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The Hepatic Happening: Confronting Waitlist Death in Liver Transplantation

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A thesis submitted in partial fulfillment of the requirements for the Doctor of Philosophy degree in Health Information Science

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Abstract

My dissertation is narrative-based interdisciplinary investigation of waitlist death that focuses on my sister's wait for a liver transplant and her death 18 years ago. While the period of waiting for a transplant is accompanied by great life-and-death uncertainty, the possibility of dying is often ignored and overshadowed by an emphasis on redemptive narratives and a "second chance at life." From the beginning, organ transplantation was a field dominated by hope and the fantasy that biomedicine can overcome illness and mortality; as such it is narrowly understood through a lens of progress where loss, failure and death are given little regard and attention. Successful feel-good narratives in liver transplantation also tend not to take into account the way that evidence-based allocation policy (based on an algorithm that predicts 3-month mortality risk) shapes patients' stories. All liver transplant patients are ranked according to a "score" that measures disease severity according to mortality risk even if a patient's symptoms and functional health status suggests they are much closer to death than the score's prediction. Decision-making based on objective data is meant to be rigorous and fair, but it is also highly impersonal and turns a blind eye to how it can map poorly onto lived experience and the circumstances of individual patients. My dissertation uses a health humanities approach and integrates elements of autobiography and creative nonfiction with scholarly research and writing. Using the concrete details of my sister's experience, I argue that the exigencies of evidence-based medicine, the plot of successful stories and conventional tidy narratives are a poor fit for the uncertainty, indeterminacy and contingency of waiting for a liver transplant and waitlist death. My examination of the unique characteristics of waitlist death, and the contextual factors that influence them, will add to the body of knowledge on liver transplantation from the patient's perspective.

Keywords

Narrative medicine, health humanities, Liver transplantation, Evidence-based Medicine, MELD, Death

Lay Summary

My dissertation is an investigation of waitlist death that focuses on my sister's wait for a liver transplant and her death 18 years ago. While the period of waiting for a transplant is accompanied by great life-and-death uncertainty, the possibility of dying is often ignored and overshadowed by an emphasis on redemptive narratives and a "second chance at life." From the beginning, organ transplantation was a field dominated by hope and the fantasy that biomedicine can overcome illness and mortality. Loss and failure are given less attention than feel-good narratives. My dissertation integrates elements of autobiography and creative nonfiction with scholarly research and writing. Using the concrete details of my sister's experience, I argue that the plot of successful stories and the conventions of tidy narratives are a poor fit for the uncertainty and indeterminacy of waiting for a liver transplant and waitlist death. My examination of the unique characteristics of waitlist death, and the contextual factors that influence them, will add to the body of knowledge on liver transplantation from the patient's perspective.

Acknowledgments

First, I gratefully acknowledge my supervisor Susan Knabe for her encouragement, insight and the generosity of her time. Our many zoom discussions propelled the writing of this dissertation, and her trust in me allowed it to come together. I also thank my committee member Lindsay Bell, who I relied on as a mentor and an ally from the start and whose interest and investment in my project always gave me the push I needed to pursue it. I am grateful to my other committee members Sandy DeLuca and Eunice Gorman for their enthusiasm and feedback.

At Western University's Faculty of Media and Information Studies, I especially thank Sharon Sliwinski who intervened when I was at the point of giving up. I recognize Warren Steele (for providing influence at the right time), Nadine Wathen (for introducing me to the critical literature on EBM), Jacquie Burkell (for shepherding me through the early years of my graduate studies), and Cindy Morrison (for being a caring administrator). I am also grateful to have received a generous summer bursary from FIMS after my financial support (a Doctoral Scholarship for Re-entering the Research Community) from the Fonds de recherche du Quebec - Société et Culture had run out.

I am grateful to the late Eugenia Canas, my friend and colleague in the HIS program, for the generosity of her attention and kind words, as well as her optimism and conviction that I was making an important contribution with my work. I am shocked and saddened by her untimely death, and I will forever be influenced by her passion, confidence and sincerity.

I wrote this dissertation during turbulent times, filled with lots of solitude but also essential friendships. I want to express my gratitude to Anna (for her unshakeable faith in me), Anne (for her loyalty, reassurance, and ability to restore a sense of normalcy), Christy (for the way her earthy artsy wellness-oriented way of being rubbed off of me and for lots of listening), and to Damien (for affinity, honesty and understanding).

This dissertation would have never been written without the support of Rob and Ashleigh Barney who provided a home for me in London, Ontario throughout my graduate studies. My perseverance was facilitated by their kindness, encouragement, warmth, comfort, and so many lifts to the train station. How lucky I was to land on their doorstep; and I am indebted for how much they did to make life easier for me (especially when it was hard).

My parents deserve recognition for their unconditional love and support, and for their willingness to lend a hand whenever and however they could. I also thank my sweet children Sasha, Neena and Kai, the helpful, clever, funny and loving people they are who bring joy, liveliness and worthwhile-ness to my life (and despite whatever chaos, still call me the “best mom”).

This dissertation is dedicated to Shauna, for us.

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Introduction

In 2004, my sister Shauna died while waiting for a liver transplant. Up until that point, I had never encountered a story about waitlist death. “Gift of life” narratives, on the other hand, are prominent. These tell of successful transplants and renewed life, and not of death and failure. There were no signs that stories of loss existed.

Early on in my research, reasons why stories of loss are “missing” began to emerge.

Reflecting on the time Shauna spent waiting, the events leading up to her demise and the decision to withdraw the life support that was sustaining her in the ICU, it was clear that there was something invisible about death and loss all along. There was *the sequestration of loss* through the rhetoric of hope, fantasies of recovery, and denial during the experience of “waiting” for a transplant, and *the warding off of loss* through the aggressive treatment and the medical management of death through the technologies of critical care. Attitudes of “fighting,” “battling the odds” and “thwarting death” were dominant. This is not exclusive to Shauna’s experience; these attitudes capture the ethos of biomedicine.

My personal experience of losing Shauna is the focus of my study. I have approached it as a narrative-based interdisciplinary investigation of waitlist death in liver transplantation, which also includes an examination of how waitlist death is situated in the broader landscape of health and medicine in contemporary culture. Organ

transplantation is exceedingly complex (medically, ethically, socially) but we tend to view it in a simplistic way. As a narrative, it is a happy redemptive story. As a medical procedure, it's perceived in a mechanistic way, where organs are simply broken down "parts" that can be replaced. Both offer only a shallow version of what transplantation entails; and neither takes into consideration patient experience in any detail and instead say much more about idealized narratives of progress that dominate the field of organ transplantation and discourses of science, technology and medicine more broadly. In this ideological context, patients are urged to orient themselves to the attainment of a hubristic biomedical fantasy, aligning themselves with the happy story by adopting a morally normative hopeful outlook, and imagining oneself among a cast of heroes and survivors.

There is no existing framework to examine the unique characteristics of loss in organ transplantation because loss is pushed outside the mold. Yet, death and loss have always been components of liver transplantation. It took decades of experimentation since the first liver transplants in the 1960s before post-graft survival achieved a 5-year survival rate of 75%.¹ In North America, still more than 1000 patients die every year waiting for a liver.² This cumulative loss is substantial, but it remains unspoken and hidden. The

¹ Mark S. Roberts et al., "Survival After Liver Transplantation in The United States: A Disease-Specific Analysis of the UNOS Database," *Liver Transplantation* 10, no. 2 (July 2004): 886-897.

² A.J. Kwong et al., "OPTN/SRTR 2019 Annual Data Report: Liver," in "OPTN/SRTR Annual Data Report 2019, special issue *American Journal of Transplantation* 19, no. S2 (February 2021); Canadian Institute for Health Information. *e-Statistics Report on Transplant, Waiting List and Donor Statistics, 2020*. Ottawa, ON: CIHI (2021).

starting point for my study is not simply that stories of loss are untold (or somehow just waiting to be told) but an exploration of how the biomedical context inhibits the telling of loss because medicine, and organ transplantation particularly, is relentlessly conceptualized as a story of “winning.”³

Writing as a Patient – narrative medicine

My research is in the realm of narrative medicine. One of the main principles of narrative medicine is that first-person experience can advance our knowledge and understanding of health and illness in significant ways, particularly in exploring the “human dimension” of disease/illness and expressing the ambiguous and layered nature of the human condition or “life problems” associated with illness that scientific biomedical discourse simply ignores.⁴ Bioethicist Martha Montello writes that the purpose of *narrative* is to understand *how* something happened. Narratives can explore contextual issues that shape decision-making, provide insight into why events unfolded as they did, and delineate features of the landscape in which they occurred.⁵ In focusing on Shauna’s story, I was able to question factors that constrained our expectations and understandings, and that generated our assumptions and explanations, untangling everything that felt so incomprehensible and fraught at the time.

³ The idea of medicine “winning” comes from Atul Gawande’s insightful book *Being Mortal: Medicine and What Matters in the End* (Toronto: Doubleday, 2014)

⁴ Arthur Kleinman, *The Illness Narratives: Suffering, Healing and the Human Condition* (New York: Basic Books, 1998); Rita Charon, *Narrative Medicine: Honoring the Stories of Illness* (Toronto: Oxford University Press, 2006).

⁵ Martha Montello, “Narrative Ethics,” *Hastings Center Report* 44, no. 1 (2014)

It's now widely recognized that illness narratives can have therapeutic value for patients by giving legitimacy and validation to their experience and exploring and working through the meaning of illness.⁶ They can also fill in knowledge gaps and enhance medical professional education. The growth of narrative medicine over the past 30 years is a testament to the way the stories of individual patients and clinicians contribute to a better way to educate doctors and practice medicine and demonstrates the unique value of writing and sharing stories.⁷ Patient stories have also increased awareness and understanding of how narratives define our lives and experiences, and shape our expectations of medicine, science and technology. Kleinman explains,

The plot lines, core metaphors and rhetorical devices that structure the illness narrative are drawn from cultural and personal models for arranging experiences in meaningful ways and for effectively communicating those meanings. Over the long course of chronic disorder these model texts shape and even create experiences. The personal narrative does not merely reflect illness experience, but rather contributes to the experience of symptoms and suffering.⁸

Kleinman's point draws on the idea that stories and narratives are not after-the-fact accounts and suggests a relationship between experience and narrative that is more complex and fluid.⁹

⁶ Kleinman, *The Illness Narratives*.

⁷ Rita Charon et al., *The principles and practices of narrative medicine* (Toronto: Oxford University Press, 2017).

⁸ Kleinman, *The Illness Narratives*, 49.

⁹ Cheryl Mattingly, *Healing dramas and clinical plots: the narrative structure of experience* (New York: Cambridge University Press, 1998); Jerome Bruner, "Life as Narrative," *Social Research* 54, no. 1 (Spring 1987): 11-32.

Taking a sociological perspective on writing about illness, literary scholar Anne Jurecic argues that in contemporary life “religious and folk explanations no longer give a satisfying and complete meaning to [illness] experiences.”¹⁰ Biomedicine also pays little attention to the social and philosophical meaning of illness. Medical anthropologist and physician Arthur Kleinman explains, “Whereas virtually all healing perspectives across cultures . . . orient sick persons and their circle to the problem of bafflement, the narrow biomedical model eschews this aspect of suffering [the *why?*] much as it turns its back on [the experience of disease].”¹¹ This deficiency in biomedicine “[opens] a space for the creation of explanatory stories about illness and healing” from the perspective of the patient.¹² Jurecic contends, “If one of the consequences of modernity is that we no longer depend upon traditional explanations for suffering, loss, and mortality, and if doctors’ offices and hospitals cannot function as spaces where personal meaning can be developed, then the existential questions about human frailty and significance have to be asked and answered elsewhere.”¹³ One of the places where this is addressed is in patient stories.

Jurecic situates the proliferation of stories of illness and private bodily suffering as a phenomenon of the latter half of the 20th century. One of the earliest literary examples of

¹⁰ Anne Jurecic, *Illness as Narrative* (Pittsburgh: University of Pittsburgh Press, 2012), 9.

¹¹ *Ibid.*, 9.

¹² *Ibid.*, 9. Here she is drawing from historian Anne Harrington, *The Cure Within: A History of Mind Body Medicine* (New York: WW Norton, 2009)

¹³ *Ibid.*, 9.

illness writing is Virginia Woolf's essay "On Being Ill" (1926). Woolf addresses how, regrettably in her opinion, illness has been perceived as too ordinary and commonplace to be the subject of literature, as though the story of the body "lacks plot" and wasn't worth writing about.¹⁴ Woolf argues that illness brings about new forms of awareness of our embodiment and an awakening to the human condition that does not justify the neglect illness has received in art and literature. She writes,

Considering how common illness is, how tremendous the spiritual change that it brings, how astonishing, when the lights of health go down, the undiscovered countries that are then disclosed, what wastes and deserts of the soul a slight attack of influenza brings to view, what precipices and lawns sprinkled with bright flowers a little rise of temperature reveals, what ancient and obdurate oaks are uprooted in us by the act of sickness, how we go down into the pit of death and feel the waters of annihilation close above our heads and wake thinking to find ourselves in the presence of the angels and the harpers when we have a tooth out and come to the surface in the dentist's arm-chair and confuse his "Rinse the mouth — rinse the mouth" with the greeting of the Deity stooping from the floor of Heaven to welcome us — when we think of this, as we are so frequently forced to think of it, it becomes strange indeed that illness has not taken its place with love and battle and jealousy among the prime themes of literature.¹⁵

According to Jurecic, some forms of illness writing became more common in the 1920s and 1930s (called "sanatorium narratives"); and the 1950s saw even more publications from patients with polio, journal articles about the last illness of famous people, and a remarkable book called *When Doctors are Patients* (1952) in which physicians reflect about their own illnesses. Additionally, medical innovations of the mid-20th century - sulfa drugs, antibiotics, vaccines - brought about a major shift in medicine from a focus on "acute disease" and infection to the "world of chronic disease." In the latter realm,

¹⁴ Ann Jurecic, *Illness as Narrative*, 13.

¹⁵ Virginia Woolf, *Selected Essays*, ed. David Bradshaw (Toronto: Oxford University Press, 2009), 101.

people not only “lived long enough to reflect on and write about their experiences” but also began to conflate personal discontent and cultural malaise, identifying ways that illness has both personal and social significance. A contributing factor was the growing influence of health movements in the 1960s that shone a light on politicized issues and “the dehumanizing experience of medical institutions.”¹⁶ Patients were frustrated and critical and this led to the denouncement of “alienation from practitioners,” suspicion about authority and medicalization, which imposed “expertise and control on intimate experience.”¹⁷

Narrative medicine reflects the changing role of patients in our current healthcare landscape (away from traditional views of the patient as a “recipient” of care), shaped as well by our media landscape that has expanded discursive practices around health, providing individuals with tools to produce, circulate and navigate health narratives, and gain influence in the construction and mobilization of health discourses. In this context, attitudes towards personal disclosure and personal writing have also changed, particularly as the possibilities and varieties for self-publication have increased (blogs and self-

¹⁶ Jurecic, *Illness as Narrative*, 7.

¹⁷ Ibid. A critique of medicalization was a focus of women’s health movement in the 1960s and the 1970s, which sought to develop women’s sense of autonomy and competence with regards to health issues. The lack of information provided to women, combined with the paternalism that was a characteristic of healthcare and medicine at the time, fostered power dynamics that made it difficult to question or challenge professional expertise and put women in the position of being disempowered and not in control of our own bodies. A key insight from feminist thinkers like Barbara Ehrenreich and Deirdre English, was that that “science” and medicine not neutral or “objective” but shaped by male dominated power structures, creating rules and standards that are more about the *control* of women’s bodies and the exertion patriarchal authority. See Barbara Ehrenreich and Deirdre English, *For Her Own Good: Two Centuries of Expert Advice to Women* (New York: Anchor Books, 2005).

documentation on social media platforms). The traditional publishing market is also flooded with illness memoirs.

Despite the popularity and market for illness memoirs, Lisa Diedrich points out that there are critics who disparage and dismiss illness writing (and other forms of memoir or the “literature of personal disaster”) as narcissistic, self-indulgent, and self-aggrandizing forms of writing that give too much weight to personal stories and not enough to “aesthetic sensibility.”¹⁸ In a CBC *Ideas* episode on the subject of reading, the author Fran Lebowitz makes a similar point about the way that reading has changed. She criticizes what she sees as the predominance of the “Oprah Winfrey way of reading,” the point of which is to identify with what you are reading, to “see yourself.”¹⁹

The criticism that illness memoirs are narcissistic and navel-gazing made me intimidated about writing a personal story. I wasn’t convinced of my own significance. I also felt like I was an “outsider,” far removed from people who were in the field of organ transplantation. My outsider syndrome reminded me of a quote from one of Theodore Roosevelt’s famous speeches (about admonishing “cynics” and giving credit to those “in the arena”). He says, “*The credit belongs to the man who is actually in the arena: whose*

¹⁸ Diedrich, Lisa, *Treatment: Language, Politics and the Culture of Illness* (Minneapolis: University of Minnesota Press, 2007), xvi.

¹⁹ “Reading with a Grain of Salt, Part 1” *Ideas*, CBC Radio, May 13, 2020. <https://www.cbc.ca/radio/ideas/think-reading-means-you-re-smart-think-again-1.5567821>

face is marred by dust and sweat and blood."²⁰ I saw doctors, surgeons, nurses, recipients, administrators, policymakers and all other experts as the kind of people who were "in the arena" accomplishing legitimate things; by contrast, I was outside the "arena," not contributing in a relevant way.

A sense of diminishment (of death/loss, of the personal) made me apprehensive about approaching my dissertation first and foremost as an illness story. Though I had an intellectual understanding of the uniqueness and importance of patient knowledge, I couldn't easily apply it to my own situation (and to recognize that I had unique and important knowledge). I first needed to acknowledge that I have a patient voice. (I self-identify as a "patient" as it is defined in the Canadian Institute for Health Research's Strategy for Patient Oriented Research: "as an overarching term inclusive of individuals with personal experience of a health issue and informal caregivers, including family and friends."²¹) When I started thinking a little bit more about Roosevelt's metaphor of a face *marred by dust, sweat and blood* (the insinuation of having gone through a trial), I saw that by this criteria I was "in the arena," along with Sauna. In a very early draft of my dissertation proposal, I wrote the all caps assertion: WE ARE HERE.

²⁰ I saw this somewhere on the internet. It's there in many places, here's one: <https://www.goodreads.com/quotes/620479-the-credit-belongs-to-the-man-who-is-actually-in>

²¹ CIHR, "Strategy for Patient-Oriented Research – patient engagement framework," <https://cihr-irsc.gc.ca/e/48413.html#a4>

Make Life Better – health humanities

Patient voice, and the inclusion of patient and caregiver’s “experiential knowledge,” is an important component of health research.²² Yet, in healthcare there can still be an attitude that the patient’s perspective is limited, “unable to comprehend complex issues fully” or lacks knowledge of a bigger picture, unlike the “disinterested expert” perspective of health care professionals.²³ The assumption that patients are unable to take into account collective interests or grasp scientific information can undermine their potential contribution by limiting it to the personal dimensions of individual lived experience.

Graham Martin refers to the example of AIDS patients to demonstrate, on the contrary, that patients can play a vital and critical role. AIDS patients (along with their loved ones and allies) organized a formidable movement that, among other accomplishments, accelerated access to treatment options by forming their own research groups and lobbying politicians and pharmaceutical companies.²⁴ In this case, Martin argues, AIDS patients were “experts” in “ways which combine experiential dimensions with

²² Angela Coulter, *Engaging Patients in Healthcare* (New York: McGraw-Hill, 2013); Karen Schipper et al., “What does it mean to be a patient research partner? An ethnodrama,” *Qualitative Inquiry* 16, no. 6 (2010).

²³ Gillian D. Callaghan and Gerald Wistow, “Publics, Patients, Citizens, Consumers? Power and Decision Making in Primary Health Care,” *Public Administration* 84, no. 3 (2006), 591. See also John Clarke et al., *Creating Citizen-Consumers: Changing Publics and Changing Public Services* (London: Sage, 2007); Sarah Wilcox, “Lay knowledge: the missing middle of the expertise debate,” in *Configuring Health Consumers: Health work and the imperative of personal responsibility*, eds. Roma Harris, Nadine Wathen and Sally Wyatt, (Basingstoke: Palgrave-Macmillan, 2010).

²⁴ Graham P. Martin, “‘Ordinary people only’: knowledge, representativeness, and the publics of public participation in healthcare,” *Sociology of Health and Illness* 30, no. 1: 35-54. See also David France, *How to Survive a Plague: The Inside Story of How Citizens and Science Tamed AIDS* (New York: Knopf, 2016).

conventional scientific knowledge to develop a new, positioned perspective and develop the capacity to bind [different kinds of] knowledge.”²⁵ It is also the people who were living with AIDS, and suffering and dying from AIDS, who indicated the cultural, social and political meanings of the disease. The devastation of HIV/AIDS was a watershed in terms of representations of illness and patient experience.²⁶ AIDS provoked a powerful literary response and a growing awareness that health matters are “a complex knot of personal, scientific, cultural, social and political issues.”²⁷

Since the rise of health movements and patients’ rights movements, there has been a widespread shift in how patients are perceived, and a recognition that the paternalistic model of healthcare, where doctors know what’s best for patients, disregards patients’ own knowledge and expertise. The well-known disabilities’ rights slogan “nothing about us without us” exemplifies the stance that patients are key stakeholders in the healthcare system, and they shouldn’t be excluded.²⁸ In the framework of “patient-centered care,” the available healthcare services should meet patients’ needs, and patients should be able

²⁵ Martin, “‘Ordinary people only’,” 39-40.

²⁶ For example: David Wojnarowicz, *Close to the Knives: A Memoir of Disintegration* (New York: Vintage, 1991); Randy Shilts, *And the Band Played On: Politics, People, and the AIDS Epidemic* (New York: St. Martin’s Press, 1987); Susan Sontag, *AIDS and Its Metaphors* (New York: Farrar, Strauss and Giroux, 1989); Harold Brodsky, *This Wild Darkness: The Story of My Death* (New York: Henry Holt & Company, 1996)

²⁷ Jurecic, *Illness as Narrative*, 9.

²⁸ See James I. Charlton, *Nothing About Us Without Us: Disability, Oppression and Empowerment* (Berkeley: University of California Press, 2000); C. Charles and S. DeMaio, “Lay Participation in Health Care Decision Making: A Conceptual Framework,” *Journal of Health Politics, Policy and Law* 18, no.4: 881-904; Janet Storch, *Patient’s Rights: Ethical and Legal Issues in Health Care and Nursing* (Toronto: McGraw-Hill-Ryerson, 1982)

to choose the healthcare options they most prefer. These days there are more and more opportunities for patients' active involvement in healthcare decision-making, service design and policy-making because it is now more widely recognized that their values and points of view need to be taken into account and that their lived experiences makes them uniquely positioned to identify and define problems and unmet needs.²⁹ Having accountability to patients means listening to patients' negative experiences, responding to the inadequacies that patients identify, putting patients at the center of research and taking political action to address systemic issues like racism, sexism, homophobia and transphobia.

