transplants), et cetera.

Transplantation shows that disability can be a treatment *and* that treatment can disable, but also be the kind of disability offering sufficient potentialities that it is simultaneously a disability aid, too. Transplantation crosses object boundaries and polarities of existence, being both supportive aid (enabling) *and* new disability (disabling) all in one.

As a child who avidly read, I clung to a compelling metaphor to make sense of the challenge of living with a disabled immune system. When I was grappling with what transplant medicines meant for me soon after my transplant, just before my eighth birthday, having been taken through the long list of complications associated with immunosuppressants, the literary metaphor of "drinking unicorn's blood … and forever living a cursed life, a half life" (Rowling, 1997) was imprinted in my mind, as a way of making sense of transplant life.

Twenty years later, as an adult, I would argue this may well be factually true, too. Not the cursed part, or at least not without the nuance of it simultaneously being a blessing, but rather the aspect of halved life expectancy. Reading up on the statistics of transplant life expectancy has led me to the discovery that transplant life expectancy is half that of the average of an untransplanted person; thus, the notion of "half life" may be interpreted literally, too.

Now, how did I work this out? The maximum years of survival post-transplant for many transplant recipients (hearts, lungs, etc.) is about 40 years (Anon, 2022a, 2022b; Graham, Watson, Barley, et al., 2022; Shaffer, 2023), and the maximum for kidney transplants is about 50 years (Anon, 2020; Matas, Gillingham, Humar, et al., 2008; McKrimmon, 2022). These statistics are true only in exceptional (minority) cases. With the human capacity to live beyond 100 years—likewise, in exceptional cases (Smith, 1997)—the maths suggests that as transplant medicine cur-

rently exists, the human body can only sustain transplant grafts (and transplant medications) for half the human life expectancy.

For those who receive a transplant in middle age, this limitation is arguably negligible. For those who receive a transplant before the age of 40, it brings genuine concerns about physical sustainability for achieving a full and long life. This concern is particularly significant for child recipients. Recent data aggregation across the UK spanning long-term multi-decade outcomes by NHS Blood & Transplant (Hogg, 2023), indicates mortality is not nearly as stark in child recipients compared to adult recipients, but it by no means matches a lifetime trajectory equitable to the non-transplant population. Ultimately: the litmus test for physical sustainability of organ transplants ought to be from the vantage point of babies who receive a transplant. As transplant medicine currently stands, for babies who receive transplants, the metaphors of transplantation as gift of life, second chance at life, and rebirth, need scrutinising.

Societal sustainability

I have never been very good at telling a "good" transplant story in a public forum. A "good" transplant story goes from disability to ability and focuses on restitution narratives. Whilst this has sometimes been true in the ebb and flow of health attendant to my experiences with chronic illness (aka immunodisability), these stories have always felt incomplete and fundamentally lacking in integrity. Transplantation, being one of the

few medical interventions that depends intensely on good PR and social approval, means that my inability to tell a good transplant story makes me a bad transplant patient.

The societal view on transplants feeds into whether individual families of brain-dead patients in hospitals decide to donate their loved ones' organs. This means that the public need to remain on side for transplantation to be a sustainable option for treating organ failure. The scarcity of sufficient organs for those on the transplant waiting list, means that the PR from organisations that desire to raise awareness about the need for an increase in donations, is caught in a holding pattern of emphasising only the positive aspects of donating organs and transplant life. This, in turn, means that there is a gap between the perception and reality amongst most people in society.

It also means that society currently is unprepared to digest a more nuanced narrative. To a general public that prizes health and stories of recovery, attaching narratives associated with chronic illness and disability to transplantation, is a massive shock to the system. There is a sense of stability and hope, in the consistency of the A to B narrative of organ failure, then transplant, then no organ failure. Stability and hope are both essential traits needed for sustainability. There is the danger that, as narratives exploring transplant life and transplant medications—from more "negative" (realistic) perspectives—gradually enter society, there will be a pendulum swing of regard. The already scarce supply of donor organs could be reduced even further, or even dry up completely.

The key root of this danger is the pre-existing societal problem of ableism. If society continues down an ableist path, the revelations of the blunt realities may be a threat to the societal sustainability of organ transplantation.