Learning about what is wrong with the healthcare system, from the patient's perspective, is harnessed to the goal of making healthcare better. This in itself is not a bad thing, but it sets parameters for what the purpose of health research should be. The notion that a valid research contribution ought to be geared toward improvement is linked to the imperative to be constructive. This can also be silencing. In the paradigm of improvement, some patient voices are not heard, only those that are "useful." The definition of what is "useful" can mean conforming to an agenda that doesn't question core values of western biomedicine, subvert social hierarchies or challenge institutional constraints that maintain

²⁹ Jo Anne L. Earp, Elizabeth A. French and Melissa B. Gilkey, eds, *Patient Advocacy for Health Care Quality: Strategies for Achieving Patient-Centered Care* (Toronto: Jones and Bartlett Publishers, 2008); T. Greenhalgh, "Patient and public involvement in chronic illness: beyond the expert patient, *BMJ* 338, no. 49 (2009); Charles and DeMaio, "Lay Participation."

dominant interests. This can serve as a kind of gatekeeping around patient involvement, to include only the “useful malcontents.”³⁰

In my first chapter, I write about how wanting to be “useful” led me to believe that I ought to do something to increase organ donation. Advocacy for organ donation is a way that patients are useful, as is other volunteer activity that offer support services like – self-help groups and patient education.³¹ The most useful patients are those who are allies and work in partnership with the medical establishment. A prime example is mainstream breast cancer advocacy that centers on the biomedical goal of a quest for the “cure.” It does not call into question the “cure,” or question whose interests this quest serves.³² As I worked on my project, I started to question what I wanted the purpose of my research to be. The goals of improvement became muddier, and it became less obvious how I could be “useful.”

When I first tried to explain the goals of my project, I found myself pledging to address a “knowledge gap” by providing a missing perspective of the patient and writing about a topic (waitlist death) that hasn’t been studied. The legitimacy of writing about my own

³⁰ The phrase “useful malcontent” comes from Mark Vonnegut’s Foreword, “Too Long Too Short,” to *The Health Humanities Reader*, eds. Therese Jones, Delese Wear and Lester D. Friedman (New Brunswick, NJ: Rutgers University Press, 2014) – Vonnegut uses the phrase to refer not to patients but to health professionals with health humanities leanings. For a critique of involving patients as mere window dressing see J.Q. Tritter and A. McCallum, “The snakes and ladders of user involvement: Moving Beyond Arnstein,” *Health Policy* 76, no. 2: 156-168.

³¹ Bruce Wood, *Patient Power? The Politics of Patients’ Associations in Britain and America* (Philadelphia: Open University Press, 2000).

³² Samantha King, *Pink Ribbons, Inc.: Breast Cancer and the Politics of Philosophy* (Minneapolis: University of Minnesota Press, 2008).

experience was that it could be “useful.” This assumes that filling a knowledge gap (creating *more* knowledge) will contribute to healthcare improvement and what can be done “better.” The first time I wrote a short piece on Shauna’s death and presented it at a health humanities conference hosted by a medical school, the audience consisted primarily of medical students. Though my voice was steady, my hands were trembling and I thought it was obvious that I had barely made it through the reading. During the Q & A I found myself fielding a question from an earnest well-meaning medical student about what we can do “better.” I fumbled a response. I couldn’t answer the question. The telling part is the fact that this question was asked.

A pragmatic application or practical target (better healthcare, better doctors) is a convincing rationale that health research will make a valid contribution. Even in health humanities, it is difficult to escape the assumption that research ought to be useful, aligned with the dominant paradigm of “improvement” and “progress” in Western biomedicine. This leads to an instrumental view of health humanities that is focused on medical education and the quest to produce “good doctors” with well rounded skills. For physicians, the humanities are promoted as a valuable way to increase the imagination, develop analytical and synthetic thinking, teach/learn humility and empathy, enhance moral judgement and cultivate “critical intelligence” not just “operational intelligence.”³³ Seen this way, the humanities, like patient stories, are a “tool” to produce better doctors

³³ Andrea Wershof Schwartz et al., “Evaluating the Impact of the Humanities in Medical Education,” *Mount Sinai Journal of Medicine* 76, no. 4 (2009); see also J. Ousager and H. Johannessen, “Humanities in undergraduate medical education: A literature review,” *Academic Medicine* 85, no. 6 (2010); Therese Jones et al, “The Almost Right Word.” The Move from Medical to Health Humanities,” *Academic Medicine* 92, no. 7 (2017)

and to challenge the context-free impersonal way of practicing medicine that creates distance from patient experience and suffering, and distance from death. Must there always be the imprint of improvement?

The field of transplantation is oriented towards improvement; research and innovation is pursued for this reason. In North America, “one transplant for life” has become a kind of catchphrase for transplantation research.³⁴ This speaks to how narrowly “improvement” is conceptualized. It means extending the number of “graft years” and the goal for transplant patients to live longer with fewer complications. Improvement means how to make transplantation a better cure-like treatment and save more lives. It’s an idealization.

The health humanities is a broad multidisciplinary field that addresses complex human and ethical issues in medicine. According to Jones et al., an interest in health humanities arose in the 1970s (at that time known more narrowly as “medical humanities”) because of the “imbalance between the technical aspects of medicine and the human facets of health and caregiving.”³⁵ The increasing power of Western biomedicine was becoming less oriented to patient experience. Meanwhile, there was growing recognition of “health” was increasingly being recognized as an interdisciplinary area of study, along with other areas of inquiry like gender, race, and sexuality, that do not belong to a single traditional

³⁴ The Canadian Donation and Transplantation Research Program uses this slogan - <https://cdtrp.ca/en/>; it is also the registered trademark of the American Society of Transplantation - <https://trademarks.justia.com/900/80/one-transplant-for-90080490.html>

³⁵ Jones et al., “The Almost Right Word.”

academic discipline.³⁶ The biomedical lens does not provide sufficient understanding of health, particularly when it comes to social, structural and political issues and to individual and cultural experiences of illness. Health humanities uses a wide lens and attempts to grasp the complexity of contemporary healthcare and the wide variety of contextual issues that affect health and illness.³⁷

Viney, Callard and Woods argue that one goal of health humanities is to interrogate the conditions that limit the improvement of healthcare.³⁸ Along these lines, the purpose of research can be to demonstrate why problems can't easily be fixed or explain how they are limited by the conditions that produced the problems in the first place. In the case of transplantation, the pursuit of "more" transplants and "better" transplants is carried out through science, technology and innovation, while ignoring social context, human limitations, patient experience and mortality. The aim to improve transplantation is tinged with hubris, fantasy and a little bit of deception; it doesn't take into consideration the scarcity and fallibility of the treatment, and the reality that patients will become too sick and die. The field is complicated by its own idealized aims that are tethered to an abstract principle that life is preferable to death. In this context, waitlist death falls through the cracks by the perpetual deference to "improvement," and the idea that science, technology and medicine will make life better.

³⁶ Ibid.

³⁷ See These Jones, Delese Wear and Lester D. Friedman, eds. *Health Humanities Reader* (New Brunswick, NJ: Rutgers University Press, 2014).

³⁸ William Viney, Felicity Callard and Angela Woods, "Critical medical humanities: embracing entanglements, taking risks," *Medical Humanities* 41, no. 1 (2015)

In organ transplantation, the object of improvement is also the “system,” which can also curtail the worth and significance of patients’ lived experience. Health researchers Gibson, Britten and Lynch refer to Habermas’ distinction between “systems” and “lifeworlds” to explain why there can be “tensions between the experiences, needs and concerns of patients and carers [lifeworlds] and the need to administer healthcare in as rational and efficient manner as possible within strictly limited resources [systems].”³⁹ Enhancements of the “technical efficiency of the system” may do little in terms of the “everyday social world” of patients. Gibson, Britten and Lynch call for more research into the cleavage between “systems” (and structural limitations) and “lifeworlds.”⁴⁰

A gap between “systems” and “lifeworlds” has particular salience in the era of evidence-based medicine (EBM).⁴¹ Even if there is recognition and value ascribed to patient experience, or the humanistic side of medicine, the EBM context of contemporary healthcare still (over)privileges data generated by quantitative methods and drowns out individual and contextual circumstances that account for patients as “whole persons”

³⁹ A. Gibson, N. Britten and L. Lynch, “Theoretical directions for an emancipatory concept of patient and public involvement,” *Health* 16, no. 5 (2012), 537.

⁴⁰ Ibid. See Jurgen Habermas, *The Theory of Communicative Action: Volume 2: Lifeworld and System*, trans. Thomas McCarthy (Boston: Beacon Press, 1985).

⁴¹ The term “evidence-based medicine” was coined in the early 1990s. It is defined as “the process of systematically finding, appraising and using contemporaneous research findings as the basis for clinical decisions” (William Rosenberg and Anna Donald, “Evidence-based medicine: An Approach to clinical problem-solving,” *British Medical Journal* 310 (1995): 1122). See also Keith Denny, “Evidence-based Medicine and Medical Authority,” *Journal of Medical Humanities* 20, no.4 (1999).

(which has real consequences for patients).⁴² The health humanities are especially pertinent as well because EBM has been rightfully critiqued for “failing to reflect on deeper questions.”⁴³ My research specifically looks at questions that EBM does not address and highlights the hard issues around organ allocation that the practices of liver transplantation avoid. EBM turns away from experience, the meaning of illness and suffering, and the responsibility to self and others “in favour of a reliance on scientific data” that are often disconnected from the lived realities of patients. There may be consensus about the need to “humanize” medicine, but in practice, scientific and statistical generalizations carry far more weight, especially in healthcare policy and protocols, than the individuality of the patient and respect for unique experience.⁴⁴

Methodology

Writing about personal experience in the social sciences or health sciences is most often associated with a genre of research called “autoethnography,” which treats the “self” as an object of study. The legitimacy of autoethnography lies in the recognition that there is a link between “self-understanding” and “social understanding.” There is an inextricable connection between the personal and the social because personal experiences are always

⁴² Trish Greenhalgh et al., “Six ‘biases’ against patients and carers in evidence-based medicine,” *BMC Medicine* 13, no. 200 (2015).

⁴³ Anna Batistatou et al., “The introduction of medical humanities in the undergraduate curriculum of Greek medical schools: challenge and necessity,” *Hippokratia* 14, no. 4 (2010): 241-243.

⁴⁴ Rolf Ahlzen, “Narrativity and Medicine: some critical reflections,” *Philosophy, Ethics, and Humanities in Medicine* 14 (2019). See also Helen Lambert, “Accounting for EBM: Notions of Evidence in Medicine,” *Social Science and Medicine* 62 (2006): 2633-2645.

embedded in sociocultural context.⁴⁵ Autoethnographic research and writing demonstrates how “personal material” can be “public mattering.”⁴⁶

Autoethnography is associated with major academic shifts in the latter half of the 20th C such as the “turn toward blurred genres of writing, a heightening self-reflexivity in ethnographic research, and increased focus on emotion in social sciences [the “affective turn”], and the postmodern skepticism regarding the generalization of knowledge claims.”⁴⁷ It is a form of research that foregrounds the subjective position of the researcher and makes no claims to the description of an “objective reality” from a disinterested researcher perspective.

Autoethnography is regarded skeptically by some academics who deem the method to be not systematic, not scholarly, and potentially not even research at all. It runs the risk of being perceived as self-absorbed, too introspective and not focused enough on others. There are also the dangers of “multitasking,” i.e. “pursuing personal goals in scholarly work.”⁴⁸ Sarah Wall warns that “the resolution of personal issues ought to occur in an

⁴⁵ Leon Anderson, “Analytic Autoethnography,” *Journal of Contemporary Autoethnography* 35, no. 4 (2006), 387.

⁴⁶ Leslie Jamison in Ann Jurecic, “The Illness Essay,” *Life Writing* 13, no. 1 (2016), 17.

⁴⁷ Anderson, “Analytic Autoethnography,” 373.

⁴⁸ *Ibid.*, 385-389.

entirely different context than an academic attempt to add to social knowledge”⁴⁹ and thinks that the risk of egocentrism can lead to “seeing only what serves the researchers’ purposes, placing passion before science,” creating “a product of assertions” that attempts to impose the author’s views on the audience.⁵⁰ Others regard autoethnography as “emotional writing” and an ill-defined method.⁵¹

To enhance the credibility of autoethnography, Anderson proposes a distinction between two kinds of autoethnography: “analytic” and “evocative.” Analytic is “committed to developing theoretical understandings of broader social phenomena” whereas evocative ethnography is more about conveying the author’s experience and relies on “an epistemology of emotion, moving the reader to feel the feelings of the other.” In evocative ethnography the emphasis is more on the storytelling, rather than on the detached abstractions and explanations that accompany the narrative. Evocative ethnography seeks “emotional resonance” in dealing with “emotionally wrenching experience, such as illness, death, victimization, and divorce,” while analytic autoethnography seeks to “understand the topic under study by placing it within a social analytical context” and connecting it to “broader social science theory.”⁵²

⁴⁹ Sarah Wall, “Toward a Moderate Autoethnography,” *International Journal of Qualitative Methods* (2008), 4.

⁵⁰ Sarah Wall, “Easier Said than Done: Writing an Autoethnography,” *International Journal of Qualitative Methods* (2008), 44.

⁵¹ Heewon Chang, “Autoethnography in Health Research: Growing Pains?” *Qualitative Health Research* 26, no. 4 (2016); Ingo Winkler, “Doing Autoethnography: Facing Challenges, Taking Choices, Accepting Responsibilities,” *Qualitative Inquiry* 24, no. 4 (2018).

⁵² Anderson, “Analytic Autoethnography,” 373-378.

As I started into my project, I was not persuaded by any of these designations, even though I think it is possible to apply them to my research. I had an urge not to categorize my research at all. I knew I wanted to write about Shauna's death and how it is linked to a broader context, including the values and ideologies that inform healthcare and are specifically embedded in transplant narratives, practices and policies; but I did not want the obligation to adhere to strict methodological procedures or a rigidly defined critical agenda. Broadly speaking, looking at the wider set of relations and tendencies that trickle down into a phenomenon or an object of analysis is a marker of cultural studies research, specifically associated with what Stuart Hall, a key figure in the discipline, describes as a "conjunctural analysis," which asks the question: "what does this have to do with everything else?".⁵³ In qualitative health research, this type of investigation is associated with a "critical theory stance," which Guba and Lincoln define as paying attention to the "social political cultural and economic antecedents of the studied situation."⁵⁴ Similarly, Carpenter and Suto identify a "critical theory approach" as one that focuses on "societal beliefs and discourses and the larger social systems that shape people's lives."⁵⁵

⁵³ Jeremy Gilbert, "This Conjuncture: For Stuart Hall," *New Formations: A Journal of Culture, Theory, Politics* 96-97 (2019): 5-37.

⁵⁴ E.G. Guba and Y.S. Lincoln, "Competing Paradigms in qualitative research," in *Handbook of qualitative research*, eds. N.K. Denzin and Y.S. Lincoln (Toronto: Sage, 1994), 112.

⁵⁵ C. Carpenter and M. Suto, *Qualitative research for occupational and physical therapists: A practical guide* (Oxford: Blackwell Publishing, 2008), 21.

A critical theory approach or stance prevents personal storytelling from becoming merely “confessional,” and it is also useful for writing about experiences that don’t easily conform to conventional narrative forms. As Linda Finlay explains, “The more we understand how structural forces shape us, the more we can escape them.”⁵⁶ This can help us recognize “narratives that are dead ends or those that “[reproduce] the processes one is trying to dismantle.”⁵⁷

Ann Jurecic argues, however, that the critical reading and writing of illness narratives has become too narrowly associated with the examination of how narratives have been constructed by political, economic and cultural forces. She argues that in searching for evidence of the “dominant discourse,” we “anticipate and contain textual and theoretical problems in advance.”⁵⁸ Jurecic’s point is based on Bruno Latour’s 2004 essay, “Why Has Critique Run Out of Steam.” Latour writes that the “explanations churned out by the machine of critique,” specifically that “human behaviour is properly understood to be an effect of factors such as economics, discourse, systems of social power,” do not

⁵⁶ Linda Finlay, “‘Outing’ the researcher: The provenance, process and practice of reflexivity,” *Qualitative Health Research* 12, no. 4 (2002), 534. I would note that it is overly simplistic to think that social forces can be “escaped.” There may be opportunities for what French sociologist/philosopher Michel de Certeau calls “procedures of everyday creativity” despite being “caught in the nets of ‘discipline,’” – i.e. the “localizable, expansionist, repressive and legal institutions” that exercise power through “miniscule technical procedures” that Foucault calls “discipline.” See Michel de Certeau, *The Practice of Everyday Life*, trans. Steven Rendall (Los Angeles: University of California Press, 1984), xiv-xv.

⁵⁷ Rose Richards, “Celebrities and spiritual gurus: Comparing two biographical accounts of kidney transplantation and recovery,” *African Journal of Disability* 4, no.1 (2015), 1724.

⁵⁸ Jurecic, *Illness as Narrative*, 3. This is a point she takes from Eve Kosofsky Sedgwick, *Touching, Feeling: Affect, Pedagogy, Performance* (Durham: Duke University Press, 2003), 130. See also Eve Kosofsky Sedgwick, “Paranoid Reading and Reparative Reading; or, You’re So Paranoid, You Probably Think This Introduction is About You” in *Novel Gazing: Queer Readings in Fiction*, ed. Eve Kosofsky Sedgwick (Durham: Duke University Press, 1997).

necessarily have much relevance when it comes to “matters close to our hearts.” Latour explains, “the mistake we made, the mistake I made, was to believe that there was no efficient way to criticize matters of fact except by moving *away* from them and directing one’s attention *toward* the conditions that made them possible.” To avoid this mistake (and in addressing matters close to the heart), Jurecic argues that we shouldn’t discount “ordinary motives for reading and writing.”⁵⁹

I associate ordinary motives with Michel de Certeau’s *The Practice of Everyday Life* in which he explains how human autonomy is practiced within acts of everyday creativity (reading, talking, dwelling, walking). While social codes may be binding, we can also make them “habitable” like a rented apartment, inserted with our own histories and furnished with own “acts” and “memories,” just as pedestrians do “in the streets they fill with the forests of their desires and goals.”⁶⁰ Ordinary motives might be what de Certeau terms *tactics* - the “guileful ruses” we use to maneuver through the “organized techniques of systems” and to seek trajectories that “do not cohere with the constructed, written and prefabricated space through which they move.”⁶¹ Tactics are outside the order and offer variables. De Certeau likens them to a form of *bricolage*, as Claude Levi-Strauss defined

⁵⁹ Jurecic, *Illness as Narrative*, 15-16.

⁶⁰ De Certeau, *The Practice of Everyday Life*, xxi.

⁶¹ *Ibid.*, 34.

it - a “production ‘that has no relationship to a project’ and which readjusts ‘the residue of previous construction and destruction.’”⁶²

The “ordinary motives” driving my study are also removed from a specific scholarly intent, aside from a commitment to “craftmanship” of scholarship - to organize ideas and work methodologically to make an object that would be useful to others.⁶³ I had to trust that my ordinary motives would allow me to sort out the complex specificities and concrete details of Shauna’s experience, as well as providing me with the material to construct convincing and explicit interpretations of factors that are more abstract, adding to the body of knowledge on liver disease and liver transplantation for the patient’s perspective.

Rather than focus on research methodology, I started to read advice on how to write creative nonfiction and about the creative process more broadly. Guba and Lincoln make the compelling argument that too much emphasis on “normative methodology” can detract from “creative thinking.”⁶⁴ I decided to adopt a looser critical narrative methodology that would allow me to combine creative writing practices and critical cultural analysis and avoid pre-set research goals in order to “keep the channel open.” Iconic modern dancer and choreographer Martha Graham claims that creative work is

⁶² Ibid., 174.

⁶³ This idea is from Umberto Eco, *How To Write a Thesis*, trans Caterina Mongiat Farina and Geoff Farina (Boston: MIT Press, 2015)

⁶⁴ Guba and Lincoln, “Competing paradigms,” 106/

achieved through “keeping the channel open.” She explains, “It is not your business to determine how good it is, not how it compares with other expression. It is your business to keep it yours clearly and directly, to keep the channel open. You do not even have to believe in yourself or your work. You have to keep open and aware directly to the urges that motivate you. Keep the channel open.”⁶⁵ This open channel creative process oriented me to focus on what can be uniquely expressed through my own observance and perception, trusting that purpose and meaning can emerge through writing and building a narrative. Susan Sontag explains, “To tell a story is to say: *this* is the important story. It is to reduce the spread and simultaneity of everything to something linear, a path.”⁶⁶ My goal was to reach a deeper and wider place of understanding.

Physician and writer Anton Chekov distinguishes the role of the “expert” and the role of the “artist.” He argues that the role of the “expert” is to find solutions for “specialized problems” whereas the artist “observes, selects, guesses and arranges” in such a way that contributes to the *formulation of problems*.⁶⁷ As I started my writing, I bended in favour of the artistic role to identify and formulate the complex problems that arise from liver transplantation and waitlist death, to ask the right questions, or to see those questions in a new light. In this regard, my project has the qualities of what the Social Science and Humanities Research Council defines as “research creation”: “an approach to research

⁶⁵ In Agnes DeMille, *Martha: The Life and Work of Martha Graham* (New York: Random House, 1991).

⁶⁶ Susan Sontag, *At the Same Time: Essays and Speeches* (New York: Farrar, Strauss and Giroux, 2007).

⁶⁷ Anton Chekov, “Art Should Not Solve Problems,” in eds, Piero Brunello and Lena Lencek, *How to Write Like Chekov* (Boston: De Capo Press, 2008), 15.

that combines creative and academic research practices and supports the development of knowledge and innovation through artistic expression, scholarly investigation and experimentation.” By engaging in autobiographical creative writing as the basis of my research, I am following the idea that “the creative process is situated within the research activity.”⁶⁸ This meant that my project began without a specific research question that I intended to solve.

“Hurt Must Be Examined Like a Plague” - Anne Sexton

I committed to write about Shauna’s death more than a decade after she died. Kleinman argues that in this kind of “retrospective narrativization” the “raison d’être is not fidelity to historical circumstances but rather significance and validity in the creation of a life story.” This is particularly true, according to Kleinman, when illness has a “catastrophic end.”⁶⁹ I recognize that in my writing I was searching for the restoration of integrity and attempting to “fix” a broken story or revise the “bad ending.” Frank Kermode defines a “good ending” as having “a satisfying consonance” with the beginning and the middle.⁷⁰ Shauna’s story lacked a “good ending.” On a personal level, I couldn’t get past the

⁶⁸ “Definitions of Terms” *Social Science and Humanities Research Council* <https://www.sshrc-crsh.gc.ca/funding-financement/programmes-programmes/definitions-eng.aspx#a22>

⁶⁹ Kleinman. *The Illness Narratives*, 51.

⁷⁰ Frank Kermode, *The Sense of an Ending: Studies in the Theory of Fiction* (Toronto: Oxford University Press, 2000).

dissonance of Shauna's death, while also understanding that a "good ending" could not be restored.

The personal part of my writing involved confronting my grief and examining how my and Shauna's identities as close sisters were constructed, and the emotional and cultural responses that were available to us throughout Shauna's experience of chronic illness (diagnosed in childhood), in the intensity of waiting for a transplant, her death and all the years that have lapsed since. I assumed that writing about the "human condition" parts would be difficult and somewhat fuzzy, but it turns out (whether or not it comes across in the final product) these were far less ambiguous than I thought they would be and made critical inquiry into the structuring conditions and shaping of experience easier to resolve. Narrative, as a mode of knowledge production, hones critical awareness.

My critical analysis stems from recognizing what matters (to me) in the story; and I've tried to maintain the narrative itself as the "analytical device," rather than positioning the "critical apparatus" outside of the text or "in some relation of exteriority to [it]."⁷¹ This approach is a feature of fictocriticism. With roots in French feminism of the 70s and 80s, fictocriticism calls for a "genre-bending" or hybridised mode of writing that moves "between the poles of fiction ("invention"/"speculation") and criticism ("deduction"/"explication") of subjectivity ("interiority") and objectivity

⁷¹ Heather Kerr, "Fictocriticism, the 'Doubtful Category' and the 'Space Between,'" *Journal for the Association for the Study of Australian Literature* (2013), 1.

(“exteriority”).”⁷² It emphasizes that the narrative and the “critical commentary” are a “single device”⁷³ and that analysis takes place in the writing itself through “nuanced and thoughtful description.”⁷⁴

Fictocriticism does not embrace traditional notions of objectivity, rigour and validity. In particular, it rejects the idea that “anyone who did the study would have come up with the same results.” In fact, it claims the opposite: fictocriticism is always “unique and personal”: “the intensity of the subjectivity and expression is central” and it “draws on thoughts and feelings that are not readily accessible to ‘standard’ forms of research.”⁷⁵ As I understand it, fictocriticism makes the claim: No one else could have written this text but me. The appeal of such a claim is that it grants authority not through external validation but from a conviction that comes from within. No one “invited” me to write this. If I had been waiting for an invitation, I would have been forever searching. Discomforting or not, I had the impetus to write. Oftentimes it was almost painful.

In 1960, the “confessional” poet Anne Sexton wrote a letter to her friend Fred, excerpted in a book titled *Anne Sexton: A Self-Portrait in Letters*. It said “I guess I mean that creative people must not avoid the pain that they get dealt. I say to myself, sometimes

⁷² Kerr and Nettlebeck in Carl Rhodes, “Writing organization/romancing fictocriticism,” *Culture and Organization* 21, no. 4 (2015), 294.

⁷³ Kerr, “Fictocriticism,” 1.

⁷⁴ Christian Ehret, “Moments of Teaching and Learning in a Children’s Hospital: Affects, Textures and Temporalities,” *Anthropology and Education Quarterly* 14, no. 1 (2018), 69.

⁷⁵ Rhodes, “Writing organization/romancing fictocriticism,” 297-298.

repeatedly, ‘I’ve got to get the hell out of this hurt’ . . . But no. Hurt must be examined like a plague. The others can run, take bottles of Miltown etc. But I think we (let’s say we have no name, this literary bunch) have got to hang around and know just what is going on.”⁷⁶

Writing this dissertation took three years. The process began with an initial outpouring that was completely unstructured and not guided by any goal or research question. This part of beginning with a blank page felt like embarking on an obscure internal project that didn’t produce results that made it seem justifiable at all. What kept me going was dancing, or an intuitive understanding that what I needed to do was not just cerebral but had a somatic, experiential, dimension to it. I participated in new-agey improvisatory dance communities that functioned for me as a kind of “dance therapy.” This is how I worked through the emotional aspects and the internal “personal” issues that interfere with (block) writing. Dancing also helped me identify my voice. One instructor of an improv dance class once said, “you are here to dance the dance that only you can dance,” which didn’t initially strike me as eloquent or profound but eventually became a kind of mantra for me. After several messy, disorganized and chaotic drafts, I turned to multicolored index cards for revising and restructuring. This editing and organization part was not aided so much by dancing so much as it was by lap swimming, a focus on the entrenchment of ideas and going over the same lines.

⁷⁶ Anne Sexton, *Anne Sexton: A Self-Portrait in Letters*, eds. Linda Gray Sexton and Lois Ames (Boston: Houghton Mifflin, 1977), 87.

Organization of thesis

My thesis tells the story of my sister's waitlist death as well as aspects of her overall illness experience of chronic liver disease (going back to childhood), organized into the following six chapters.

Chapter One, "Learning about the Organ Shortage," provides background context about how I initially came to graduate studies to pursue research on public awareness and education about organ donation. I explain how along the way I had to come to terms with my assumption that waitlist death is a problem that can be summarized as an "organ shortage," and my realization that it is an oversimplified view to think that it's possible to eliminate waitlist death through an increase in organ donation. It became especially obvious that public awareness of the organ shortage would not solve the problem, even though I had imagined this as the go-to solution. Framing waitlist death as a dilemma of the "organ shortage" reveals instead a relentless orientation to the happy ending - that we can or should only ever understand organ transplantation as a successful story of transplantation as though no other stories existed. Thinking in terms of "supply" and "demand" offers little in terms of understanding the way transplant patients are left to contend with death, loss and failure.

Chapter Two, “The Story of Progress,” addresses the dominant transplant narrative and how the “reassuring plot” of successful stories can contrast with patient experience. This chapter also considers historical context and the origins of organ transplantation as a medical success story. From the beginning, organ transplantation was a field dominated by hope and the fantasy that biomedicine can overcome illness and mortality. The successes of transplantation bury a history of failures. I argue that transplantation is narrowly understood through a lens of progress, and as a result, we don’t consider loss and death to the extent that we should, limiting our understanding of patients’ lived experiences. Success in transplantation is, in reality, a far more ambiguous story; and it’s not the “whole story.” I demonstrate how historically, and up until the present, there has been a disproportionate amount of attention paid to the “heroes,” the rewards of transplantation and the stories of survivors.

Chapter Three, “The Suffering of Waiting” turns towards Shauna’s personal experience of waiting for a liver transplant. In progress stories, a transplant is the “endgame” so waiting is glossed over as something that happens on the way. I attest to the way that “waiting” is dominated by optimism and how “staying hopeful” is an attempt to align experience with the dominant transplant narrative. From my perspective as a family member desperate for my sister’s second chance at life, I consider that the consequence of clinging to “hope” is the disconnection from patient suffering, and a failure to engage with the here-and-now of waiting. Bound to the hope that a transplant would save Shauna (a future-oriented fantasy), I failed to understand what the experience was really

like and fully grasp the significance of what it is like to live with uncertainty and contend with the physical reality of liver failure.

Chapter Four, “The Role of MELD,” places Shauna’s experience in the context of organ allocation policy and the system that rates disease severity known as MELD (Model End-Stage Liver Disease). MELD is an algorithm that calculates three biochemical indicators to predict 3-month mortality risk. The purpose of MELD is to give priority to patients who are most likely to die, echoing the biomedical ethos of “warding off death” and reiterating transplant’s status as a life-saving technological intervention. This chapter explores how MELD is a product of evidence-based medicine (EBM) and examines the implications of the systematic “objective” decision-making that EBM stands for. I explain how MELD has shortcomings and inconsistencies, including a systemic gender bias, that shaped Shauna’s trajectory to waitlist death, and even made her death a likely outcome. I also emphasize that in the MELD context, patients are reduced to impersonal statistics that renders unique experience insignificant and makes individual patient stories invisible.

Chapter Five, “The Erasure of Death,” considers death’s looming but unacknowledged presence in the field of transplantation and biomedicine more broadly. Transplantation uses euphemistic devices and happy narratives to avoid addressing the death of the donor. Waitlist death is likewise an avoided and unspoken outcome that patients and families are ill-prepared for. I explain how the endless quest for transplant and a happy ending found Shauna, for the last two weeks of her life, in the ICU on life support. The ICU, with its

dehumanizing aggressive treatments, obscures death further and impedes any human connection with the dying in order to avoid death at all costs. The fixation on a miraculous recovery creates a disorientation to death, and a refusal to see it with any clarity, awareness and acceptance.

Chapter Six, “Fixing a Broken Narrative,” demonstrates the way in which we use narrative to construct identity, and how Shauna’s waitlist death had an impact on the level of her identity, as well as my own and the bond we had as sisters. I also address the difficulty of locating an alternative narrative to the dominant transplant story or finding ways to avoid referencing narrative conventions of plot (organized according to a beginning, middle and an end). I conclude that it is not a “story” that can best represent the uncertainty, indeterminacy and contingency of waitlist death, but figurative devices like metaphor and irony that are complex and layered and don’t offer the shored-up meanings of a tidy narrative. Using insights from narratology and literary theory, I explore the idea of exchanging the notion of a “hepatic happening” in place of a “liver transplant story.”

1 Learning About the Organ Shortage

Death by Organ Shortage

Every year thousands of patients are listed for a liver transplant. Approximately, 10-25% of those people become “delisted.” Some succumb to “waitlist mortality”; others are removed for being too sick.¹ In the US, eight people waiting for a liver transplant die every day. This translates into one in six dying on liver transplant waitlist every year.²

Despite its predominance, little has been written about waitlist death in liver transplantation. It’s a marginal subject that’s not often discussed. When it is, it is often linked to the cause of increasing organ donation. To “die waiting” refers to a transplant that didn’t happen, and implies that death is produced by an organ shortage, the “supply” that falls short of the “demand.” A waitlist death is a life that could have been saved if an organ was available.

Sixteen years ago, this is what happened to my sister Shauna. Her obituary stated, “Shauna died at age 29 while waiting for a liver transplant.” Another tribute in a newspaper, published a few months later, said “Shauna’s fight for life while waiting for a liver transplant drew to a close on December 3, 2004.” At the time, emphasizing that

¹ Saleh Elwir and John Lake, “Current Status of Liver Allocation in the United States,” *Gastroenterology and Hepatology* 12, no. 3 (March 2016).

² David A. Goldberg, Richard Gilroy and Michael Charlton, “New organ allocation policy in liver transplantation in the United States,” *Clinical Liver Disease* 8, no. 4 (October 2016), 108.

Shauna “died waiting” seemed to make the point obvious - that there aren't enough organs for everyone who needs them.

Shauna was diagnosed with autoimmune hepatitis in 1986 when she was 11 years old. Over the course of the next few years, she developed inflammatory bowel diseases (Crohn's and ulcerative colitis) and then Primary Sclerosing Cholangitis (PSC), an autoimmune disease that hardens the bile ducts. One autoimmune disease creates a predisposition for others and this cluster of diagnoses was not outside the norm in gastroenterology. When Shauna's PSC was diagnosed in 1994, she was a 19-year-old university student. Her prognosis was that she would eventually need a liver transplant.

From the time that Shauna was listed for a liver transplant, a year and a half before she died, I easily counted on it happening. Though it may seem strange, I don't think that I had ever thought seriously about the shortfall of organs and that the need for transplantation exceeds the rate of donation. In fact, I don't think I ever thought about organ donation much at all. There are clues in the journal our family kept when Shauna was dying and evidence in the phrases we used that show how we distanced ourselves from the reality of organ donation or overlooked how organ donation was even part of the process. When she deteriorated to a critical point and was hanging by a thread (she was sedated and on life support but we said she was “fighting”), my father wrote, “*Shauna is doing her part to give all of us hope and the liver procurement system more time to come up with a new liver.*” I once wrote that we hope “*for a new, healthy liver to be delivered soon to Shauna.*” It is not as though there was a surfeit of organs readily available, but we

talked about it as though there was an effective “system” in place that could “deliver” organs when they were needed. At least this is how I thought it should be.

Ten years after Shauna died, there was an episode of the *Fifth Estate* on CBC television called “Dead Enough.” The show probed into doubt and questions around death determination and organ donation - namely whether organ donors are really dead and whether doctors are inconsistently applying diagnostic criteria for death determination. As I watched it, I hated it. Not just because I thought public support for organ donation ought to be protected, I disparaged it as an incoherent piece of journalism, a pastiche of unrelated storylines. In part, “Dead Enough” was a remake of a *60-Minutes* documentary that aired in the 1980s about some conspiring doctors at the Cleveland Clinic, joined together with a more contemporary issue about how long it takes to be truly dead once a heart stops beating (related to the increasing use of non-heart beating cadaveric donors), and also the personal story of a young man who recovered following a diagnosis of brain death and an overly hasty request for organ donation. The different threads of the program were unified by a common tone - that there is something dodgy about organ donation. I was alarmed by how far it strayed from offering a positive message about the altruistic act of donating organs and the importance of saving lives through transplantation. I thought it was deliberately misleading. It made me feel naive and guilty that I hadn’t done more to increase organ donation.

After Shauna passed away, I avoided the topic of organ donation as much as I could. It made me tentative, wary and overwhelmed with hopelessness, though I furtively signed my donor card that came with my driver’s license renewal each year. Occasionally I did

little fits of late-night research on the internet, resulting in nothing productive. In my gloomy vision, organ donation seemed doomed by a panoply of fears and anxieties related to mortality and the boundaries of death, and squeamishness about bodily integrity. I worried that most people viewed organ donation as a sacrosanct and inviolable individual choice that was none of anyone else's business. I was cynical about efforts to raise "awareness" and had trouble engaging with it proactively despite having anxiety that the public's negative perception of organ donation was, in part, responsible for why Shauna died.

The *Fifth Estate* episode disturbed me because it confirmed my cynicism. Even though, in most public discourse, organ transplantation is firmly anchored in our dominant values of rationality (you don't need your organs after you die so why "waste" them) and the generosity of the human spirit (giving the "gift of life"), public perception of organ donation seemed fragile to me. Organ donation and transplantation is vulnerable to "bad publicity." Scandals, or anything that will threaten public support or make people feel reluctant or less likely to donate, can have real consequences in the lives of transplant patients - what they need is more donors.

Waiting for a liver transplant is a life-or-death crisis. The uncertainty of waiting produces paralysis and lethargy, as well as a panicky sense of urgency that can't be addressed with any action. Feeling totally helpless, about a week before Shauna died, I called the local newspaper in Raleigh-Durham, North Carolina, where Shauna lived at the time. This phone call resulted in a short 500-word article that was published in the *Raleigh News and Observer* on Saturday November 27, 2004, titled "To Save a Sister's Life." I hardly

recall speaking to the journalist, Ruth Sheehan. I remember trying to reach her shortly after our interview because I thought of something I wanted to say (who knows what) but in that short interval the article had already been submitted and gone to press. I certainly don't know what good I thought would come out of this very modest publicity (a side column on the front of the B pages). The article explained Shauna was on life support but stated she could go back to normal life with a "new liver." Sheehan laments, "If only one would surface." In the article I describe myself as "desperate" and state my case as follows (attributed as a direct quote from me): "*What we are concerned about is this shortage and this kind of reluctance people have about donating . . . We were just thinking Shauna's situation would let them know what this really means. This is not some kind of abstract notion of donating organs. This is somebody. This is a concrete person. This is my sister.*"

It is clear my fixation at the time was wanting recognition that Shauna needed a donor or else she would die. Indeed, Sheehan makes this the point of the story ("To Save a Sister's Life"). The article urges readers to donate organs and tells readers that Shauna's death would be "needless." Sheehan writes, "*It needn't end badly.*"

Shauna's death seemed tragic because it was avoidable - a "cure" was available, but the problem, it seemed to me at the time, was that not enough people donate organs. The doctors and the field of transplantation, on the other hand, had everything within their power to save Shauna from her death. The medical side of things was almost enthralling, like being under a spell - the mystification, heroism or the wizardry of it was part of what gave it power, or its *magic*. This is why the abruptness of Shauna's death, the sudden

decision that there was no more “hope” and nothing else to do, felt like a spell being broken. Now that I can think about Shauna’s death with a little bit of critical detachment, it’s hard for me to really believe that I had unshakeable faith in the medical system and organ transplantation, that I felt a deep allegiance to it. To an extent, I vilified the public, not as evil, but as indifferent. The doctors *cared* but the rest of the world was disinterested in Shauna’s suffering.

The idea that Shauna’s death could have been avoided by increasing organ donation is seemingly logical however it also expresses a culturally specific notion that illness and mortality are conquerable and preventable. A “lack of organ donors” frames waitlist death as an epiphenomenon of the organ shortage rather than a result of liver failure itself and underlying diseases. While promoting and increasing organ donation may be vital, it has deeper stakes in death avoidance and denial. The fact is I was convinced that Shauna wouldn’t actually die, a sentiment that was sturdily reinforced by cultural attitudes to “be optimistic” and heroic narratives of transplantation. When it didn’t happen, it was devastating. I shut down.

The Organ Donation Trail

I accidentally overdosed my 2-year-old daughter with Tylenol one night when she had come down with a fever. Due to carelessness and a badly organized medicine cabinet, I had mixed up the concentrated infant formula with the regular children's. In a panic, I rushed my daughter to the emergency room at the Children's Hospital having already formed the conclusion that the overdose would cause acute liver failure and a replay of

what happened with Shauna eight years earlier. Like her, my daughter would be hanging for her life in the ICU waiting for a liver transplant. She would very likely die.

At the hospital I anticipated a high-intensity flurry of a medical team attending to my (probably by then) unconscious daughter; but at first, the nurse tried to turn us away at triage. She was completely unconcerned because the overall Tylenol dosage my daughter had was still under the daily limit for her size and weight. This was all very matter of fact. The advice: "don't give her any more Tylenol until the morning" (as if more Tylenol was under consideration) was all the "urgent care" we needed. That was my cue to pick up and leave with apologies for wasting everyone's time, but I didn't move. The nurse, sensing something was off with my demeanor, directed us to the waiting room. Not long after, another nurse brought us into a consultation room and, cutting to the chase, asked me rather gravely: "is there something you're not telling us?"

By then, I had collected myself enough to convince the nurse that I was not withholding. I admitted I had been "overreacting" and then we went home. While everything was "fine," the nurse's question ("is there something you're not telling us") had jarred me and shot a brutal glimpse at everything that I had been repressing (waiting, death, grief, the organ shortage, self-reflection); and I was mad that I hadn't done anything about it.

One of the first books I read on organ donation and transplantation was the seminal anthropological work on the early years of hemodialysis and kidney transplantation in the 1960s titled *The Courage to Fail: A Social View of Transplantation and Dialysis*, published in 1974. I found the title of the book evocative and was fascinated by the idea

that the field of transplantation was founded on the dedication, determination and perseverance of physicians, patients and families who endured losses in order to build up its life-saving potential.

The authors of *The Courage to Fail*, Renée Fox and Judith Swazey, analyze kidney transplantation as a social and cultural phenomenon. They pay particular attention to the way kidney donation created a new way of “demonstrating an ultimate kind of concern for another person” and how the practice of organ donation is shaped around notions of altruism and concepts of a “gift.” Drawing from the influential anthropological theory of the French ethnologist Marcel Mauss, they explore the way in which organ donation interacts with norms of gift-giving. According to Mauss, in a “gift economy” the typical social function of the gift requires it to be “symmetrical and reciprocal.” A donated kidney, however, is a non-reciprocal gift. It’s meant to be given with the expectation of nothing in return. Thus, it has the moral significance of being a selfless altruistic act, something you do for the benefit of others. Fox and Swazey see this as a unique kind of gift exchange that, in their interpretation, can have a downside, which they call the “tyranny of the gift.” They describe this as an ongoing feeling of indebtedness for a gift that can never be repaid.³

As the field of transplantation developed, the idea that an organ donor ought to be motivated by altruism became entrenched. In Fox and Swazey’s view, this gives organ donation and transplantation “enduring significance” beyond its medical implications,

³ Renee Fox and Judith Swazey, *The Courage to Fail: A Social View of Transplantation and Dialysis* (Chicago: University of Chicago Press, 1974), xii-5.

related to ethical and existential questions about the relationship between the self and the other. They write, “Problems of uncertainty, meaning, life and death, scarcity, justice, equity, solidarity and intervention in the human condition are all evoked by these therapeutic innovations.” Furthermore, they had “the intuition that the ramifications of these developments were significantly related not only to changes in contemporary medicine, but also to more general changes in our society’s ‘common conscience’.”⁴ When they published *The Courage to Fail*, Fox and Swazey saw these changes in a positive light and regarded them with openness and curiosity.

Twenty years later, Fox and Swazey published a second book, *Spare Parts: Organ Replacement in American Society*. The concluding chapter titled “Leaving the Field” describes why their decades of research on organ donation and transplantation has ultimately led them to disillusionment and a decision to sever ties with it. Fox and Swazey think organ donation and transplantation has reached a point of “structural forgetting” of the “existential implications of what it involved.” In its place, they see the influence of the economic and political thinking that was dominant in the 1980s and 1990s, namely the privileging of rational self-interest. They argue that organ donation has been taken over by a “market-based outlook” that has resulted in a narrow focus to increase the “supply of organs” without a wider discussion about the distribution of health resources and “society’s ability and willingness to meet other’s needs in the medical commons.” They critique the “business approach” to organ donation that aims to “maximize donation” through marketing, advertising and fundraising strategies, while

⁴ Ibid., xi-xv.

ignoring problems like systemic health inequities. They ask why we should care so much about interventions like organ transplants when there are so many people lacking basic care.⁵ Their position is that organ transplantation has become a lucrative industry, reflecting that healthcare, in general, is now a matter of “private consumption rather than a social good in American society.” They write, “millions of people [in the US] do not have adequate or even minimally decent care [which, in their opinion] speaks to a values framework and a vision of medical progress that [they] find medically and morally untenable.”⁶

Their social justice/health equity reason for “leaving the field” is also accompanied by an outright moral objection. Fox and Swazey write that it is “the escalating ardor about the life-saving goodness of repairing and remaking people in this fashion that [they] have found especially disturbing,”⁷ claiming that for them it shows “a relentless hubris-ridden refusal to accept limits to our biological and human condition” and a lack of “moral limits surrounding our efforts to save lives.” They see organ transplantation as encapsulating “a bellicose ‘death is the enemy’” perspective, and a “rescue-oriented, zealous determination to maintain life at any cost.”⁸ Using even more incendiary language, they explain:

We have come to believe that the missionary-like ardor about organ replacement

⁵ Ibid., 45-74.