What is ableism? Ableism occurs when the standard of ableness is expected as the default in life, and those who are disabled are expected to conform to this standard to be included in society. Those who cannot conform are expected by society not to exist in able-bodied spaces. Ableism taken to its most extreme conclusion becomes everyday eugenics, where nonconformity to being abled means death.

As a result, 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. What it boils down to is the ableist belief that if transplant medicine as it currently stands qualifies transplant recipients as disabled, perhaps transplantation is bad overall, and people are better off dead than disabled. The danger of societal unsustainability of transplantation rests with the continuation of the not-infrequent ableist societal belief that chronically ill disabled people should want to prefer death, rather than gladly choosing to elect into a new life of (immuno)disability.

Transplant sustainability depends on the success of disability justice to overcome ableism as a prevailing outlook and to overcome health supremacy eugenics as its praxis. The continuation and advancement of transplant medicine in our time of global crisis depends upon a societal

embrace of disability accessibility and effective challenge to the rise of health supremacy, a form of health fascism that has been on the rise since the start of the pandemic in 2020. Disability accessibility in society from transplant recipients' point of view means bridging the equity gap from immunodisability and an associated health condition point of view: development and availability of monoclonal antibodies, use of (improved) face masks, and widespread installation of HEPA-grade air filtration, to name but a few.

Logistical/financial sustainability

The dimensions of logistical and financial sustainability are highly under-researched. It is typically the domain of health insurance companies and health funding bodies; raw data is hard to come by and, when funded by those with a vested interest in promoting organ transplantation, weighted towards encouraging the outcome of increasing donations, rather than a comprehensive account of the situation as it currently stands.

Organ transplantation depends on a complex infrastructure: technology, enough skilled staff, and enough space in hospitals for transplant recipients and donors. Wherever there are bed shortages, or reductions in available hospital beds, there will be a *de facto* reduction in transplants that can be performed. All those who campaign for increased hospital capacity are supporting the logistical sustainability of transplantation. Currently, hospitals around the world are facing staffing shortages in healthcare. From my vantage point of attending national and in-

ternational transplant healthcare meetings in my role as patient advocate, I have heard that these shortages are already hitting transplant centres and are projected to increase if logistical changes are not implemented to enable more staffing and more bed space. Improving both financial and logistical sustainability is essential for transplantation to fully expand to developing countries that is needed if transplantation is to embody the values of disability justice, which includes intersectional equity, across continents and nations.

Psychological sustainability

Whilst I truly believe that having a mental health condition is a disability and not anything to be ashamed of or at all a reflection of the person's personality or character … for some reason I pride myself in having successfully avoided getting formally diagnosed with a mental illness. Yes, sure, I see a psychologist and my record says a tendency towards anxiety. And yes, I see a separate department for neurodivergency. When it comes down to it, this pride is rooted in how I can tell my transplant team that I am of sound mental health: nothing to declare. This originates from a place of primal survivalism; were I ever to need another organ transplant—a genuine probability—having nothing to mentally declare would be an advantage to me. People are sometimes denied the opportunity to even be put on the transplant waiting list on the basis of mental illnesses, indeed even for being neurodivergent. Proportional to how any psychological difference gets earmarked as a potential weakness, any avoidance of having

certain psychological labels added to one's medical records can bring with it certain advantages and privileges.

Psychologically, in parallel with the normalised restitution narrative, transplant patient behaviour is being directed by primary protector selves: the mask of the Clinic Self. To be clear, this particular mask is performative. The mask of the Clinic Self is what the "good patient" wears, predominantly to the transplant clinic, but also in society and at home.

The Clinic Self presents the superficial front that everything is fine, conforming with the popular story that the transplant has fixed the problem, that the patient is now living life to the full and is very much in the moment. The future will unfold the same as that of someone who is not a transplant recipient, in trust and faith of the transplant team and the institution of transplantation. The mask's voice says: "I will not speak a negative word, for doing so is ungrateful to the donor and the doctors may not want to treat me if I need their help again, and I may die." The Clinic Self does not speak of new comorbidities without restitution framing.

The lived experience of transplantation contains feelings, emotions, and thoughts that are constellated within "selves" separate to the Clinic Self and counter-clinical narratives. Since the Clinic Self censors all other selves within and also within other people, it is difficult for the voices of the other selves to be able to speak.

There exists a hierarchy around what is considered "reality" or "truth." This hierarchy gives rise to the Clinic Self unconsciously perpetuating:

normalised toxic positivity, medical gaslighting, internalized gaslighting, ableism, and internalised ableism. Other rationalised forms of physical and psychological violence as means to the end of preserving the restitution narrative in relation to transplantation. Inevitable cognitive-somatic dissonance creates significant baseline stress within transplant participants which, in my view, contributes to a lowered quality of life and lowered length of life. More extensive research needs to be conducted; the results of which will hopefully either dismiss or verify these theories.

My hope is that by expanding the selves which are allowed and creating safe spaces for the clinical self (and by extension the clinic and clinicians) to enter into dialogue with other psychological selves through other institutions, such as art organisations and participant-led support networks, a rich assemblage of multivocal narratives would be able to coexist, thus creating a greater psychological wellbeing.

Psychological sustainability is interconnected deeply with physical sustainability. However, I believe that it is far more complex than the commonly touted "think positive and you'll stay healthy" ideas floating around. Health is homeostasis and psychological distress is unresolved stress. Instead of focusing only on the positive, the negative needs to be tackled directly in a way that resolves the distress, or at least lessens it. It is true that for some, positive mindsets may be sufficient for reducing distress. I suspect this relief is short lived, as it soon only reinforces low level alienation from the self and others.

Spiritual sustainability

Organ transplantation brings with it the potential for greater connection to the universe at large, an awareness of the precariousness of life, and the realization that one can no longer consider oneself as just an individual: we transplant recipients have become hybrid, forever tethered to connection with the flesh of another, and to the twenty-first century, via advanced pharmaceuticals, and to medical institutions. The ever-present closeness to illness that living immunocompromised brings, gives rise to increased stark consideration of what is truly important.

Transplant recipients carry the burden of extra layers of intensity of reality. We are in a position where we often contend with topics important to being human: loss, uncertainty of life, proximity to death, the questions of living a good life. We do so with our bodies as the crucible of philosophical debates. Our bodies are the embodiment of a very specific spiritual understanding of the world: that the mind is severable from the flesh. The interchangeability of body parts, sacrificing one system for another. We hold the experience of margin of error of a certain kind of philosophy in our bodies every day. That doing so is possible, is one of the many paradoxes that the paradise of transplantation brings.

Spiritual sustainability of transplantation requires resilience in holding space for contradictory ideas and feelings in one's mind and spirit at once. The capacity to hold space for paradox, both individually and collectively, is essential. Embracing the spiritual principle of paradox by

society is necessary for sustainability under the intensifying crucible of increasing pressures of the world. We need to do our part to co-create a world that can appreciate the value of paradox and not just value it but desires it; a society that seeks it out and nurtures it and wants to build it up. A world resistant to paradox will inevitably be hostile to organ transplantation and organ transplant recipients.

Choose a transplant, choose life, choose paradox.

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Transplant Tarot Triptych: Cards and Descriptions

The following three cards and their descriptions are the initial few of a projected full deck of transplant-themed tarot cards. The artistic medium was a combination of back fineliner on paper with digital colourisation. Here, the first three cards, are laid out one by one; when cut out and placed side-by-side (L to R, in order) their geometry combined is greater than the sum of the parts alone.

The Surgeon

The Surgeon is the archetype of a modern Prometheus. Wielding the scalpel, wearing ritual robes, and creating transformation via the mimetic tools of the physical dimension: oxygen, blood, organs, electrical impulses; these can all be substituted. The Surgeon is the master of the atomic world, capable of deftly working amidst the balance of life and death. The hourglass of finitude hangs above. Paradoxically, the Surgeon uses the amplification of fragmentation to create greater unity within a person: the human self is divided into separable, interchangeable organs, the immune system is made the altar's sacrifice; for generating a new kind of