⁶ Ibid., 209.

⁷ Ibid., xv.

⁸ Ibid., 199-205.

that now exists, the overidealization of the quality and the duration of life that can ensue, and the seemingly limitless attempts to procure and implant organs that are currently taking place have gotten out of hand . . . By our leave-taking we are intentionally separating ourselves from what we believe has become an overly zealous medical and social commitment to the endless perpetuation of life and to repairing and rebuilding people through organ replacement – and from the human suffering and the social, cultural and spiritual harm we believe such unexamined excess can, and already has, brought in its wake.⁹

When I read *Spare Parts*, Fox and Swazey’s scathing appraisal of organ transplantation affected me deeply. The conclusions they draw (“gotten out of hand,” “unexamined excess,” “social, cultural and spiritual harm”) were hard to integrate while I was still trying to come to terms with my personal loss. I couldn’t apply their perspective to what I had lived through with Shauna. I dismissed them as ideological naysayers taking an intellectual stance that was disconnected from patient experience.

Much scholarship on organ donation treats it as a complex phenomenon, an uncomfortable gray area. It includes works in medical anthropology, as well as works that deal with its representation in fiction, folklore and popular culture as a source of fascination, fear, anxiety and revulsion.¹⁰ In this eclectic body of work, organ donation is

⁹ Ibid., 204-210.

¹⁰ For example: Orit Brawer Ben-David, *Organ Donation and Transplantation: Body Organs an Exchangeable Socio-Cultural Resource* (Westpoint, Conn.: Praeger Press, 2005); Lenore Manderson, *Surface Tensions: Surgery, Bodily Boundaries and the Social Self* (New York: Routledge, 2011); Nancy Scheper-Hughes, “The last commodity: post-human ethics and the global traffic in ‘fresh’ organs,” in *Global Assemblages: Technology, Politics and Ethics as Anthropological Problems*, eds. A. Ong and SJ Collier (Malden, MA: Blackwell, 2005); Brittany Anne Chozinski, “Science Fiction as Critique of Science: Organ Transplantation and the Body,” *Bulletin of Science, Technology and Society* (February 2016); Anita Wohlman and Ruth Steinberg, “Rewinding Frankenstein and the body-machine: organ transplantation in the dystopian young adult fiction series *Unwind*,” *Medical Humanities* 42 (2016); Ruth Richardson, “Human dissection and organ donation: a historical and social background,” *Mortality* 11, no. 2 (2006); Veronique Campion-Vincent, “Organ Theft Narratives as Medical and Social Critique,” *Journal of Folklore Research* 39, no. 1 (2002); Ruth Penfold-Mounce, “The Afterlife of Corpses: Organ Transplantation,” in *Death, The Dead and Popular Culture* (Sommerville, MA: Emerald Publishing, 2018); Ann Mongoven, “Sharing Our Body and Blood: Organ Donation and Feminist Critiques of Sacrifice,”

a curious hybrid of a niche concern (not a significant issue for the general population) and a “rich topic” that touches on important matters of general interest - death and the circumstances under which we die, medicine and the healthcare system, cultural values of biomedicine, technology, the body and a blurred boundary between self and other, just to name a few. To focus too much on what makes organ donation and transplantation *interesting*, however, detaches it from everyday reality and it becomes an abstract object of inquiry, an indulgent intellectual fetish, such as expressed in the introduction to one scholarly volume on organ donation which describes it as ‘intrinsically and profoundly connected to experiences and questions of the human condition that are at once elemental, transcendent and fraught with ambiguity and mystery.’¹¹ If that’s the case, from my perspective, there’s something that makes it seem unapproachable or too enigmatic to bother with.

A conclusion I came to ten years after Shauna died was that I wanted to take part in research that would contribute to an *increase* in organ donation and reduce the organ shortage. When I set that goal, one of the first things I did was register to attend the annual meeting of the Canadian Society for Transplantation (CST). I was motivated by the fact that there was a “Donation Group” meeting on the program and I wanted to know what that was all about (also that the conference that year happened to be held in

Journal of Medicine and Philosophy 28 (2003); Margrit Shildrick, “Staying Alive: Affect, Identity and Anxiety in Organ Transplantation,” *Body and Society* (June 2015).

¹¹ Stuart J. Younger, Renee C. Fox and Laurence J. O’Connell, eds, *Organ Transplantation: Meaning and Realities* (Madison: University of Wisconsin Press, 1996), x.

Montreal, where I live). Specifically, I wanted to learn more about the “organ shortage” and what could be done about it to prevent what happened to Shauna. The conference was eye-opening. It was nothing like what I anticipated. At the “Donation Group” meeting, everyone was talking about the results of a strategic planning session that had been held the previous year regarding how to include “the voice of donation” at the CST. There were a lot of questions around “what is the purpose of the donation group?” as well as concerns about a lack of leadership, funding and organizational support. I don’t know what I was expecting but not this doubt and searching. There was even questioning about whether there was a need for a “Donation Group” at the CST and whether it “belonged” there.

Organ donation is in a separate sphere from organ transplantation. For ethical reasons, transplant teams are not involved in the procurement of organs. The “donation” people, like the ones at that conference, are doctors and nurses who work on the frontlines with critical care patients and their families and assume responsibility for facilitating organ donation in hospitals around Canada. To say I felt novice and out of place at the CST conference is an understatement. I doubt I could have felt more insignificant and unsure of myself. I met a sympathetic doctor and I tried to explain why I was there. He told me that he sensed that the backstory (Shauna, who “died waiting”), the underlying purpose of my interest in organ donation and transplantation, was very meaningful. When this conversation was over I went to the bathroom and cried.

At that conference I found out key facts about organ donation that I hadn’t known - that organ donation is restricted to those who die in a hospital intensive care unit and more

specifically to those who are mechanically ventilated to maintain sufficient oxygen levels so that organs are viable for transplantation. I hadn't realized that the major players in organ donation are critical care physicians and critical care nurses - the people who talk to families about withdrawing life support and the opportunity for organ donation.

Without this basic knowledge, I realized I really didn't understand very much about organ donation at all. I was familiar with public outreach efforts that urged people to sign donor cards. I had a simplistic impression that increasing organ donation was a matter of increasing the number of individuals who sign organ donor cards or join organ donor registries. This is what I thought (or something like this): that there is a group of self-identified organ donors, motivated by a desire to help others, such that at the time of their deaths their organs would be retrieved and distributed to transplant patients. My assumptions were based on what I think gave me the most psychic comfort. That is, I imagined an abundance of organs from people who "die anyway" so we might as well put their organs to good use. I had a utilitarian perspective combined with the moral stance that organ donation is a good deed that saves lives. But it is much more complicated than it seems. I knew that the "demand" for organs was greater than the "supply." But it wasn't clear what this abstract economic language really meant in terms of the lives and deaths of real people.

Initially it seemed pertinent to look more deeply into public opinion of organ donation. Knowledge about this seemed sparse to me, mostly coming from quantitative survey data that lacks complexity and detail. Part of me cultivated delusional ideas about changing the discourse about organ donation. I wondered if it was possible to identify some kind of effective "message" about organ donation that would change the way people thought

about it. I was critical of what I saw as a relentless “charity” emphasis in the approach to organ donation promotion rather than establishing a stronger sense of organ donation as a common good, such as highlighting that there are shared benefits in reducing wait times, which are costly to our healthcare system, and self-interest in improving the precarious odds and outcomes for organ transplant patients given that any one of us could be in the position of needing a transplant one day.¹²

Despite our collective dependency on our medical system and our shared vulnerability to accidents and disease, we can lack a sense of solidarity given an overall individualistic approach to health and wellbeing that so many of us have. I thought a significant barrier to achieving solidarity around organ donation might be our negative cultural attitudes about asking for things. This was inspired by reading Amanda Palmer’s book *The Art of Asking*. Palmer is a musician/singer-songwriter renowned for her legendary Kickstarter campaign that greatly surpassed her fundraising target. She pieces together her Kickstarter success and other experiences she had as a struggling artist to argue that asking is a valuable social skill. According to Palmer, we harness resources from our social circles, not out of personal inadequacy, but because it helps solidify community membership and creates feelings of belonging and connectedness to others.¹³ In a TED talk promoting her book she says, “People associate asking with failure, or a humiliating

¹² This idea seemed especially pertinent when I found out that the chances you will need an organ transplant in your lifetime is greater than your likelihood of becoming an organ donor, given the constraints of the medical criteria for donor eligibility. See S.D. Shemie et al., “Lifetime Probabilities of Needing an Organ Transplant Versus Donating an Organ After Death,” *American Journal of Transplantation* 11, no. 10 (October 2011).

¹³ Amanda Palmer, *The Art of Asking, or How I Learned to Stop Worrying and Let People Help* (New York: Grand Central Publishing, 2014).

experience. People tend to turn down help, insisting on doing things yourself. Asking for help is a fundamental part of human life. Asking for help is the opportunity to build community, not a sign of weakness. Asking communicates the idea that we have the power to help each other.”¹⁴ Normalizing the idea of asking for help, and seeing it in a positive way, struck me as a potentially beneficial way of rethinking the ethics of “altruism” (selflessness) and “heroism” (extraordinary individual nature) that dominate organ donation public awareness campaigns.

Although I am attracted to the idea that we do things for other people as form of social self-realization rooted in care and our dependency on other people, I also understood that this kind of broad community ethic can falter when it comes to the specifics of organ donation. There are deeply rooted structural inequalities and health disparities related to unjust political and economic systems that are difficult to wash over with “let’s just help each other” kind of thinking. Social experience such as alienation, exclusion and discrimination, division and conflict, social fragmentation and erosion of trust in public institutions can contribute to negative perceptions and attitudes towards organ donation.¹⁵

Jeffrey Prottas, a health policy scholar who has researched public willingness to donate organs, argues that “that lack of support for organ donation merely reflects a more

¹⁴ Amanda Palmer, *The Art of Asking*, TED (2013)
https://www.ted.com/talks/amanda_palmer_the_art_of_asking

¹⁵ See Myfanwy Morgan, Maya Mayblin and Roger Jones, “Ethnicity and Registration as a Kidney Donor: The Significance of Identity and Belonging,” *Social Science and Medicine* 66, no. 1 (2008); Keren Ladin et al., “Does Social Capital Explain Community-Level Differences in Organ Donation Designation?,” *Milbank Quarterly* 93, no. 3 (2015).

general sense of alienation, exclusion and discrimination. The social facts underlying these attitudes are not illusory.”¹⁶ As Fox and Swazey argue so forcefully, we should not ignore these concerns. However, most studies on organ donation do.

There is an enormous volume of research aimed at understanding what motivates people to sign donor cards and join donor registries using models from behavioural psychology. The goal is to predict how a favourable view of organ donation can translate into signing up for organ donation. These studies are uniquely focused on *individual* behavioural change and acknowledge wider social factors in only a limited or superficial way.¹⁷ For instance, a study may use the “theory of planned behaviour” (Hyde and White, 2009) to understand the pathways between “intention” (support for organ donation) and “action” (registration).¹⁸ This cognitive psychology/behavioral change approach prioritizes “self-efficacy” over socio-cultural contextual issues. Self-efficacy concerns feelings of individual competency or a “sense of individual capacity,” as well as the perceived ease or difficulty of a task. It’s a perception or a belief that one is capable to “enact a

¹⁶ Jeffrey Prottas, “Advertising and Its Role in Organ Donation” in *Social Marketing: Theoretical and Practical Perspectives*, eds. Marvin E. Goldberg, Martin Fishbein and Susan E. Middlestadt, (Mahwah, NJ: Lawrence Erlbaum Associates, 1997), 381.

¹⁷ See Ashley E. Anker and Thomas Hugh Feeley and Hyunjung Kim, “Examining the Attitude-Behavior Relationship in Prosocial Donation Domains,” *Journal of Applied Social Psychology* 40, no 6 (2010); Melissa K. Hyde and Katherine M. White, “To Be a Donor or Not to Be?: Applying an Extended Theory of Planned Behaviour to Predict Posthumous Organ Donation Intentions,” *Journal of Applied Social Psychology* 39, no. 4 (2009); Melissa K. Hyde and Katherine M. White, “Are Organ Donation Communication Decisions Reasoned or Reactive? A test of the utility of an augmented theory of planned behaviour with the prototype/willingness model,” *British Journal of Health Psychology* 15, no. 2 (2010); Susan E. Morgan et al. “Facts versus ‘Feelings’: How Rational is the Decision to Become an Organ Donor?,” *Journal of Health Psychology* 13, no. 5 (2008); Jason T. Seigel et al., “Passive-Positive Organ Donor Registration Behaviour: A Mixed Method Assessment of the IIFF Model,” *Psychology, Health and Medicine* 15, no. 2 (2010).

¹⁸ Hyde and White, “To Be a Donor or Not to Be?”

recommended behaviour to avoid consequences,” to succeed at a task, to solve a problem; and the belief that one has the power to affect situations whether it is accurate or not. Supposedly self-efficacy is a great motivator - people avoid tasks when self-efficacy is low and undertake tasks when self-efficacy is high.¹⁹

This kind of behavioural psychology research informs the way organizations come up with messages to promote organ donation, and their public campaign strategies. For example, signing a donor registry is often presented to the public as highly efficacious, focusing on the positive outcomes of transplantation. In Canada, people register for organ donation in their provincial jurisdiction, but the national organization Canadian Blood Services (CBS) serves as a type of umbrella agency for organ and tissue donation and its promotion. To this end, the CBS website homepage for organ and tissue donation addresses visitors with the question: “What Does It Take To Save Up To Eight Lives?” Underneath, the answer is simply: “Saying ‘yes’” (the dying part is left out). The rest of the copy enhances the reader’s perception of self-efficacy - that everyone has the capacity to save the lives of dozens of people. It says: “Thousands of Canadians are in need of organ, tissue and eye donations. Hundreds die each year waiting for vital transplants. You can help change that by consenting to be an organ and tissue and eye donor. One donor can save up to eight lives. Tissue and eye donors can improve the lives of 75 more!”²⁰

¹⁹ M. Pulvirenti, J. McMillan and S. Lawn, “Empowerment, patient centered care and self management,” *Health Expectations* 17, no.3 (2014), 309. See also A. Bandura, “Self-efficacy: Toward a unifying theory of behavior change,” *Psychological Review* 84 (1977).

²⁰ The website has since changed its design and copy; I am describing the version circa 2016.

Such dog and pony show language states the benefit of donation in almost exaggerated terms, amplifying a “happy ending” narrative by projecting it onto 83 imagined people.

The promotion of organ donation often relies on a simple feel-good message that organ donation and transplantation saves many lives. It is hard, however, to determine whether this (or any kind of public messaging) even has a significant impact on organ donation registration. Though few public awareness campaigns have been designed to allow their outcomes to be evaluated (baseline comparison, pre/post testing, control groups etc.) and it’s hard to gauge results that aren’t measurable or cannot be easily evaluated (such as “exposure” to the issue of organ donation), research in the US has estimated that promotional and awareness campaigns, on average, have an overall effect of increasing organ donation registration by only 5%.²¹ Furthermore, it’s questionable whether this modest increase in registration has a substantial impact on *actual* organ donation.

Public awareness is almost exclusively focused on urging organ donation registration; but increasing organ donation is much more than a matter of increasing the number of individuals who sign up. Promotional campaigns encouraging people to sign donor cards and join donor registries obscure the fact that most people (signers or non-signers) will never meet the medical criteria to become organ donors, or contribute, in practical terms, to an increase in organ donation. Only 1.4% of people who die in hospital meet the

²¹ Thomas Hugh Feeley and Shin-Il Moon, “A Meta-Analytic Review of Communication Campaigns to Promote Organ Donation,” *Communication Reports* 22, no. 2 (2009)

medical eligibility criteria to be an organ donor.²² Strictly speaking, registration is a limited tool for increasing actual donation. Asking everyone to be an organ donor (the mainspring of public awareness) runs the risk of distorting public perception regarding the scarcity of organs (suggesting that everyone is an eligible donor) and leaves the process of organ donation largely undefined.

Historically, donor cards were intended to establish that organ donation is a voluntary and autonomous choice and gave individuals the right to offer their organs as a “gift.” At the time, the late 1960s, this responded to the need to garner widespread public approval for organ transplantation (an unfamiliar practice) and provide a framework for organ donation that was aligned with medical, legal and ethical standards; but it was not intended as a means to *increase* organ donation. One researcher points out that even the gift-giving analogy was never intended to be a *persuasive* message, rather “the analogy between gift-giving and organ donation was originally adopted because it was believed most accurately to capture what was thought to be the most desirable way to procure organ donation,” i.e., an emphasis on voluntary altruism.²³

In 1969, lawmakers in the US created the Uniform Anatomical Gift Act, which suggested a donor card could be used as “evidence of the gift,” i.e. evidence of voluntarism (action based on non-coercion), which along with autonomy and altruism are what bioethicist

²² Gouvernement du Quebec, “Organ and Tissue Donation” <https://www.quebec.ca/en/health/blood-tissue-and-organ-donation/organ-and-tissue-donation>. For example, in the province of Quebec there is a total of 400-500 eligible donors each year.

²³ Nicole Gerrand, “The Notion of Gift-Giving and Organ Donation,” *Bioethics* 8, no. 2 (1994), 135.

Arthur Caplan calls the “ethical linchpins” of organ donation.²⁴ In the mid-1980s, however, there was a shift from a concern with the acceptance (in moral principle) of organ donation to a need to increase the willingness and readiness of the public to actually donate their organs. This was because there was a “transplant boom” when transplant success rates increased due to a pharmaceutical breakthrough - the immunosuppressive drug Cyclosporine- which allowed organ transplantation to evolve from something experimental to a standard practice of care. The number of patients listed for a transplant began to rise in the 1980s and it has been ever since.²⁵

A national report in Canada states that “it is difficult to link registries directly with higher donation rates.”²⁶ Convincing people to sign up *en masse* is not the prime remedy for the growing organ shortage. Health policy scholar Jeffrey Prottas made the seminal observation that it is more important to obtain the cooperation of hospital and medical professionals in the processes of organ procurement. Since then, professional education has been prioritized over public awareness campaigns. The “willingness of the public” has widely been regarded as a matter of far less importance from a practical point of view.²⁷

²⁴ Arthur L. Caplan, “Beg, Borrow or Steal: The Ethics of Solid Organ Procurement” in *Organ Substitute Technology*, ed. D. Mathieu (Boulder: Westview Press, 1988), 61.

²⁵ See Nicholas Tilney, “The Industrialization of Transplantation” in *Transplant: From Myth to Reality* (New Haven: Yale University Press, 2002): 244-256.

²⁶ Sonya Norris, “Organ Donation and Transplantation in Canada” (Background Paper). Library of Parliament, Ottawa, Canada (2014). Publication No. 2011-113-E.

²⁷ See Margaret Verble and Judy Worth, “The Case against More Public Education to Promote Organ Donation,” *Progress in Transplantation* (December 1996).

A key development occurred in 1986, when “required request” became federal law in the U.S. and eventually did so in Canadian jurisdictions as well.²⁸ This means that when a patient is brain dead, or brain death is imminent, or if a patient meets certain criteria of cardiopulmonary death, hospital staff are required to ask the family about organ donation, making it standard practice and an operational norm. Required request has since been elaborated to include the creation of professional roles to support and facilitate organ donation in hospital critical care units. An example are “donor physicians” who specialize in donor identification and referrals and having conversations with families, and who devise and follow “best practices” in those areas.²⁹

In current lingo, healthcare professionals are responsible for increasing the “conversion rate” - that is the rate at which potential donors (those who are clinically eligible) become actual donors. In Canada, a study done in 2014 (using data from 2012) showed that nationwide there was a total of 3,088 potential donors while only 520 became actual donors.³⁰ This 17% conversion rate is considered low and means that opportunities are being missed. To increase conversion rates hospitals need better guidelines and practices to establish a “culture of donation” where all aspects of organ donation are integrated into

²⁸ For the US see “Organ Donation and Transplantation Legislation History” Health Resources and Services Administration. <https://www.organdonor.gov/about-us/legislation-policy/history> For Canada, consult the statutory laws of each province: Alberta Government *Human Tissue and Organ Donation Act* (2006); British Columbia Government *Human Tissue Gift Act* (1996); Government of Manitoba *The Human Tissue Gift Act* (1987); Government of Newfoundland and Labrador *Human Tissue Act* (1990); Government of Nova Scotia *Human Tissue Act* (1989); Government of Ontario *Trillium Gift of Life Network Act* (2000); Government of Prince Edward Island *Human Tissue Donation Act* (1992); Government of Quebec *Civil Law of 1993 Articles 42, 43, 44* (1993); Government of Saskatchewan *Human Tissue Gift Act* (1978); New Brunswick Government *Human Tissue Gift Act* (2004).

²⁹ “Deceased Organ Donation in Canada,” Canadian Institute for Health Information (2014)

³⁰ *Ibid.*, 4-6.

their standard operating procedures. Both Canada and the U.S have opt-in systems of organ donation (donor cards and registries) but functionally they operate somewhat like an opt-out system. Organ donation is a “choice” but mostly it is dictated by circumstances that are out of your control (how you die) and the extent to which the “hospital culture” encourages and facilitates donation.

The strategies for increasing organ donation are to increase willingness and consent among eligible donors (which falls to the staff having the “family conversations”) and by increasing the donor pool. The ideal donor has a fatal brain injury but is otherwise young and healthy, but these kinds of deaths are rare and so other potential donors need to be considered. This expanded pool of donors is stretched to the limits of medical viability, given factors like age and health status. The increasing demand for transplantation has led to reconsidering who is young enough and healthy enough to be an organ donor in an effort to produce more donors. It has also expanded beyond those who are clinically brain dead but “kept alive” by life support to include some individuals with no chance of recovery from their injuries or ailments and who die within a short window following the withdrawal of life support.³¹

The upshot is that the “organ shortage,” as I imagined it, is not the forefront issue I thought it was. It is neither the problem nor the go-to-solution I initially assumed it could be. As I read more about the field, and attended related conferences and events, it became

³¹ See Committee on Increasing Rates of Organ Donation Board on Health Science Policy, *Organ Donation: Opportunities for Action*, eds. James F. Childress and Catharyn T. Liverman (Washington DC: The National Academic Press, 2006)

obvious that the professionals and experts in organ donation and transplantation are concerned with overall “system improvement.” One preoccupation here in Canada for the past 20 years, is the fractured provincial system of organ donation and transplantation and the need for a national network, something like the United Network of Organ Sharing (UNOS) in the United States.³² The Canadian Council for Donation and Transplantation (CCDT) was established in 2001 as an advisory board with a broad mandate to provide “extensive consultation on standards and clinical practice guidelines and making recommendations” for all aspects of organ donation and transplantation in Canada. In 2008, the CCDT merged with Canadian Blood Services (CBS) and this same kind of work continued, culminating in the publication of a “Call to Action” in 2011, described as “a strategic plan to improve organ and tissue donation and transplantation performance for Canadians.”³³

CBS’s “Call to Action” takes a “program management” approach to “national system design” and the “delivery of organ donation services.” It’s dominated by the language of managerialism, outlining priorities, targets, outputs, goals, plans and recommendations, all with regards to “system management” and “strategic action.” Such a “system” approach uses market models, sets targets and performance assessment measures with an emphasis on being strategic, efficient and results oriented. It's concerned with such things as performance metrics to understand the gap between supply and demand, data

³² J.S. Gill et al Deceased Organ Donation in Canada: An Opportunity to Heal a Fractured System,” *American Journal of Transplantation* 8, no. 8 (2008): 1580-1587.