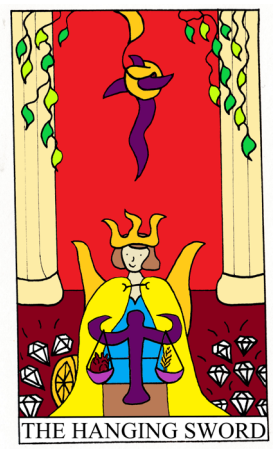
THE SURGEON

human order. Transformation at this scale comes at a cost: maintaining equilibrium is a never-ending battle. Sustaining the finite is an infinite battle. Chained to the operating table, the Surgeon must carry on replacing organs for all eternity, transplant after transplant. The end is not in sight. From donor to recipients. Donor to recipients. Donor-Recipient. Donor. Recipient. Cutting and stitching. Cutting and stitching. First, second, third transplants. Never enough transplants can be done, surgeries are always needed. Transplant after transplant, the Surgeon carries on. Rinse and repeat. And all the while, an Eagle—the Eagle that destroys organs that the surgeon uses to regenerate others—is poised and ready to swoop in to devour the organ—as soon as the patient leaves the hospital. And where the Eagle can, it will swoop in even before the patient leaves. And then the Surgeon must step in again. With the delivery of immunosuppressants, a transplanted organ can last anything from fifteen seconds or fifteen years, or less, or beyond. The science of transplant medicine can be an unpredictable art. This allows wonder to remain. The Surgeon has the strength and determination to keep on keeping on. This archetype is the force encompassing both the power and limitations that mastery of the physical realm brings. The problem is the solution, the solution is the problem, round and round the cycle of transplant

life turns. Physical substitution of transplantation can lead to needing more transplants: sometimes of the same organ, other times another organ (often the kidneys due to their vulnerability to damage by immunosuppressants), sometimes immune cells to compensate for suppressed immune systems; all of which solve issues arising out of transplant medicine itself. For transplantation can sometimes set the stage for next challenges, which transplant medicine can then, once again, solve … for a while. The Surgeon is the archetype of all authorities that make organ transplant physical reality. As such, physical existence is the start and the end of the domain of the Surgeon.

The Hanging Sword

The Hanging Sword, short for the full name *The Hanging Sword of Damocles*, is the ever-present dread-doom that accompanies being a transplant recipient with a critically engaged understanding of transplantation's complexity. Transplantation is not just the transfer of organs but also its requisite immunosuppression. It is the paradoxical experience of having both extraordinary privilege and living with extraordinary peril. Heavy is the crown, plentiful are the jewels, high are the stakes, precariously thin is the thread, upon which the sword hangs. It is the archetype of gravity: the force pulling us to earth, to rock solid reality,


THE HANGING SWORD

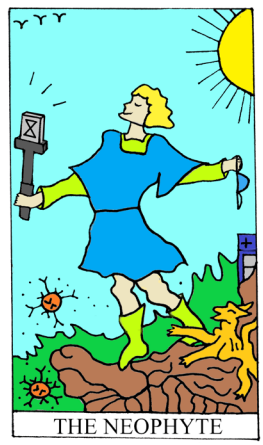
to seriousness, into graves. All other archetypes can be subsumed by the weighty power of this archetype. Transplant recipients must live with both the possibility and actuality of a great many life-threatening complications, due to the immune system being disabled, and with the uncertainty when they may strike. It is the sinking feeling in the back of one's mind. If one looks beyond the initial persona of privilege, where one's existence is as though a monarch on a throne, to the bigger picture, one can see that proportional to the excess privilege, there is also excess potential peril. The scales of justice are constantly being weighed up. The sparkling diamonds in the throne room are covered in the blood of all the transplant recipients that came before and who have already been hit by the falling sword. A second chance at the gift of life comes bound up with additional lottery entries into the grim reaper's list of who is next for the gift of death. The presiding judge, holding the scales of justice, comes in the spirit of the ancient Egyptian goddess Maat: on one side, there is a heart; on the other, there is a feather. The classical myth tells how in traditional ancient Egyptian death rites, the test for progression to heaven rather than hell, on the way to the Underworld, is whether the heart can be lighter than a feather. With transplant life, transplanted organs must match the levity of a single feather, for the recipient to remain spared the fall of the hanging sword perched directly above.