³³ Norris, “Organ Donation and Transplantation in Canada”; Canadian Blood Services, “Call to Action: A Strategic Plan to improve organ and tissue donation and transplantation performance in Canada” (2011).

collecting and reporting to measure success and drive performance improvement, and strengthening measurement and accountability by standardizing inconsistent definitions in data sets and instituting mandatory standardized reporting.

In this context, public awareness and organ donation registration receives scant attention. It is recognized that organ donation registration can make the facilitation of organ donation easier at the bedside, rather than having to seek consent from families where the wishes of the deceased are unknown; but the activities surrounding the promotion of organ donation registration are seen more like non-professional volunteer work.³⁴ In the bigger picture, it is not what's needed the most. I had to digest that lacking both the skill set and the mindset to insinuate myself into the professional activities associated with "system improvement," I wasn't positioned to do anything that practicable and substantial about the organ shortage at all.

My angle of apprehension

My conviction to do research related to organ donation promotion eroded and left me feeling purposeless. The Norwegian writer Torbjorn Ekelund describes an experiment he

³⁴ Developing a coordinated national public awareness effort was part of the mandate the House of Commons Standing Committee on Health and Health Canada gave to the Canadian Council for Donation and Transplantation in 2002, later inherited by Canadian Blood Services in 2008 as part of an overall ODT "system re-redesign." The 2016 Systems Progress Report from Canadian Blood Services gives scant attention to reporting on public awareness and education, but describes it as "improved," indicating that: "There are many organizations working to increase awareness of organ donation among Canadians. Patient advocacy groups and health charities continue to work diligently to promote the social and economic benefits of organ donation and transplantation." See Canadian Blood Services, "Organ Donation and Transplantation in Canada – Systems Progress Report 2006-2015"

did with a friend where they attempted to walk in a straight line through a dense forest without any navigational aids. After two days, they consulted the GPS that had been tracking them on their phones all along to find out how successful they had been. They had been walking in zig zags the whole time and were only 3.5 miles from where they started.³⁵ The goal of increasing organ donation had once seemed like a straight path to me but all I had done was wander aimlessly, making little progress. Like any failed plan, it required reflection and reconsideration. I realized that I wasn't just a little bit off track, I was at sea.

Early in my graduate program I had the opportunity to work on a preliminary study, a collaboration with a public relations firm. The purpose of the project was to better understand what messages encourage people to sign up for organ donation, particularly among individuals who identify as “undecided” about organ donation. I conducted focus groups to elicit audience reactions to a variety of organ donation promotional campaigns. One of the campaigns we used in our study was from 2013, called Waiting for Seven Years, created by Ogilvy in Germany. It features a young man named Michael receiving his dialysis treatment in the middle of a busy Frankfurt train station. Participants in our focus groups watched a video that documented this event as well as the media attention that resulted from the campaign, including the fact that it brought about a 33% increase in website visits and 16,000 downloads of organ donor cards and apps (a 24.8% increase over the monthly average according to the ad agency).

³⁵ Torbjorn Ekelund, *In Praise of Paths: Walking Through Time and Nature* (Vancouver: Greystone Books, 2020).

Most respondents in our study liked the concept of the ad but also had questions about it. It wasn't the shock of this public display of hemodialysis but that the ad ended with a blank screen captioned with the words: Michael is Still Waiting. Some of the focus group respondents found this to be a confusing message to end on because it made Michael's situation seem hopeless and futile. It would have been better, they thought, to end with Michael getting a transplant, to see the happy ending, rather than ending on a note of uncertainty.

When I was confronted with this audience reaction, I realized how much I liked the ending of *Waiting For Seven Years* precisely because it underscores the uncertain and precarious way transplant patients are positioned in relation to the "happy ending." Glossing over or ignoring other outcomes perpetuates that the only thing the public needs to know about organ transplantation are the lives that are saved. Organ donation promotion is dominated by such feel-good narratives that shape public perception and expectations about organ transplantation. Recognizing this was more than an observation of what was "out there" but an avowal of something I had internalized. There was no space to reflect on death and loss. Something was subtly erased every time I acknowledged Shauna's death by saying she "died waiting." It smuggled in a hopeful outlook and nodded to a cultural preference for progress stories and happy endings. Likewise, my concern about the organ shortage, and the promotion of organ donation, seemed to extend the fantasy I had for Shauna - that there can or should be happy endings for all.

It's the happy stories that are the most visible and the most valued. Stories of loss are hidden. There is no perspective on waitlist death, and the pain, uncertainty and fragility it entails, a void that I increasingly felt was mine to fill. According to cultural theorist Stuart Hall, the multiple forces that make up conditions of existence is a "conjuncture," which he explains in more everyday language as the "accumulation of different things coming together." The ability to recognize and understand the details of a conjuncture is, according to Hall, "the product of the particularity of a life or. . . an *angle of apprehension* that will make some aspects of a conjuncture vivid to one person and invisible to another."³⁶ The practice of organ transplantation is a distinct conjuncture - a major accomplishment in Western biomedicine and the development of modern surgery buttressed by dominant ideologies that define legal, moral and ethical thinking regarding science, technological advancement, the body and the role of modern medicine. What might be apparent to me, from my vantage point, that wouldn't be accessible to others is my "angle of apprehension." In this case, it is my close proximity to waitlist death that produces a different kind of scrutiny of liver transplantation, one that takes into account what it means to "die waiting.

³⁶ Stuart Hall in Ben Highmore, "Aesthetic Matters: writing and Cultural Studies," *Cultural Studies* 32, no.2 (2018), 254.

2 The Story of Progress

Conventional Narratives

We referred to Shauna's "new liver" as soon as there was mention of a potential donor. This rapid appropriation of someone else's body part reflects the way getting a transplant was already part of Shauna's story. Shauna's "new liver" existed somewhere out in the world, the same way someone might believe their "future husband/wife" is, or even claiming to have met them after a fleeting exchange. Both are examples of inhabiting a fantasy or thinking that all events lead toward the fulfillment of a narrative. To my mind, "Shauna's new liver" was a real thing, not a narrative construct.

My naive belief that Shauna was going to have a successful transplant is an example of the way we embed our experiences in conventional narratives. In an edited volume on narrative analysis, Colette Daiute and Cynthia Lightfoot explain that narratives are "more than just words: they guide perception, thought and action . . . interpretations of the past and plans for the future."¹ Narrative gives us the tools to shape and communicate the significance of our experiences and to interpret meaning by giving it a storied form.

¹ Colette Daiute and Cynthia Lightfoot, "Editor's Introduction: Theory and Craft in Narrative Inquiry" in *Narrative Analysis: Studying the Development of Individuals in Society* (Thousand Oaks, CA: Sage, 2004), xi.

Stories transform our lived experiences into “a coherent and plausible account of how and why something happened”²; and these storied elements of our lives help us anticipate what the future will bring.

Our expectations and the imagined outcomes of any given story do not “come out of nowhere.” Philosopher Paul Ricoeur explains, they are “tied in one way or another to the models handed down by tradition.” It is entirely possible, Ricoeur argues, to “enter into a variable relation to those models. The range of solutions is broad indeed between poles of servile repetition and calculative deviance”; but, he contends that we have a tendency of “sticking to the pole of repetition.”³ Repetition validates, reinforces and stabilizes certain stories as dominant narratives, or normative cultural scripts that function as socially sanctioned explanatory constructs. The sense-making aspect of narrative to give meaning and coherence to experience is directly tied to “culturally developed ways of organizing experience and knowledge” and the expression of “cultural meanings and interpretations.”⁴

Dominant narratives can be boring, repetitive but also captivating. The television was always on in the ICU waiting room. There were times it was background noise, and other

² John A. Robinson and Linda Hawpe, “Narrative Thinking as a Heuristic Process” in *Narrative Psychology: The Storied Nature of Human Conduct* ed. Theodore R. Sarbin (New York: Praeger, 1986),

³ Paul Ricoeur, “Life in Quest of a Narrative” in *On Paul Ricoeur: Narrative and Interpretation*, ed. David Wood (New York: Routledge, 1991), 25.

⁴ Daiute and Lightfoot, “Editor’s Introduction,” x.

times I couldn't take my eyes off it. One of the shows that enraptured me was *What Not To Wear*. It was on so often it seemed like the network aired back-to-back episodes around the clock. *What Not To Wear* is a reality show featuring two fashion experts giving a makeover to an unstylish contestant, a before-and-after transformation. It was a satisfying formula for a 30-minute television show, and pretty uplifting: you can be rescued from your poor fashion choices, you will be moved to tearful gratitude, your family and friends will be pleased and your life will be improved.

The basic storyline of *What Not to Wear* plays the same notes as the dominant feel-good transplant narrative. There is something bad (your clothes, your vital organ), an intervention (reality tv makeover, transplant), and a joyful transformation (a new life with better clothes, a new life with a better organ). This type of fantasy is ingrained into how we regard organ transplantation. I can't help thinking that when I watched that show (and I did, many times) I must have felt a degree of reassurance in its familiar, comforting blueprint and its resonance with a "[storyline] [I had] unwittingly internalized"⁵ that made me hopeful that Shauna would soon have her "second chance at life."

Anthropologist Ciara Kierans argues that the status of organ transplantation as a life-saving technology, coupled with the tendency to see "therapeutic outcomes as resolutions," gear patients toward seeing organ transplant as a "happy ending." Kierans writes, it "is a function of the biomedical narrative to orient patients towards treatment

⁵ Mark Freeman, *Hindsight: The Promise and Peril of Looking Backward* (Toronto: Oxford University Press, 2010), 127.

interventions, organized around the idea of specific outcomes and endings.”⁶ The dominant narrative of transplantation perpetuates the idea that organ failure can/should/will be overcome through transplantation (and renders death invisible). This has served to construct transplantation as an “end game”; a culmination; a tale told,”⁷ a view of transplantation that trickles down into patient stories.

The “endgame” of transplantation is compatible with “gift of life” messaging in organ donation promotion. A fantasy of transformation is what makes organ donation the “gift of life” in the first place. In this regard, the trope of the “gift of life” is another constraint on the way organ transplantation is represented. Recent research on public service announcements (PSAs) promoting organ donation found that a “thank you for the gift of life” message is often used (VanderKnyff 2015). These PSAs highlight recipients’ triumphant stories and their expressions of gratitude for the generosity of the donors. In focus groups conducted by a researcher at the University of South Carolina, audiences responded favourably to such PSAs in which they could “[witness] the effects of donation,” namely see a transformation, especially by including details that show how the patient was “really sick” before the transplant, e.g., using an oxygen tank, being confined to a wheelchair. They liked PSAs to depict the suffering and hardship of the patient on the waitlist and to see how their life is improved by receiving a new organ.⁸

⁶ Ciara Kierans, “Narrating Kidney Disease: The Significance of Sensation and Time in the Emplotment of Patient Experience,” *Culture, Medicine, Psychiatry* 29 (2005), 353.

⁷ *Ibid.*, 345.

⁸ Jeremy T. VanderKnyff, “Framing Death: Politics, Meaning, and the Strategic Communication of Organ Donation Messages in South Carolina,” Ph.D. dissertation. University of South Carolina (2015), 119.

Transplant stories that are constructed to promote organ donation draw upon themes of life improvement and transformation. When transplant recipients are recruited into promotional campaigns their stories are treated like tools to increase organ donation and may offer only a limited understanding of their experience. Anthropologist Lesley Sharp is critical of this practice and argues that while patients can genuinely feel like they want to “give back” by sharing their stories, this can translate into feelings of indebtedness that they owe it to share their *happy* stories for the sake of the donors. As a result, patient stories may be disingenuous in order to be the stories that organ donors want to hear and will motivate more support for organ donation. According to Sharp, patient transplant stories are “highly scripted” so that “organ transplantation is always represented as a radical and successful form of personal transformation, where the generous gifts from one person have offered renewal of life to others.” The struggles are left out.⁹

Kierans, who conducted research with kidney transplant recipients, also found that recipients don’t find it easy to truly voice their experiences. She writes, “patients feel constrained or held hostage to both the medical might of technology and the public perception of transplantation as a ‘gift’.”¹⁰ According to Kierans, this creates “a complex web of intention and interaction” that is not just about “personal experience” of transplant patients but also “the deeply institutionalized commitment to donor campaigns,

⁹ Lesley Sharp, *Strange Harvest: Organ Transplantation, Denatured Bodies and the Transformed Self* (Berkeley: University of California Press, 2006), 109-110.

¹⁰ Kierans, “Narrating Kidney Disease,” 345.

biomedical investment and obligations to family.”¹¹ Kidney transplant recipient Rose Richards (2008) likewise acknowledges that the need to promote organ donation makes organ recipients wary of openly acknowledging “ambivalence about the miraculous gift or confusion about the second chance at life.” She worries it “could compromise the chance of people becoming organ donors.”¹² Kierans argues the complexities and contradictions experienced by transplant patients can be overshadowed by the “responsibility” that they may feel: “the responsibility to be well; healthy; independent; to be champions of donor campaigns; to fulfill a powerful medical narrative.”¹³

The need to fulfill a biomedical narrative can dictate what patients will disclose and what they will keep hidden. Shildrick et al. found that heart transplant recipients “appeared to feel that experiences that went beyond the feel-good narrative of life restored should be kept to themselves.” They write, the “powerful external narratives that privilege restoration to wholeness” following transplantation creates a “system that makes [patients] feel that they should not voice their anxieties to healthcare professionals.”¹⁴ Richards also asks, “what if the truth about our anger, grief and confusion alienated the doctors? We shall always need them to treat us.”¹⁵ There is a real conflict in terms of

¹¹ Ibid., 353.

¹² Rose Richards, “Writing the Othered Self: Autoethnography and the Problem of Objectification in Writing about Illness and Disability,” *Qualitative Health Research* 18, vol. 12 (2008), 1723.

¹³ Kierans, “Narrating Kidney Disease,” 353.

¹⁴ Margrit Shildrick et al., “Messy entanglements: research assemblages in heart transplantation discourse and practices,” *Medical Humanities* 44 (2017), 52.

¹⁵ Richards, “Writing the Othered Self,” 1723.

patient interest: the dependency on life-saving biomedicine and public support for organ donation that inflate social expectations about powerful transformations that result from organ transplants vs. the potential isolation that recipients may feel when their fears, anxieties, distress and suffering are silenced or masked.

An important insight from scholars of narrative medicine is that stories about illness may say more about “socially sanctioned narratives” than they do about the illness “experience.”¹⁶ Rebecca Garden explains: “Readers of illness and disability narratives may not realize to what degree ‘cultural validation’ and other social forces shape those accounts.” She argues that illness narratives should be analyzed carefully to examine “the constructedness of first-person accounts” and to look for the repetition of cultural scripts. Writers themselves, Garden suggests, may “[mask] the norms that shape narratives” and not acknowledge the way narrative conventions influence “expectations about illness,”¹⁷ specifically by perpetuating our celebratory attitude about overcoming loss and failure and converting it into gain.

The popularity and ubiquity of restitution illness narratives reinforces a culturally normative way of viewing health and illness as a means of proving humanity is resilient. Physician and author Arthur Frank (who coined the term “restitution narratives”)

¹⁶ Lisa Diedrich, *Treatments: Language, Politics and the Culture of Illness* (Minneapolis: University of Minnesota Press, 2007), 54.

¹⁷ Rebecca Garden, “Telling Stories about Illness and Disability: The Limits and Lessons of Narrative,” *Perspectives in Biology and Medicine* 53, vol. 1 (2010), 123-124.

explains, “the sick have a very strong ethical and social responsibility” because stories of the sick are “proof of survival and the human ability to find meaning in disorder and chaos.”¹⁸ “Finding meaning” in illness, however, can mean conformity to moral conventions. According to historian and literary scholar Hayden White, narrative constructions are based on moral constructions. He writes, “narrative, certainly in factual storytelling and probably in fictional storytelling as well, is intimately related to, if not a function of, the impulse to moralize reality.”¹⁹ The moralizing function of storytelling is evident in the ubiquity of hopeful stories. Dominant transplant narratives are the “norm” because they are aligned with normative cultural values like being hopeful and positive, not because they are grounded in actual patient experience.

In her investigation of published narratives on end-stage-renal-disease, transplant and recovery, Rose Richards found that “When people do write about their experiences of renal disease they tend to adapt their accounts to fit conventional narrative forms.” The results are overly simplistic and “elide ambiguity.”²⁰ I know that Shauna was aware of this. After she died, I sorted through her books and found a copy of a transplant memoir she had read. The book clearly seemed to conform to a typical redemptive narrative of suffering and salvation. Thumbing through it, I noted that in the margins Shauna had

¹⁸ Arthur Frank, *The Wounded Storyteller: Body, Illness and Ethics* 2nd ed. (Chicago: University of Chicago Press, 1995), 139.

¹⁹ Hayden White in Kevin Murray, “Finding Literary Paths: The work of popular life constructs” in *Narrative Psychology: The Storied Nature of Human Conduct* ed, Theodore R. Sarbin (New York: Praeger, 1986), 279.

²⁰ Rose Richards, “Celebrities and Spiritual Gurus: Comparing two biographical accounts of kidney transplantation and recovery,” *African Journal of Disability* 4, vol. 1 (2015), 1-2.

been writing: trope, trope, trope. She was reading with a critical eye and probably doubted how authentic the story really was.

The idea of an improved life after a transplant is a reassuring plot. We wanted to believe that Shauna's suffering would lead to redemption and a sense of closure. Rose Richards, who had a successful kidney transplant, finds this mentality misguided. She questions whether "redemption" is really the most important thing compared to "what happened when one was ill or the nuances of who one becomes afterwards." She explains, "Sometimes illness narratives can seem to be 'so invested in recovery' that closure may become more important than 'consideration of what dysfunction feels like and how it alters self-perception'."²¹

For Richards, the conventional story built around the transplant as an "ending" does not reveal the ways in which post-transplant experience can be emotive and complex and how "closure" prevents an understanding of what Richards terms "post-transplant liminality." She argues that most stories don't cut it, they amount to a "muzzled" version; so she looks for "traces of perturbation" in transplant stories that speak to her lived experiences of "liminality." She writes:

I have a personal interest in this because I have had a kidney transplant myself and I have finally started to write about my own experiences as part of my autoethnographic doctoral research. It has taken me more than 20 years to reach this point, because I have felt constrained not only by the overwhelming complexity of the experience, but also the narrative restrictions imposed by others on the meaning I am allowed to make. And, quite importantly, I did not

²¹ Ibid.

previously have the verbal or emotional means to address the weirdness of liminality . . . I myself wanted to understand the extraordinary events that had so altered my life and so I told over and over the medical narrative of how I was ill, what I had suffered from, how I had got my new kidney and how I was well afterwards. And whilst telling it I felt muzzled. There were many things I could not identify, that lurked just beyond my frame of perception.²²

Liminality is erased (or minimized) in an idealized narrative of progress. For transplant recipients, this can mean the stories they are telling and hearing don't entirely ring true.

Shauna, for her part, was aware that the dominant narrative of transplantation influenced the way we perceived reality and created a framework for what life ought to be like. She planned to share her transplant journey through an online journal. When she finally composed the first entry (dictated to me because she was beyond the point of being able to type on a computer), it started with the words, "*Dear Friends and Family. This is not the storybook beginning to my transplant story that I hoped to write when I created the template for this page last year.*" She knew the storybook beginning would have been "the call" and an expedient route to the outcome that we wanted. Shauna's wait, on the other hand, was fraught with turmoil, and a complex and precarious medical situation that put her on a trajectory toward the thing no one ever talked about - waitlist death. At the time, I saw no reason why the rocky start and harrowing path we were on would eliminate the promise of a happy ending, despite the extent of her deterioration and how elusive a transplant had proven to be so far. It's an example of how we live our lives

²² Ibid., 2.

according to the stories we have heard the most and our inclination, despite our better judgement, to see these stories in our lives.

The Dominance of Progress and the Success of Transplantation

Arthur Frank, author of *The Wounded Storyteller* argues we have a cultural preference for illness narratives that follow the norms of the “restitution narrative,” i.e., those that involve recovery, redemption, and happy endings. When illness narratives are told as personal success stories, they are compatible with what Frank calls medicine’s “single-minded *telos* of cure.” They echo the paradigm of progress that has dominated Western history and culture. A self restored through transplantation falls in with what Frank calls “medicine’s modernist project: an insistence in endings [and] a linear drive towards resolutions.”²³ Patient narratives that support the paradigm of progress (recovery, survivorhood) are validated by the institutional, political and ideological conditions of organ transplantation and Western biomedicine more broadly. They are part of the same framework. Anthropologists Lock and Nguyen argue, “Biomedical technologies are not autonomous entities: their development and implementation are enmeshed with medical, social and political interests that have practical and moral consequences.” An investment in the notion of human *progress* binds them together, namely the idea that the development of science and technology *will* result in the “advancement of humankind.”²⁴

²³ Frank, *The Wounded Storyteller*, #.

²⁴ Margaret Lock and Vihn-Kim Nguyen, *An anthropology of biomedicine* (Malden, MA: Wiley-Blackwell, 2010), 1-20.

The unquestioned link between technological innovation and progress is, according to Brian Pfaffenberger, the “standard view” that is so widely accepted that it is “too obvious to require examination” akin to what Langdon Winner calls “technological somnambulism” or “the unreflective acceptance of technological innovation.”²⁵ In medicine, surgeon and author Atul Gawande argues that we are collectively invested in the shared belief that medicine is “winning.” Winning is conceived as triumph over illness and the avoidance of death and failure.²⁶

Physician Arthur Kleinman writes that “Biomedicine instantiates the Western tradition’s idea of progress.”²⁷ More specifically, anthropologists Fox and Swazey describe organ transplantation as an example of “modern medicine’s institutionalized commitment to doing all it can to prevent death” and represents the “active, undaunted striving of modern medicine to control death and its growing ability to do so.”²⁸ As a technique to save lives, organ transplantation is a “great success story.”²⁹ The normative view of organ transplantation is that it is a biotechnical *solution* that will transform us for the better; it increases our health and wellbeing.

²⁵ Ibid., 21.

²⁶ Atul Gawande, *Being Mortal: Medicine and What Matters in the End* (Toronto: Doubleday, 2014)

²⁷ Arthur Kleinman, *Writing at the Margins: Discourse Between Anthropology and Medicine* (Berkeley: University of California Press, 1995), 34.

²⁸ Renee Fox and Judith Swazey, *The Courage to Fail: A Social View of Transplantation and Dialysis* (Chicago: University of Chicago Press), 367-377.

²⁹ Nicholas Tilney, *Transplant: From Myth to Reality* (New Haven: Yale University Press), xi.

The first organ transplant that was a resounding success occurred in December 1954. Dr. Joseph Murray at Brigham hospital in Boston transplanted a kidney, donated from Ronald Herrick, into Richard, his identical twin. Richard Herrick “unexpectedly rapid[ly] transform[ed]” from “a terminally ill individual to one who had completely recovered.” Strikingly, Richard even returned to “normal life,” married and had children with one of the nurses who had cared for him in the hospital.³⁰ The success of this transplant stood out from the many failed attempts before it and set expectations for transplantation as a transformative cure-like form of therapy, a template for the achievement of a “happy ending.”

A complex surgery like organ transplantation has its roots in the development of surgical specialties in the WWII era. War surgeons in the field developed techniques in vascular surgery to repair combat injuries, improved treatment of trauma and burns and the management of fluid balance. This advancement of surgical know-how occurred alongside other medical developments like blood banking and antibiotics that created a context in which surgical horizons were expanding and “surgeons became bolder.”³¹ The first experiments in transplant surgery were kidney grafts. While the surgeries themselves could be successful, the major impediment was graft intolerance (the host’s rejection of foreign tissue). By the mid-1950s, the only viable transplants were kidney transplants

³⁰ Ibid., 62

³¹ Ibid., 45

between genetically identical twins. There were no effective ways of overcoming the immune barrier.

Early attempts at immunosuppression were ghastly-sounding experiments with abject total body irradiation. Distinguished transplant surgeon Nicholas Tilney describes, “All received the massive dose as they lay curled on the floor on a mattress within the circumference of the beam.”³² The intent was to increase recipient tolerance of a graft; instead, everyone died owing to the total suppression of immune defenses. Radiation treatment was adapted to intermittent small doses; and cortisone was administered to reverse episodes of rejection. Under these conditions, post-transplant survival was minimal. Tilney describes the early years of transplantation as “isolated, usually hopeless . . . attempts of a few innovative surgeons to preserve by any means available an occasional patient dying from nonfunctioning kidneys.”³³

The future of organ transplantation depended on gaining more understanding of the complexity of the immune system. Nobel prize winning microbiologist Peter Medawar is renowned for his pioneer work in immunology in the 1960s and 1970s and its influence in the development of organ transplantation. Medawar, who happened to be “too tall to serve in the army” during WWII, began experimenting on the treatment of burns. He studied the way “the body discriminated between its own and foreign tissue” and the

³² Ibid., 70

³³ Ibid., 3

rejection of skin allografts. Medawar eventually identified the lymphocyte as an “immunologically competent cell” and focused his attention on the role of antibodies in the immune system. He clearly articulated rejection as an immune system response, and defined “tolerance” as “a state in which an animal or even a patient can be made selectively unresponsive to the antigens of a given graft, while the remainder of immunological defense mechanisms remain intact.”³⁴ Tilney argues that it was Medawar’s precise definitions of tolerance and rejection that guided the development of organ transplantation, explaining “his clarity of observation and ability to organize data into a comprehensive whole; and his speaking and teaching talents made him a central figure in the new science of transplantation biology.”³⁵

In the beginning, kidney transplantation had limited therapeutic value. One of the first drugs experimented with for immunosuppression was azathioprine (Imuran), which was effective at delaying and reducing rejection. Combined with a steroid like prednisone, some transplant recipients achieved immunological tolerance of a graft but many patients still died. There were also numerous negative side effects of immunosuppressants. Their long-term use led to cancer and renal failure such that Tilney notes the “treatment [was] sometimes worse than the original disease.” Halting acute rejection was a necessity but it meant that recipients ran into problems later on. There were also more immediate problems like thinning of the skin. Tilney writes, “I vividly remember firmly shaking the

³⁴ Ibid., 96-113.

³⁵ Ibid., 117.

hand of a transplant recipient and inadvertently stripping off a patch of skin with my thumb.”³⁶ The ongoing need to control rejection led to poor outcomes in terms of long-term survival and quality of life due to side-effects of anti-rejection treatment. As a result, Tilney argues that “no one envisioned [kidney transplantation] as a surgery that could widely be implemented in clinical practice.”³⁷

In 1963, thirteen kidney transplant teams from around the world convened to discuss all available clinical information on kidney transplantation. The numbers were dismal. 52% of grafts from related living donors had resulted in death and 82% of those who had received kidneys from cadaveric donors had died. Of those who had received kidneys from cadavers, only 4% had lived for more than a year. Two-thirds of kidney graft recipients died within months, even after a decade of experimentation.³⁸ The fact that surgeons pursued transplantation given the high mortality is, according to Tilney, an example of “hope winning out over experience.”³⁹

In spite of these dubious results, kidney transplantation rapidly evolved into a standard treatment. This was because in 1972 the US Congress passed a bill that allowed patients with kidney disease to be funded under Medicare and receive a transplant as a therapeutic

³⁶ Ibid., 129.

³⁷ Ibid., 80.

³⁸ Ibid., 80

³⁹ Ibid., 34.

option. Integrating treatment for end-stage-renal-disease into the United States' socialized medicine program (Medicare) also created equitable access to transplantation (and dialysis), which was previously only accessible to the wealthy population. The compelling argument for the funding of kidney transplantation was that it was far more cost-effective than lifelong hemodialysis.⁴⁰

Transplant surgeon Barry Kahan argues that the government decision to fund kidney transplantation "was amazing not only because the results were not worthy of it, nor was transplantation in 1972 prepared for this imprimatur. Not only were organ recovery systems primitive, but one-year success rates of transplantation were 60 percent at best, unless administered intensive, frequently fatal, levels of immunosuppression."⁴¹ Tilney explains further, "The singling out of this relatively small patient population was due in no small part to extensive lobbying by individuals afflicted with kidney failure, national patient organizations, interested physicians, and dialysis and transplant units across the country trying to finance their operations."⁴² This lobbying deliberately downplayed the fact that the failures outnumbered the successes in kidney transplantation. Thomas Starzl argues, "To justify and continue the national program that was in place, it was necessary to minimize its shortcomings." Starzl thinks this occurred to the point that "the integrity

⁴⁰ Richard Rettig, "The politics of organ transplantation: a parable of our time," *Journal of Health, Policy, Politics and Law* 1, vol. 14 (1989), 194.

⁴¹ Barry Kahan, "Organ Donation and Transplantation: a surgeon's view" in *Organ Transplantation: Meanings and Realities*, eds. Stuart J. Younger, Renee C. Fox, and Laurence J. O'Connell (Madison: University of Wisconsin Press, 1996), 132.

⁴² Tilney, *Transplant*, 152.

of the field” was nearly compromised. Overly optimistic claims about kidney transplantation floated around, which, according to Starzl, “were deceptive at best and potentially fraudulent at worst.”⁴³ Starzl contends the “display of optimism” with regards to transplantation “would not be tolerated in the clinical research climate of today” where “the rare exception” is no longer given “more weight than the customary failure.”⁴⁴

The lack of transparency, overstatements of success, and the concealment of death meant that the public also received a “far more optimistic message” about transplantation than was warranted.⁴⁵ Some of the boasting can be attributed to the “surgical machismo” of the pioneers of transplantation. The media also played a role in hyping up transplantation. Tilney’s interpretation is that the general public embraced the promise of transplantation because it was thirsty for optimism. He writes, “In contrast to the continuing national crises, disruptions, and self-doubts of that period, apparently positive medical ‘miracles’ caught the public interest and improved its mood.”⁴⁶ Public optimism about organ transplantation was particularly fueled by the media spotlight on heart transplantation in the late 1960s. The first doctor to perform a human-to-human heart transplant was the South African cardiologist Dr. Christiaan Barnard. This feat earned a Time magazine cover story (December 15, 1967) and kicked off a spate of sensationalistic media

⁴³ Thomas Starzl, *The Puzzle People: Memoirs of a Transplant Surgeon* (Pittsburgh: University of Pittsburgh Press, 1992), 207-208.

⁴⁴ In Tilney, *Transplant*, 78.

⁴⁵ Starzl, *The Puzzle People*, 208.

⁴⁶ Tilney, *Transplant*, 173-175.

coverage on heart transplantation. Some argue that a “bandwagon” arose from this hype - surgeons seeking fame, adulation and fortune by being at the forefront of an innovation that was so captivating to the public’s imagination.⁴⁷

Anthropologist Margaret Lock argues the publicity around transplantation had the consequence of fostering a distorted, overly optimistic, public perception of its potential. For her this is exemplified by a published photograph of Philip Blaiberg, the third South African recipient of a heart transplant, swimming in the ocean. The photograph was meant to be a testament to his recovery and good health. The truth was that Blaiberg could never walk again. Lock writes, “for the photograph he had to be taken down to the water’s edge in a wheelchair, carried into the ocean, photographed, and then hauled out again.” Blaiberg lived for 19 months and 15 days with his new heart before he died. The photograph is a narrative construction of heart transplantation, a contrived representation of triumph and medical progress that masks the limited benefits of heart transplantation at the time.⁴⁸

Starzl explains that the “federal flow of gold” into kidney transplantation through the Medicare program in the early 1970s secured its place in modern medicine but also

⁴⁷ Ibid. See also Fox and Swazey, *The Courage to Fail*; Marina Joubert, “1967: Reflections on the first human heart transplant and its impact on medicine, media and society,” *Public Understanding of Science* 27, no.1 (2018): 110-114.

⁴⁸ Margaret Lock, *Twice Dead: Organ Transplantation and Reinvention of Death* (Berkeley: University of California Press, 2001), 85. The media attention, however, ultimately contributed to a moratorium of heart transplantation in 1970 as the public became aware of low success rates as well as some questionable practices around organ donation, see Tilney, *Transplant*, 178-179.

“fixed” the “therapeutic practice at an unsatisfactory level.” Specifically, transplant programs were essentially restricted to using living related donors, which were the least immunologically complicated transplants. Starzl argues this resulted in lack of progress in transplantation in the 1970s and particularly no progress with anti-rejection therapy. He describes the 1970s as a decade of “loose ends” that contrasted with the strides and breakthroughs in the 1960s.⁴⁹

There was a significant leap forward in the late 1970s with the discovery of a new drug - cyclosporine A. It was derived from fungi that field botanists with the Swiss pharmaceutical company Sandoz had collected from “a bleak highland plateau in Norway . . . and a valley in Wisconsin.” Cyclosporine had impressive immunosuppressive abilities as well as a lack of toxicity and was able to rapidly boost post-transplant survival.⁵⁰ This drug was a “game changer” and would eventually become the standard treatment for transplant patients and significantly expanded the horizons of the field of transplantation. It paved the way for making liver transplantation a standard practice by the mid-1980s.

Liver transplantation got off to an even rockier start than kidney transplantation. The first experimental liver transplants (on dogs) in the mid-1950s went very badly. They died from shock in surgery. Compared to the kidney, transplanting a liver required more

⁴⁹ Starzl, *The Puzzle People*, 177-207.

⁵⁰ Tilney, *Transplant*, 232.

sophisticated and demanding operative techniques. The challenges of the liver stem from its functional complexity. Complications like uncontrollable bleeding, infection, bile leaks, obstructions were common. The need for innovations and refinements in surgical techniques account for why liver transplantation “lagged behind.” Unlike kidney patients, most liver patients died of operative complications.⁵¹

The most prominent pioneer of liver transplantation Thomas Starzl describes the liver as “hostile to surgeons.” He explains, “For centuries the liver, an enormous and silent reddish brown organ, had withheld many secrets of its own function . . . Those who tried to remove part of the liver, or cut it for other reasons, placed their patient at risk for fatal bleeding. Almost half of the blood circulating in the body every minute passes through the liver. Part of this flow is arterial (delivered by the hepatic artery) and the rest is venous (delivered by the portal vein).”⁵² One of the reasons why liver transplant surgery was so “bloody and difficult” is because cirrhosis (the scarring of the liver that occurs with end-stage-liver-disease) causes blood flow problems. The portal vein cannot pass through scar tissue. In seeking a way around the liver, portal blood finds alternative channels called “collaterals” which are tiny blood vessels with thin walls unaccustomed to pressure and flow. These can become distended and burst They can also fuse to the stomach, intestines and liver. Liver damage also leads to poor clotting, another cause of

⁵¹ Ibid., 202-204.

⁵² Starzl. *The Puzzle People*, 54.

“torrential bleeding” during surgery.⁵³ Starzl experimented with a technique of clamping the two major blood vessels (the inferior vena cava and the portal vein) during transplant surgery for a duration of only 30-60 minutes. With this time constraint, Starzl explains the “operations [are] carried out in a crisis atmosphere” and require a “virtuoso performance” on the part of the surgeon and the anesthesiologist.⁵⁴

The success rate of liver transplantation was poor. By the mid-1970s there had been a total of 130 liver transplants but only 12 recipients survived. With these marginal results there was “little enthusiasm” for liver transplantation. According to Tilney, the field was driven by “a handful of single-minded surgical-scientists” who “labored to wrest the technically demanding transplantation of these complex organs from the realm of total failure.” Chief among them is Thomas Starzl, considered to be the “father” of liver transplantation, as well as Roy Calne. Tilney argues it was “the drive and dedication of these two individuals alone kept the entire field going.”⁵⁵

Thomas Starzl was a confident and talented surgeon who considered various career options and who could have followed many trajectories in the practice of medicine (he had a PhD in neurophysiology). By his own account, the resolve to make liver transplantation a reality was a personal mission and perfecting liver transplant surgery

⁵³ Ibid; Joshua D. Mezrich, “Prometheus Revisited: Liver Transplants and Thomas Starzl,” in *When Death Becomes Life: Notes from a Transplant Surgeon* (Toronto: Harper Perennial, 2019).

⁵⁴ Starzl, *The Puzzle People*, 257.

⁵⁵ Tilney, *Transplant*, 199-202.

was his significant career accomplishment. He was the first to execute a successful human liver transplant in 1967. He also worked at controlling rejection and his experiments with Cyclosporine were influential in garnering its FDA and making its use a clinical standard in liver transplantation.

In Starzl's memoir *The Puzzle People*, he emphasizes that his work in liver transplantation was not initially regarded with much respect, esteem, confidence and certainly not prestige. Nor was it lucrative. Early in his career, working at the University of Miami, Starzl set up a lab in a garage across from the hospital, content with its basic amenities - running water and a central drain. Research funds were so limited he was required to maintain his laboratory out of his own pocket. Starzl moved on to Northwestern University, where in 1959, he was awarded a prestigious Marckle scholarship, the purpose of which was to enable promising physicians to do research at a medical university with a stipend of 6,000 dollars per year. This allowed him to work in the lab "all day everyday" but the conditions of research were meager. Starzl experimented using dogs from the city pound, that were cared for by his wife, and used castoff or "borrowed" equipment from the hospital. Starzl recalls that money was so tight that on one occasion when the head of the medical school of the University of Western Virginia visited him in Chicago, his wife cooked them a dinner that consisted of a rabbit Starzl stole from the laboratory.

In his memoir, Starzl claims that he didn't like performing surgery because he had difficulty handling mistakes and failure. He confesses that in his first attempt at a liver

transplant, the patient bled to death. He doubts he had the “right temperament” to deal with the inevitable losses; but it also drove him to do his utmost to avoid them. Starzl advocated for a “policy of non-concealment.” Namely, he thought it was important to be transparent about failure and not exaggerate the benefits of a procedure that was in its experimental phase especially when the early trials of liver transplantation produced harsh results (all recipients died within 5 weeks). Starzl writes, “It is not sufficient to only report successes. Failures must also be fully documented, no matter how painful and humiliating these may be, in order to prevent repetition by others in the field of transplantation.”⁵⁶

Starzl’s rationale for reporting failure was pragmatic but the idea that failures are *humiliating* is consistent with what Kleinman terms “therapeutic hubris,” which he argues arises from the fact that “physicians are not educated to feel humble or to place limits on the utilization of powerful technologies.”⁵⁷ Loss, on the other hand, is incompatible with “therapeutic hubris.” The high mortality of the early years of liver transplantation also raised ethical questions about what is “experimental” and what is “therapeutic.” In the late 1960s, Starzl deemed liver transplantation “feasible but impractical” and questioned whether “it worth this much trouble to save so few people.”⁵⁸

⁵⁶ Starzl, *The Puzzle People*, 165.

⁵⁷ Kleinman, *Writing at the Margins*, 34.

⁵⁸ Starzl, *The Puzzle People*, 170.

As survival increased in the early 1980s, Starzl became a strong advocate for changing liver transplantation's status from "experimental" to "therapeutic." Meeting with the US surgeon general in 1982, Starzl initiated a consensus development planning session and a hearing was set for 1983. A panel of experts would hear all available data on liver transplantation and decide whether they could conclude that liver transplantation was a medical "service" now that Cyclosporine could treat rejection far more effectively. The evidence was: "of the 170 Starzl transplanted from 1963-1979 only 33 had survived for 12 months, but for 40 people transplanted in 1980 and 1981 using cyclosporine, 28 (70%) were alive 12 months later." This data was sufficient to determine liver transplant was the "preferred treatment for end-stage liver disease" despite some concern about the cost of transplantation and whether the benefits were widespread enough.⁵⁹ In 1984, liver transplantation's designation was officially changed to a therapeutic service. Starzl calls this "the liver transplant goldrush of 1984."⁶⁰

The "goldrush" is inextricable to the history of Cyclosporine, which Tilney identifies as the beginning of the "industrial phase" in transplantation. This era of transplantation saw the rise of big multicenter trials funded by pharmaceutical companies, part of their "commercial machinations" that determined whether a certain pharmaceutical warranted investment and marketing. In the case of Cyclosporine, it was unequivocal that it was the superior treatment over azathioprine and steroids. It was also clear that immunosuppression had the potential to become "big business." The profit-making

⁵⁹ Rettig, "The Politics of Organ Transplantation," 204-205.

⁶⁰ Starzl, *The Puzzle People*, 257.

interests of the pharmaceutical industry ushered in a new way of doing medical research that relies on multicenter data for exhaustive statistical analysis, and randomized trials that included a large number of patients. Tilney explains this “rigor and discipline” in determining the efficacy of treatments would become the new standard for the FDA.⁶¹

The success of cyclosporine substantially changed the scope of transplantation by increasing the number of institutions offering services. Transplantation evolved, with the influence and financial backing of Big Pharma, into an industry based on a steady stream of scientific research.⁶² Tilney notes that early transplantation research was driven by an iconoclast, non-conformist attitude, but “The 1980s heralded a different spirit driven by private and corporate opportunity.” Transplantation had become “a commercially sponsored or underwritten area of medicine.” Tilney, from his perspective as a transplant surgeon, sees both advantages to this change, such as enhancement of drug development, support and organization of multicenter drug trials, and increased networking. He also sees disadvantages, which he describes more abstractly as a “break with the humanitarian tradition of medicine,” and also threats to “intellectual independence and integrity” and a move away from “curiosity-driven science” (the kind that fueled transplantation to begin with) to an “increasingly research-directed, technology-based and pharmaceutically oriented thrust of medicine.”⁶³

⁶¹ Tilney, *Transplant*, 241-242.

⁶² *Ibid.*, 246.

⁶³ *Ibid.*, 254-255.

Tilney argues that the commercialization and industrialization of transplantation is “a product of its own success.” He writes, “It was not lost on anyone - from scientists to clinicians, from industrial marketers to hospital administrators, from third-party payers to patients - that the stakes were high. The subject had become a potential monetary and public relations bonanza.”⁶⁴ With more and more transplant programs, the breadth of the field increased, and the demand for transplantation accelerated. The grandiose idea that the field of transplantation could be without limits came up against the reality of an “organ shortage,” the fact that there was a scarcity of organs that could be used for transplantation. A simple desire “to improve” the lot of patients with organ failure becomes more complicated than initially visualized. For reasons that range from ethics to the influence of market forces on patient care, Tilney suggests that the field of transplantation, over the course of its development, has created “more arcane, less solvable problems.”⁶⁵

Contending with failure

In the mid-1990s, when Shauna was told she would eventually need a liver transplant, my views on it were pretty ignorant and overly optimistic. I believed that liver transplant was a well-established fix-it procedure that saves lives. I didn't know that the early

⁶⁴ Ibid., 245.

⁶⁵ Ibid., 281.

experimental years were inauspicious, a procedure that mostly led to the death of patients, and that it was only in the latter half of the 1980s that liver transplantation picked up through the rapid expansion of programs everywhere offering liver transplantation as a treatment option for pretty much all causes of liver failure - hepatitis B and C, alcoholic liver disease, NASH, cancer, autoimmune liver diseases, metabolic disorders, and acute liver failure from toxins like Tylenol. I thought that a liver transplant would be successful and Shauna's health problems would become less severe and debilitating if not instantly disappear. I had an unquestioned assumption that life-saving biomedical technologies relieved suffering - it seemed obvious in the case of organ transplantation. It would mean "liberation from disease."⁶⁶

On the day that Shauna died, I had a brief exchange with Shauna's hepatologist Dr. S. in the hospital hallway. He was clearly devastated because Shauna had been a dear patient of his for several years. He acknowledged it was a shame that a transplant never happened but added something vague and disparaging about liver transplant as a "rough and ready" solution as he scanned his hospital ID card on the wall next to where we were standing and disappeared behind a locked door. It seemed a strange thought to part on. Why would anyone think a liver transplant was "rough and ready"? The "rough and ready" comment is still obscure to me. The dictionary defines it as "not complete but good enough to use" also as "not having polite or fancy skills but ready and able to do what needs to be done."

⁶⁶ When Shauna had an organ offer, my father declared in the online journal: "liberation from disease is dawning."

After losing Shauna, I don't think Dr. S. thought there was anything he could say that would have really been consoling.⁶⁷ I don't think he thought that describing liver transplantation as "rough and ready" could cut through the awkwardness and difficulty of knowing that it seemed to us like he, and all the other doctors, had let us down. It hadn't yet occurred to me that I never truly confronted the reality of the diseases Shauna had, nor did I consider the range of realistic transplant outcomes, including surgical complications, rejection, the side-effects of immunosuppression, and perhaps even death. The dominant narrative of transplantation is one in which the recipient thrives post-transplant. I didn't imagine other versions of this story. Conventional narratives determine "who the heroes are [and] what life should be like" as well as our understanding of "what should be heralded or hidden."⁶⁸ The history of transplantation established that it is success that should be heralded and loss, failure and death that should be hidden. The heroes are the survivors. Life post-transplant should be "normal."