Bound up with gravity is its polar opposite, levity. Both are core forces in the universe. Whereas gravity is the force pulling down, levity can

mean going up or moving sideways. Levity is a form of levitation. It is pliability, adaptability, a weightlessness—associated with the etheric realm. The Hanging Sword is always there, ready to fall. In order to be able to have a Mona Lisa smile whilst the sword could fall at any point, one must either learn to fly up and repair the weakened threads or learn to move sideways. The first option may one day be achieved by pharmaceutical innovation. The latter is a more immediate option. Thankfully, the throne is poised to transform into a wheelchair: one of its two wheels is visible (if one knows to look). The wheelchair is a disability aid, and the option of a moving throne alludes to the possibility of all kinds of disability aids being employed to enable moving out of the path of various falling swords. By embracing a more nuanced understanding of disability and including transplantation within its realm, at least sometimes, and putting theory into praxis with a new approach to the vulnerability of transplant recipients, there can be better responsiveness in relation to real dangers and complications that transplant life can bring. The proactivity of a moving chair rather than a fixed throne allows greater success against injury and fatality from falling swords. Full acceptance of what is, and proportionate proactivity, gives rise to the possibility of sustaining a deeper, more substantial, lightness to being. The lesson of the archetype of the Hanging Sword is that the force of gravity can only be kept at bay with equanimous levity.

The Neophyte

The Neophyte, from the Latin for "newly planted," is the archetype of the newly initiated into the gift of life that is given via organ transplantation. Every participant in the process of transplantation can be a Neophyte. Typically, this lens or perspective is centred to that of the organ recipient. With overt mirroring to the Fool card in the traditional Tarot deck, the Neophyte holds a selfie stick and dangles a face mask in place of the wanderer's travel accoutrements. The sun is shining and we're on top of the world. The Neophyte is determined to relay the best of life back to the universe (via social media). Where the Fool, with his trusty dog nipping at his heels, wears a harlequin's tunic, the Neophyte wears a hospital gown and medical compression socks. Instead of a dog, there is a clawed supernatural creature growling a warning at the crumbling cliff edge up ahead and the virus particles floating in the air. In the distance, to the left, there are three birds, eagles, flying towards the Neophyte; to the right, a hospital exists on sturdier ground. The Neophyte is both the exhilarating, enlivening force of the happy ending, with its attendant gratitude and spirit of adventure, and simultaneously the wider context that a happy ending is only the beginning of another far greater adventure, with proportionally greater peril too. The lesson of this archetype is that looking away from



THE NEOPHYTE

what is in front of you and subscribing to a "positivity only or else!" mindset can, paradoxically, set people up to encounter more issues than taking in what's there in the moment and responding accordingly. Being transfixed by the brightness of the sun (reflected back in one's technological intermediary) and looking away from danger doesn't make the negatives vanish. Wanting to exclusively see the bright reflection of the sun can lead to blind spots to approaching danger, which can lead to one's premature end. There is a beauty in this way of shining brightly, but for a shorter time. Its bleached white sweetness can also leave an artificial saccharine aftertaste. It is the shiny, bloodless PR image of transplantation. Every transplant participant has the potential to remain in or, at times, slip into the Neophyte archetype, even with years of lived experience with transplantation and its ups and downs. One embodies the spirit of the newly planted when one is caught up in the moment, the past and future out of mind, in a world of pretence of normalcy, losing oneself in meeting the all-too-human need for belonging in the world—amongst the non-transplanted—or simply a moment of being careless, not thinking of possible consequences. The present moment gifts us the luxury of simplicity and novelty. For a while, only giving validity to the correspondingly high proximity to the light can serve very well as a coping mechanism for the proportionate excess of darkness. But light cannot exist within the dark. An excess of brightness, without corresponding darkness, can be just as treacherous as only darkness. Without the interplay between light and dark, the light loses its sparkle.

The Neophyte is fundamental to transplant life. Indeed, the archetype can often be seen as the end goal of transplantation and the sign of success by clinicians and society alike. It is only the most surface persona, the public face, but sometimes making a positive persona one's whole identity can be enough. After all, life is short, so let's put complexity to the side. Let's focus on the new and the now. I'm doing fine, you are too, right? Everything's amazing. Best make the most of this very moment!

Acknowledgements

Beginning my Transplant Tarot project was made possible by funding from the Liverpool City Council and was commissioned by Casula Powerhouse Arts Centre, Sydney, 2023.

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