It never occurred to me that liver transplantation might be a flawed form of therapy and not the medical miracle I had made it out to be. I recently came across this slogan on the Canadian Donation and Transplantation Research Program website: "Together we will

⁶⁷ That day he left an envelope with my parents with a note inside that said, "Dear Shauna, it is almost too much to bare [sic] that our last meeting on earth has taken place."

⁶⁸ Colette Daiute and Cynthia Lightfoot, "Editor's Introduction: Theory and Craft in Narrative" in *Narrative Analysis: Studying the Development of Individuals in Society* (Thousand Oaks, CA: Sage, 2004), x.

turn transplantation into a cure.”⁶⁹ On the surface this is a nice optimistic message, but it has backhanded meaning, obliquely stating that transplantation is not now, and has never been, a “cure.”

The idea that a liver transplant would be a miraculous transformation or a “cure” had something to do with me seeing transplantation as the acme of modern medicine from a scientific/technological standpoint and also from a moral point of view. Physician Leonard Bailey contends that organ transplantation “arose from the desire to help fellow human beings live,” even emphasizing it was “*nothing more*” than a simple, elemental human urge to help others in need. Transplantation, in his view, is a “tribute to the humanness of mankind” and fulfills “a basic human need to help.” It was, in his words, “fathered” by “medical altruism”. It was all about catering the gravely ill and saving people from dying.⁷⁰

In Bailey’s interpretation, it was not science or technological advancement that drove the field of transplantation. In fact, as he sees it, the “science” of transplantation lagged behind the altruistic ideals that fueled it. His argument is directed to bioethicists and others who see organ transplantation as a problem of society being unable to cope with the consequences of technological developments. He refutes the idea that as technology evolves (in the case of transplantation) we’ve created moral quandaries and ethical issues

⁶⁹ (<https://cdtrp.ca/en/>)

⁷⁰ Leonard Bailey, “Organ Transplantation: A Paradigm of Medical Progress,” *Hastings Center Report* 20, no.1 (1990), 25.

that we are incapable of solving. For Bailey, the history of transplantation, and the early years marked by failure, is evidence that the imagined potential of transplantation (helping human beings live) outreached the scientific capabilities. He implies that there is an underlying “human need” that transplantation is merely trying to adapt to or rise to the occasion to meet. Some of the critics, however, see it the other way around, that medical and technological advancements are shaping those “human needs,” and not necessarily for the better.

In 1973 philosopher and biomedical ethicist Daniel Callahan published a book called *The Tyranny of Survival* in which he argues there is a problem with the satisfaction of human needs through technology because “satisfaction of needs through technology often, if not inevitably, leads to the creation of new desires which in turn call for still more technology for their solutions.” This results in “the escalation of technological commitment.”⁷¹ The growth of organ transplantation (and the prediction that the demand for transplantation will only increase in the future) is an example of the “escalation of technological commitment.” The “need” for transplants can only be met through enormous amounts of knowledge, technology and resources.

According to Callahan, we live in a society where the concept of survival dominates (hence what Callahan refers to as the “tyranny of survival”). Furthermore, survival is often treated like “the only decisive variable.” Callahan writes, “There is almost nothing

⁷¹ Harold Moore, “Beyond Survival – Daniel Callahan: The Tyranny of Survival,” *The Review of Politics* 37, no. 3 (1975), 418.

people won't do once they are convinced that survival is at stake."⁷² This mentality makes pursuing transplantation seem like an obvious course. However, Callahan warns that "joining technological possibility with demands for survival" is a "noxious combination" because, in his opinion, there are no obvious limits.⁷³

Callahan's argument echoes Fox and Swazey's critique that transplantation has "gotten out of hand." His point that I relate to is the emphasis on "survival" as the "decisive variable." When Shauna's survival was at stake, *it was* the only decisive variable, and the only thing that mattered. I didn't think about anything else but Shauna's survival. Indeed, Callahan argues that survival is first and foremost oriented to the satisfaction of *individual* needs and promotes individualistic thinking. As much as there is talk about transplantation being a technological development for the *greater good*, the stakes and drama of transplantation are highly individualized. The goodness (and the success) of organ transplantation is tied to the survival of *individual* patients. I saw liver transplantation as the only thing that would save Shauna from dying. For this reason and this reason alone, is why I thought liver transplantation was a good thing. The more Shauna's survival was at stake the more the goodness of transplantation seemed all about *her*.

⁷² Ibid., 418.

⁷³ Daniel Callahan, "Science: Limits and Prohibitions," *The Hastings Center Report* 3, no. 5 (1973), 6.

Individual success stories have had a meaningful place in the history of transplantation (even starting with the Herrick twins). Tilney notes the pioneers in kidney transplantation were continually motivated by the anomalous successes in their practice. He singles out a patient named John Riteris who, in 1959, went on to have a “normal life” after receiving a kidney graft from his *non-identical* twin. Tilney states that Riteris “became in principle the single most important case, psychologically and otherwise, in the history of the field of clinical transplantation.”⁷⁴ He even claims his survival was “more influential” than the majority of patients who had died. Riteris represented the benefits of transplantation and the orientation to individualism in a field largely driven by hope, optimism, and the possibility of survival. The successes mattered far more than the failures.

A narrow focus on individual success stories defines the history of transplantation. Health policy scholar Richard Rettig argues this also shaped the way policy about organ transplantation evolved. A prime example for Rettig is the congressional hearings on liver transplantation in 1983 that would determine whether liver transplantation was “experimental” or “therapeutic.” The case for liver transplant was spearheaded by Tomas Starzl, but, as Rettig emphasizes, there was very little clinical data available at the time. Liver transplant success was gauged by 12 month-survival post-transplant, which at the time amounted to 28 individuals, or 70% of all the liver transplants that Starzl had performed (using Cyclosporine) in 1980 and 1981. Starzl's strategy was to persuade

⁷⁴ Tilney, *Transplant*, 73.

Congress by demonstrating the individual plight of patients and the benefit of liver transplant in the lives of individuals. Testimony was heard from liver transplant patients themselves, or in the case of pediatric patients, from their parents.⁷⁵

The 1983 Congressional hearings on liver transplantation garnered media attention.

Rettig highlights an excerpt from ABC's Nightline that aired on April 14, 1983. The host Ted Koppel asks guest Thomas Starzl to explain why liver transplant is "not experimental." Starzl responds that there are patients who have successfully received a transplant and resumed their normal lives. Koppel tells him he is "begging the question" because, he points out, there are failures also. He asks, "*What if we turn to the failures?*" Starzl answers: "*I think the fact that there are failures is probably irrelevant because there are failures in any form of therapy. What one looks at is that there can be stunning success and in significant numbers.*"⁷⁶

Starzl's position that failures are not worth considering is striking. He is saying that if transplant is beneficial to a privileged few it justifies not thinking about the experience of others for whom it is not. This stance also implies that it is not worth thinking about any of the socio-economic contextual factors like gender and racial privilege that contribute to success stories. It promotes a kind of blindness to only acknowledged and recognized organ transplantation as a progress story, whether at the level of patient

⁷⁵ Rettig, "The Politics of Organ Transplantation," 199.

⁷⁶ Ibid., 201, my emphasis.

narratives/experience, in the broader history of the field, and in the context of health inequalities. Paul Farmer argues that economic, social and political forces deny equitable access to the “fruits of scientific and social progress”; those who are left out are victims of what he calls “structural violence.”⁷⁷

In focusing uniquely on the success and optimism that propelled transplantation, we reinforce the ideology of Western biomedicine that sees science and technology on a linear path toward humanity’s progress and advancement, as well as the ideology that propels colonial and white supremacist thinking, specifically that “advancement” should be measured in terms of the advancement of white people and their goals. The exaltation of success in organ transplantation has commonalities with a colonial worldview that embraces “development” while concealing, minimizing or ignoring harms.⁷⁸ It also emphasizes a “medical way of seeing” that treats individuals as isolated from social contexts, and a preoccupation with personal health, wellbeing and achievement.⁷⁹

Despite drawing attention to the “silent mortality” of transplantation (a phrase Starzl uses several times in his memoir), he heroizes the patients who survive. In his words, “Failure

⁷⁷ Paul Farmer, *Infections and Inequalities: The Modern Plagues*, (Berkeley: University of California Press, 1999), 76.

⁷⁸ For example, the concealment of colonial violence in Canadian nationalism is analysed in Sunera Thobani, *Exalted Subjects: Studies in the Making of Race and Nation in Canada* (Toronto: University of Toronto Press, 2007).

⁷⁹ Robert Crawford, “Healthism and the Medicalization of Everyday Life,” *International Journal of Health Services* 10, no. 3 (1980).

was abundant but success was spectacular.”⁸⁰ He ends his memoir with a tribute to the “heroic” patients who through will and courage represent the “glory of striving,” as though surviving the longest is the best and most heroic thing one could do. The survivors are the ones who have the “remarkable stories.” For surgeons like Starzl they are the “rewards” of the demands and sacrifices they have made in their careers.

Starzl’s dismissal of Koppel’s suggestion to *turn to the failures* shows the degree to which a Eurocentric paradigm of progress dominates and defines us, in transplantation and more broadly. Anthropologist Anna Lowenhaupt Tsing writes that “Categories and assumptions of improvement are with us everywhere. We imagine their objects every day: democracy, growth, science, hope.” Progress, she argues, has a strong grip on our imagination and thinking outside of progress is an “imaginative challenge.”⁸¹ In fact, she writes, “*Progress still controls us even in tales of ruination.*”⁸²

Lowenhaupt Tsing’s arguments come from her book *The Mushroom at the End of the World*, a fascinating ethnography of wild mushroom hunters in the Pacific Northwest of the United States. The mushroom hunters she writes about experience conditions of precarity and “life without the promise of stability.” She argues that these kinds of stories are typically ignored (even though they are “endemic to globalized capitalism”) because

⁸⁰ Starzl, *The Puzzle People*, 173.

⁸¹ Anna Lowenhaupt Tsing, *The Mushroom at the End of the World: On the Possibility of Life in Capitalist Ruins* (Princeton, NJ: Princeton University Press, 2015)

⁸² *Ibid.*, 21, my emphasis.

“progress stories have blinded us” and orient us to a dream version of modernization, a fantasy of living in a “controlled world” where endless improvement is possible. In the “dream version of modernization,” we have been blinded by the progress story of transplantation. It captures the imagination and distorts our perception of transplantation as a field that is continuously progressing without recognizing that it is also continuously engaged in the pursuit of a fantasy. The “progress stories have blinded us” in the sense of dismissing the despair encompassed by all its failures (for example, the people who “die waiting”).

A distinguishing feature of humans is that we “look forward” (unlike the rest of the living world). As Lowenhaupt Tsing puts it, we march to the “driving beat” of progress. But, accordingly, this forward-looking tendency means that we don’t “notice other temporal patterns”; and we ignore and neglect what doesn’t fit the timeline of progress.” As a result, Lowenhaupt Tsing argues that we over-rely on the lens of progress, assuming that “the trope of progress is sufficient to know the world.” It determines how we understand both *success and failure*. She writes, “The story of decline offers no leftovers, no excess, nothing that escapes progress.”⁸³ Failure is understood according to progress rather than examining how failure can be another story entirely.

Admitting Ambivalence

⁸³ Ibid., 21.

The story of failure in organ transplantation hasn't been adequately told because it hasn't been adequately conceptualized. This applies to the field as a whole where the success story dominates, and also in the individual experience of someone like Shauna. There is evidence that failures may creep in as a sense of ambivalence or ghostliness. Tilney, for example, dedicates his book on the history of transplantation to "our patients, whose thirst for life, steadfastness in facing an unknown future, and unflagging optimism and support drive forward those of us who struggle in this challenging field." But, in his conclusion, he acknowledges that "heart-breaking tragedies" and the sad experiences may result in "professional ambivalence." For all the exalting lifesaving of transplantation, Starzl acknowledges that "ghosts remain."

Transplant surgeon Bud Shaw's candid memoir, *Last Night in the OR* demonstrates a career haunted by ambivalence. Shaw is the son of a surgeon who operated a general surgery practice and had the status of a "town hero" in the small town where they lived. He considered following directly in his father's path, but he was drawn to the idea that the prestigious field of transplantation attracted the very best surgeons. Shaw trained with the "father" of liver transplantation Thomas Starzl, who doesn't get a flattering treatment in the book. He describes Starzl "acting like a god in the operating room," admonishing the rest of the team, and repeating a mantra about "life" ("I don't want anyone here who doesn't believe in life!") that made him sound like a zealot. Shaw found Starzl so difficult to work with that during one surgery he writes he was tempted to punch him in the side of the head.

According to Shaw, Starzl discouraged him from putting too much energy into a life outside his career (this was his way of consoling him when Shaw told him about his failed marriage). Starzl, for his own part, writes in his memoir that when he retired after 10 years of living in Pittsburgh, he had no idea where the city parks were. He worked all the time. Starzl thought that total dedication to transplantation would have an enormous payoff. Shaw remembers Starzl telling him: “These are epic times . . . And you’re right in the middle of it. The epicenter . . . You’re riding a rocketship to the stars you know. The sky’s the limit. Shit, the limit’s beyond the sky. It’s . . . stratospheric. Your career is just getting started and it’s already reached the stratosphere.”⁸⁴ Teetering on burnout, Shaw is never as dedicated to his career as Starzl thought he ought to be.

Shaw, however, does take to the heroics and machismo of performing transplant surgery. He describes the operating room as “our fiefdom” where surgeons exert “supreme command,” directing the troops, fighting the battle, winning. He writes, “It usually worked. When it didn’t - when I lost someone despite my best effort - I could usually find someone or something to take the rap, at least in my personal summary of what happened, the summary that let me off the hook, and allowed me to maintain that necessary sense of power and control.”⁸⁵ The sense of control was enthralling to him; and it particularly was the thrill of escaping death that made him feel most powerful. He explains, “I felt a kind of wildness that wasn’t so much victory as escape, thrilling escape

⁸⁴ Bud Shaw, *Last Night in the OR: A Transplant Surgeon’s Odyssey* (New York: Plume, 2015), 170-171.

⁸⁵ *Ibid.*, 237-238.

from near death [any patient could die during surgery]. I was a beast and I daily walked up to the brink and jumped in, ripping and tearing and slashing and screaming, always crawling out the other side reaping air and worshipping the weight of my bones.” Shaw offers vivid descriptions of the surgeries themselves and the harrowing attempts to stop patients from bleeding to death. His descriptions accentuate the volume of blood involved, pooling in his shoes and “dripping off his balls.” The stress (and often sleep deprivation) induced a high (or a mania): “Living on the front lines, trying to save everyone while death seemed so close by, not in the shadows, but right there in those brightly lit rooms where we worked.”⁸⁶ The experience was so intense that he admits he sometimes masturbated in the shower afterwards.

Last Night in the OR ends with a childhood memory of a family vacation in Florida. Shaw got a fishhook caught in foot. His surgeon father employed a technique he had perfected in his small-town practice to remove the hook quickly and painlessly. Later that day, Shaw recalls, *and this is the last line in the book*: “I pressed my cut foot into the solid edge of the pool and felt the release of a sharp pain shooting through the sole” (291). This unexpectedly poignant line made me think about what the release of buried pain alluded to. I realized much of the book is dedicated to failure and loss.

The primordial loss in the book is Shaw’s mother’s battle with cancer and her eventual death. Shaw recounts how his father was cross with him for failing to recognize how

⁸⁶ Ibid., 164-167.

much his mother masked her pain for the sake of others in the family. Though I don't doubt it is the unacknowledged family pain that scars him most deeply, I think it reverberates in his relationships with his patients. Notably, Shaw didn't like patient reunions because of the way, in his experience, doctors are treated like heroes. The attention and the adoration makes him uncomfortable, or worse, he says, "These people made me panic with all their talk of miracles and saving their lives." He reflects on the patients who died, either on the operating table, or after, even the "successful" cases, the ones who initially seemed to be doing well, and realizes he is ambivalent about miracles and lifesaving after all. Now retired, Shaw says that when someone asks him what he misses about transplant surgery, he "struggles to give an honest answer". His scripted response is to say he misses the reward, the high, the joy, the successes, the camaraderie and teamwork. This gets a "knowing nod." But he writes, "If I begin to remember how rarely things went so well. I usually stop then. These seem to be the answers they expect to hear, so that's enough. If I go on, I lose them. But it's not the whole story, nor the most important part of it, at least for me."⁸⁷ The "whole story" as I understand it, is that transplant surgery is less rewarding than it expected to be.

In an essay promoting his book, titled "Real Surgeons Can't Cry: How writing healed a doctor," Shaw admits to the difficult emotions that he tried to shield himself from during his career. These emotions only came to the surface when he started writing. He wonders if he had been more "reflective" whether he even would have continued his career in

⁸⁷ Ibid., 238-239.

transplant surgery. He also admits that his colleagues have doubted whether the public would like his questioning perspective, suggesting that they wouldn't understand it.⁸⁸ Why probe (pressing the foot on the edge of the pool) only to discover that something that is meant to be painless actually aches? I also question whether others will appreciate my perspective, or if they only want to hear the "hopeful" stories" that give attention to the rewards of organ donation and transplantation. For patients as well, it seems that only successful transplants get acknowledgement, the nods, and the approval. What about the "rest" (*turning to the failures*); what about *ambivalence*? Is it true that others "wouldn't understand"?

⁸⁸ Bud Shaw, "Real Surgeons Can't Cry: How writing healed a doctor," electricliterature.com (September 15, 2015)

3 The Suffering of Waiting

Scratching the surface of limbo

Over the past decades, there has been little research on patient experience of end-stage liver disease (ESLD). Overall, it has been “sparingly described.” Boyd et al. note this lacuna and write, “Given the plethora of complex physical, psychological, existential, social and family problems that are the norm in advanced liver disease it is perhaps surprising that so little attention has been paid to understanding and addressing the wider illness experience of these people and families.”¹ The experience of liver failure can differ dramatically from patient to patient, owing to unique disease etiologies and illness trajectories. For some it is erratic and entails rapid deterioration, rendering their outlook extremely poor. Liver failure is the third most common cause of death in the US but only about one third of people with ESLD are listed for a transplant. The vast majority of people who die from liver failure are never listed to begin with. The subset of patients who qualify for a transplant undergo a process of selection requiring extensive evaluation by surgeons, hepatologists, psychiatrists, social workers, and nutritionists. These are the

¹ Kirsty Boyd et al., “Living and dying well with end-stage liver disease: Time for palliative care?” *Hepatology* 55, no. 6 (June 2012). See also Steven P. Wainwright, “Transcending Chronic Liver Disease: a qualitative study,” *Journal of Clinical Nursing* 6, no.1 (January 1997); Ida Torunn Bjork and Dagfinn Naden, “Patients’ experiences of waiting for a liver transplantation,” *Nursing Inquiry* 15, no.4 (December 2008).

patients who deal with the physical effects of liver failure and the emotional and psychological aspects of waiting for a liver transplant at the same time.²

In Shauna's case, I don't recall a multidisciplinary evaluation of whether she was a suitable candidate. There was no question that she would be listed, it was only a question of when she would become "active" on the list, a mentality that extended to the transplant itself - it wasn't a matter of "if" but "when." Taking it for granted that Shauna would be eligible for a transplant when the time came is a reflection of Shauna's age, diagnosis and privilege. I know that my thinking skewed to believing Shauna was a "good" candidate because of her personal attributes, but it should also be acknowledged that social status inevitably plays a role, and the fact that the storied version of a liver transplant that was already playing out in my head had overtones of the kind of self-realization that our social structure fosters and supports primarily for privileged white people.

The trigger for Shauna's activation on the waitlist was bleeding esophageal varices in the summer of 2003. Along with this alarming event, it was obvious she had worsening symptoms of liver failure: lack of appetite, cramping, abdominal distention, dizziness, and lethargy. I thought this suffering was an inevitable part of the story of "transformation."

² Jill Brown et al., "Waiting for a Liver Transplant," *Qualitative Health Research* 16, no. 1 (February 2006).

In late November of 2003, Shauna got an exciting call to be a back-up candidate for a liver transplant. When a deceased person is medically suitable and consenting to organ donation, two recipient patients are prepped - a primary candidate and the back-up. If the primary candidate cannot proceed to transplant surgery (something contraindicating is discovered at the last minute), there needs to be another patient in the hospital ready to go to the OR. Once organs have been removed from the body of the donor they rapidly start deteriorating and no precious time can be lost on logistics and preparations that could have been sorted out beforehand.

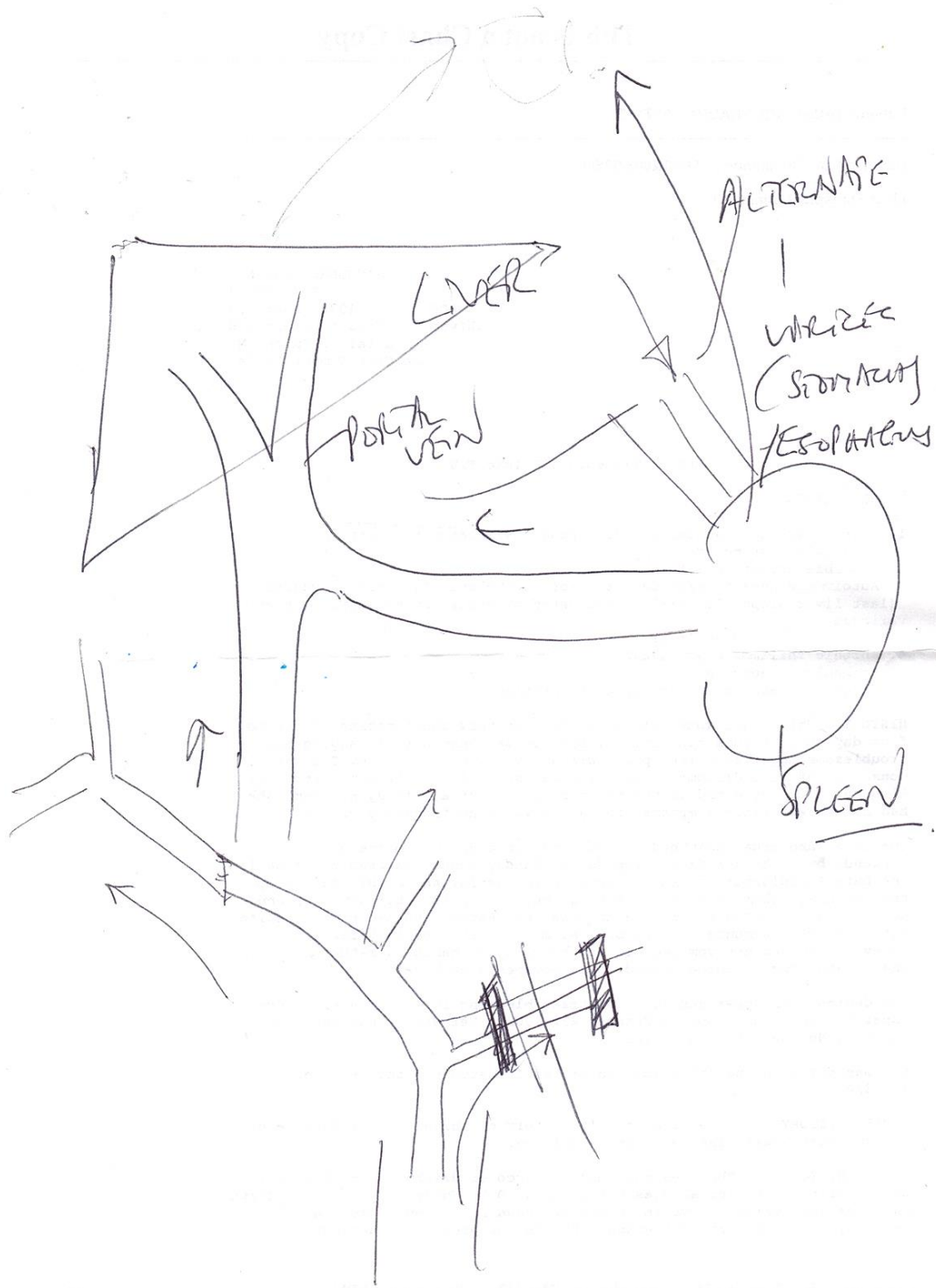


Figure 1: Gastroenterology drawing by Dr. S (found in a notebook of Shauna's), 2003.

When Shauna called to tell me she was a back-up candidate I immediately jumped on a plane to Raleigh-Durham, NC, where Shauna had been living for the past 5 years. I wasn't going to miss her transplant surgery. I was optimistic that she would be lucky. Maybe this was it. My flight from Montreal to North Carolina, via Washington DC, left in the evening. It was a small plane that was half empty, quiet and calm. The cabin was dim with sporadic pools of overhead lights and the muted glow of screens. Though I couldn't see much from my vantage point, the flight attendant noticed something wrong with one of the passengers several rows ahead of me. A slumped-over man could not be roused. The flight attendant requested a doctor or nurse on the intercom and when none came forward, resorted to enlisting the help of another passenger in lifting the man from his seat, lying him down in the aisle and performing CPR. The flight was rerouted for an immediate emergency landing and soon the plane touched down somewhere in Pennsylvania where an ambulance was waiting. The paramedics came on-board, strapped the man on a stretcher and removed him from the aircraft. I overheard them say that he had no pulse and he wasn't breathing. It seemed like such an abrupt and astonishing way to go: dropped dead on a plane, a stranded body in Pennsylvania.

When the flight arrived in Washington DC, I called Shauna to tell her I had missed my connection. She told me that the transplant went ahead with the primary candidate and she had been sent home. I was on pins and needles but I knew this was the most expected outcome, plus it strengthened my confidence that Shauna would be transplanted soon. If she was already the back-up candidate, it wouldn't be much longer until she was the primary. There wasn't another flight to Raleigh-Durham until the morning so the airline

put me up in a hotel. I watched a late-night movie on TV to distract myself from thinking about Shauna and the other person having the transplant. The significance of the man dying on the plane wasn't apparent to me. Maybe it sort of registered that the universe wasn't giving a very auspicious sign, possibly sending a death omen, if there are such things. Now, in hindsight, I can reframe his death as a clue that I didn't pay attention to at the time: *to die up in the air, to die in limbo.*

Waiting is often described as a kind of limbo - caught between life and death. Lumby calls it a "time paradox" - the paradox of facing life and death at the same time, explaining that the "thanatological issues" patients face can be complicated by the feeling that one is "lucky" to be listed for a transplant in the first place.³ Research on patient experience of waiting tends to acknowledge this as some kind of "existential crisis" but it has never been elaborately described. One study likens it to the biblical end of the world, referring to "the people of the List" as "denizens of a strange land with dark terrain" facing "their own private *eschaton*."⁴ More common than this overdramatization is the reduction of an "existential crisis" to the language of disease symptomatology. For example, Baker and McWilliam call for more ESLD research aimed at "[assisting] people in an existential crisis."⁵

³ Judy Lumby, "Liver transplantation: The death/life paradox," *International Journal of Nursing Practice* 3, no. 4 (December 1997). See also Aluko A. Hope and R. Sean Morrison, "Integrating palliative care with chronic liver disease care," *Journal of Palliative Care* 27, no. 1 (Spring 2011).

⁴ Brown et al., "Waiting for a Liver Transplant."

⁵ M. Susan Baker and Carol L. McWilliam, "How Patients Manage Life and Health While Waiting for a Liver Transplant," *Progress in Transplantation* 13, no. 1 (2003). See also Barbara Kimbell and Scott A. Murray, "What is the patient experience in advanced liver disease? A scoping review of the literature," *BMJ Supportive and Palliative Care* 5 (2015): 471-480.

The remedy for an “existential crisis” is not obvious. One web article on a site called “Medical News Today” offers four tips for coping with or “overcoming” an existential crisis: keep a gratitude journal, do not give in to pessimism, look for smaller answers, and talk it out.⁶ All of these suggest that the goal is to banish negativity. The idea that it’s bad for mental health to have a “negative outlook,” or ask questions that are “too big,” reflects our cultural preference for optimism. This, in itself, can create the context for an existential crisis if we are continually told to “keep smiling” and “be positive” when we are faced with many good reasons not to. Barbara Ehrenreich has offered this critique of breast cancer culture, arguing that those who feel alienated by the imperative to be optimistic and upbeat are shunned for their negative emotions like anger, despair and hopelessness. Ehrenreich contends in breast cancer there is a “tyranny of cheerfulness.” The public face of breast cancer is dominated by hope and life (think “survivor parades”) while women facing death are relegated to the shadows.⁷ The documentary film *Pink Ribbons, Inc.* interviews a woman with Stage 4 breast cancer who explains that celebrating those who “beat cancer” is also “painful messaging” for those facing inevitable mortality. She suggests that there needs to be more of a balance between hope and “understanding that it may not work out.”⁸

⁶ Jon Johnson/Timothy J. Legg, “Facing an existential crisis: What to know,” *medicalnewstoday.com*, (December 6, 2019).

⁷ Barbara Ehrenreich, “Welcome to Cancerland,” *Harper’s Magazine* (November 2001).

⁸ *Pink Ribbons, Inc.*, dir. Lea Pool, National Film Board of Canada (2011).

Limbo is the condition of hope vs. “understanding it may not work out.” Ultimately, it is a state of powerlessness. Transplant patients are advised to be organized and to get ready for their transplant but this preparation is very superficial and doesn’t hold a candle to the crushing inner experience of knowing that you have no control over what is going to happen to you. Depression and anxiety are acknowledged symptoms of waiting for a transplant. But there is no “treatment” for the overwhelming uncertainty and insecurity of waiting, especially because having a precarious status related to mortality, and the possibility of being saved, is seen as preferable to knowing, without a doubt, that you are going to die. Unlike a typical dying patient for whom mortality can be acknowledged and accepted, the liver transplant patient is faced with a mortality that is profoundly uncertain. This can give rise to a range of conflicting emotions: anger, guilt, frustration, acceptance, denial, hope and despair.⁹

In the months that followed Shauna’s call to be a backup candidate, her condition appeared to stabilize. She became less medically urgent, and a transplant (though she was still “waiting” on the list) felt further away. Life had to go on as semi-normal. Regular life activities continued in the context of “waiting,” a perpetually vacant but entirely

⁹ This is touched on by Lumby, “Liver Transplantation,”; Boyd et al., “Living and dying well”; Bjork and Naden, “Patients’ experiences of waiting”; and Brown et al. “Waiting for a Liver Transplant.” See also: Anne M. Walling and Neil S. Wenger, “Palliative Care and End Stage Liver Disease,” *Clin Gastroenterol Hepatol* 12, no. 4 (2014); Anne M. Larson and J. Randall Curtis, “Integrating Palliative Care for Liver Transplant Candidates: ‘Too Well for Transplant, Too Sick for Life’.” *JAMA* 295, no. 18 (2006); Benjamin Hudson et al., “The incompatibility of healthcare services and end-of-life needs in advanced liver disease: A qualitative interview study of patients and bereaved carers,” *Palliative Medicine* 32, no. 5 (2018).

consuming state “*outside the rhythm of [one’s] own [life]*”¹⁰ that is inherently “greedy” (as Shana once described it) and destabilizing.

While she was waiting, Shauna was pursuing a PhD in Economics at a top US university. Despite being encumbered by uncertainty and fatigue, Shauna continued to work on her dissertation on the history of public funding for the arts in the United States. She was conducting an economic analysis using US census data and contextualizing it with social history that examined the cultural, political and economic ideas that shaped public goods theory and federal arts policy. She was also teaching a senior undergraduate seminar that she developed entitled “Historical Perspectives on Women in Economics.” She jotted in her journal however that she was miserable, “shocked” at how life was still going on around her, and if she could stay in bed all day she would

One study of patient experience of ESLD found that patients “seemed resigned to the inevitability of their suffering” because there is little that can ease symptoms of ESLD, particularly because patients experience fatigue and lack of energy as the most debilitating issue of all.¹¹ Shauna took medication for her nausea and sleeplessness, but her extreme fatigue was insurmountable. Depression is linked to fatigue. People feel down because they are capable of doing so little. Lack of energy and not being able to

¹⁰ Sharon Kaufman, *And a Time to Die: How American Hospitals Shape the End of Life* (New York: Scribner, 2005), 148.

¹¹ Bjork and Naden, “Patients’ experiences of waiting”

work produce feelings of loss and frustration with the limitations of illness. Wants, dreams and desires are on hold.¹²

Not being “productive” can also lead to loss of self-esteem. We live in a culture that measures self-worth by high productivity. The bar is high for everyone, let alone those who are ill. Shauna felt social pressure to be hard-working and high achieving, which also became a means for her to outwardly eschew illness. She was ambitious, polished, and exhibited a self-assured demeanor, all of which minimized or concealed the appearance of illness. Decades ago, Arthur Frank, author of *The Wounded Storyteller*, argued that while individuals may not feel responsible for being ill, they still feel “responsible for how they present themselves and manifest the signs of their illness.”¹³

Assuming this responsibility of self-presentation is a good way to understand how Shauna navigated living with a chronic illness. Above all, I think she wanted to avoid ever coming across as conspicuously needy, wounded or struggling. Instead, Shauna always had an aura of competence. If she was in pain, it was inscrutable.

Shauna largely kept her illness to herself. While concealment may have fulfilled an inner need for privacy and self-protection, these needs are also formed and shaped by what is socially desirable - fitting in, passing and avoidance. In her case, I think this led to a degree of isolation. Deep down, I don’t think Shauna was in denial. I have no doubt that she approached the insecurity of her health with acceptance. I think it gave her an

¹² Ibid. See also Wainwright, “Transcending Chronic Liver Disease,”; Brown et al., “Waiting for a Liver Transplant”; Hudson et al., “The incompatibility of healthcare services.”

¹³ Arthur Frank, *The Wounded Storyteller: Body, Illness and Ethics*, 2nd ed. (Chicago: University of Chicago Press, 1995), 32.

awareness and understanding that fundamentally there is no lasting security in life so she was able to face it in a way that was courageous and brave. She worked hard though at what the late anthropologist Robert Murphy calls the “social skills in sickness.” “As with all other social roles,” Murphy writes, “a person can succeed or fail at sickness.”¹⁴ She lived up to the social standard of someone who can “thrive “while being chronically ill and not impose her “problems” on others. This became increasingly harder for Shauna to do the sicker she became. It wasn’t easy for her to turn to people and say, “I’m needy.” The result was that so much of the difficulty of waiting she faced alone. To preserve some sanity (or perhaps to treat her existential crisis) she ordered two cross-stitch patterns on the internet and started to work on one of them that says, in pastel, all caps, cross-stitch lettering DO NOT FUCK WITH ME. The second pattern is a line of four hearts, each with a letter inside: F-U-C-K.

I tried to be there for Shauna, but I know that I was consumed with my own anxieties, anger and guilt that she was sick (why her?) and at the unfairness that she was still waiting (why not her?). My prime fixation was the transplant - when was it going to happen?!? - and it made me unavailable and maybe even oblivious to her suffering. Overall, the monofocus on Shauna’s transplant put me in a grey zone with regards to my concern for the suffering of others. It almost verged on total disregard. The rivalry and competition for donated livers is so high that other patients on the waitlist seem like a nuisance, or an obstacle, rather than fellow human beings whose lives are similarly

¹⁴ Robert F. Murphy, *The Body Silent: The Different World of the Disabled* (New York: WW Norton, 1987), 20.



Figure 2 Shauna’s unfinished cross-stitch

imperiled. I can’t deny that I sometimes had unkind thoughts and feelings of resentment about the recipients who got liver transplants during the time that Shauna was waiting, especially because two common reasons for liver transplantation are hepatitis C and alcoholic cirrhosis, both of which are associated with “bad lifestyle choices.” I know it is wrong to blame addicts for their problems and think that they brought liver failure on

themselves, but I couldn't stand the thought of losing Shauna. I didn't feel genuinely happy that others were getting their "second chance." I admit it.¹⁵

Regardless of the question of whether some candidates are more "deserving," waiting clashes with the sense that you shouldn't just passively wait for anything in life. Losers do that. Successful people are proactive. But there was nothing to do to expedite the transplant. We sometimes heard the advice to "pressure the docs" or "lean on the docs," as though a more aggressive attitude was required - that the doctors could do more to procure a liver donor, and we could forcefully insist upon it. But it just didn't work like this. You wait your turn. Our society is accustomed to using privilege and power to get what we want. Organ transplantation is hardly exempt from this mentality - it is what has led to the black-market organ trade, a stark example of the way that racial and economic inequalities are exploitable, and have been exploited, by transplantation. There are other less egregious ways of "gaming" the system. In the US patients can be listed at more than one transplant center at a time to increase their chances. This is perceived as an advantage that only wealthier people have because it involves travel costs, additional living expenses, and paying out of pocket for services at multiple transplant centers, including doctor's visits, tests and evaluations because any insurance provider would most likely only cover the cost for these things at one center, not two or more. Deceased liver transplant recipient and Apple CEO Steve Jobs did multiple listings like this. Jobs was a

¹⁵ Transplant surgeon Joshua Mezrich, author of *When Life Becomes Life: Notes From a Transplant Surgeon* (New York: Harper Perennial, 2019), suggests that patients with "primary liver disease" (like Shauna) could be prioritized over patients with "secondary" diseases of the liver caused by alcohol, fatty liver and hepatitis for which he suggests "preventative, incremental care is the desired treatment," 246.

California resident but he was transplanted in Tennessee, leading to questions about whether or not he really got his transplant fair and square.¹⁶

Our family, as a general rule, didn't lean on people, pressure them, or game systems; even being demanding and assertive didn't sit right with our family principles and moral system. Shauna and I were reared as do-gooders. When we were girls, our mother brought us along with her to volunteer at the Ronald McDonald House, a large home near the University Hospital converted to a boarding house for out-of-town and financially-in-need families of critically ill children. Our mother did housework there and Shauna and I helped with chores, like we did at home. The chores we did there were not that significant - tidying, sweeping, dusting - but the general thread of doing things for the benefit of others extends to the ethos of organ donation and defined the way we saw it. We didn't acknowledge that organ donation requires someone's demise and is on many levels a fight for resources. Seeing organ donation only as an act of generosity requires blinders and wrapping it up in rosy thinking but that was the narrative of transplantation that we embraced. The family story would be written as the donor who was so generous and the life that was saved.

¹⁶ The media attention around Job's transplant made the point that he didn't "cut the line" – see Ray Hainer, "Did Steve Job's Money Buy Him a Faster Transplant," *CNN Health* <https://www.cnn.com/2009/HEALTH/06/24/liver.transplant.priority.lists/> In Chapter 4 I discuss the allocation system, it is worth noting that a cancer patient like Steve Jobs would have had exceptional MELD points (patients with hepatocellular carcinoma are allotted standardized exception points, but Jobs had a rare pancreatic cancer so his points would have been non-standardized), which may have given him an advantage.

The denouement of Shauna's wait

In summer 2004, after a year of waiting, Shauna's health status took a sharp turn for the worse. I didn't have a sense of how catastrophic ESLD could be, and therefore all my memories of what follows are colored by my assumption that things really weren't (or couldn't be) that bad, a (willed) ignorance that made me blot out any notion that this could be a story of "failure." The hope of transplantation eradicated despair. In retrospect, this has been a source of frustration. I wish I could give a more fulsome account of the experience of waiting, but I know that it's limited by the attitude I had at the time - not unlike Thomas Starzl's - that failure isn't worth considering.

Cirrhosis impedes the circulation of blood through the liver and causes portal hypertension (the increase of portal venous pressure), which, in turn, causes ascites - the collection of fluid in the abdominal cavity. Ascites can be treated with diuretics but for Shauna it reached the point of being unmanageable and refractory. With the worsening ascites, her serum sodium levels also decreased, a serious condition known as hyponatremia. Shauna's sodium level dropped low enough that she needed to be treated in the hospital, which involved tinkering with different ratios of diuretics, fluid intake, and albumin infusions. Low sodium causes overall weakness and has neurological impacts such as headaches and inability to think clearly; severe effects can be seizures or going into a coma.

Hyponatremia also leads to complications and increased risks in surgery and post-op recovery so Shauna was temporarily deactivated from the waitlist. She needed to meet a

minimum threshold of low-normal sodium levels to be eligible for transplant surgery. Shauna's "low sodium" became the forefront issue and also seemed nearly impossible to correct. Unfortunately, the only treatment that kept her sodium levels from falling too low was a brutish form of punishment - severely restricting her fluid intake. Initially, her fluid restriction was more manageable at 1.5 L a day, but it was eventually reduced to only 500 mls per 24 hours. Acute thirst became a perpetual source of torment but Shauna approached it with stoicism because it had the purpose of getting her ready for transplant surgery. She had to pace and measure her water intake carefully, alternating taking small sips of water with moistening her mouth with a sponge. She was also offered the less dignified option of sucking on a wet rag, but I don't think she ever did this.

Very little could be done to ease Shauna's suffering overall. She regularly had a "tap," the short and colloquial word for a paracentesis to help with the discomfort of her abdominal distention. This involved inserting a needle and catheter into her abdomen to drain off the excess accumulation of fluid. Taps helped reduce bloating and difficulty breathing by lessening the volume of fluid in her abdomen that put pressure on her lungs. They came with the risk of introducing infection, hitting major arteries or piercing her massive spleen. Her hepatologist was extremely deft at this procedure and could easily remove 2L of fluid into a bottle each time he did it, but the inexperienced residents were sometimes tasked with the procedure and were never quite sure of inserting the needle at the right spot. They would send Shauna for an ultrasound so that the radiologist could mark an X with a sharpie on a precise location for the puncture. While the residents approached the task worried and tentative about the pending ordeal, the hepatologist

could do it swiftly, fully engaged in jovial conversation with Shauna as though the procedure itself only required a fraction of his attention.

Infections were a major setback. In the hospital Shauna caught C-difficile, a bacterium that is commonly spread through hospitals. This meant a period of deactivation on the list for antibiotic treatment. Patients cannot undergo transplant surgery with an active infection because of the post-transplant immunosuppression that is required to prevent rejection. I was now routinely gowned and gloved when I was with Shauna, as was anyone who came into her room, even momentarily. The trash can overflowed with discarded billowy and weightless yellow paper gowns.

Then came what I thought of as “another infection” - Spontaneous Bacterial Peritonitis (SBP). The consequence of deactivation was what bothered me the most, along with Shauna’s suffering from abdominal pain and gastrointestinal symptoms. It didn’t register at the time that SBP is a serious complication of advanced liver failure. It means that bacteria are “leaking” from the intestines into the abdominal cavity and infecting the ascitic fluid. One of Shauna’s childhood friends became a doctor. Our mother and her mother were close friends. I remember my mother saying that “Becky said” Shauna’s condition was really serious (the low sodium and the SBP). I took this information with substantial denial, what did Becky know?

During this time, I temporarily moved from Montreal to Durham. I planned to stay until Shauna recovered from her transplant surgery. I was more or less with Shauna 24 hours a



Figure 3 Shauna in her hospital room (fall 2004)

day, trying to be useful and supportive. I kept Shauna's cramped and sunny hospital room as cheerful as possible. There were tight little flower arrangements lined up on the windowsill. I brought her duvet from her bed at home, which made the hospital bed seem a little more cozy and less institutional. She wore her own pretty nightgown, instead of a hospital gown, and a lamp, also brought from home, created a more calming and soothing

ambience. These were small adjustments and transformations to make the best of the circumstances. I tried to keep all surfaces orderly and tidy and made sure she always had a hairbrush, and lotion close at hand. She used an expensive hand lotion described as “an intoxicating scent of gardenias wrapped in white exotics,” which, at least temporarily, gave her hospital room the ambrosial scent of an upscale boutique, masking its usual smell of drugs and the pain that lingers beneath them, bodily odors mixed with chemical agents, a combination of disease and sanitation. I lived on the chair at her bedside as constant company for her. Shauna relied on me for a semblance of liveliness when visitors came. It was my job to make conversation.

There was a window of no infections and sodium stable at low-normal so Shauna was able to spend some time at home. By this point, her lethargy was extreme. She spent most of the time in bed. Her bedroom was luminous with four large windows covered with rice paper blinds. The walls were painted a soft blue, and her bed had crisp white linens. It was immaculate, spacious and airy, like a page in a catalogue, and exuded the care and consideration she put into her surroundings. I slept on the floor of her room on an air mattress that, for the sake of tidiness, I deflated and hid under her bed as soon as I got up each morning. I was available if Shauna needed anything during the night, but I don't think she often did. She was still taking sleeping pills.

Shauna and I spent the time talking, sometimes listening to radio shows on NPR to follow along, or at least feign interest, in the upcoming 2004 US presidential election. We also watched movies on her DVD player. Shauna had a television on a rolling cart that was put away in a hallway closet most of the time. It came out of the closet when it was in

use, otherwise Shauna thought it was cumbersome and unsightly. We only watched what Shauna called her “encore presentations” - the same movies over and over again, mostly romantic comedies with Hugh Grant. We also binge-watched Anne of Green Gables. As girls, we had been obsessed with Anne of Green Gables. On a family trip to the Canadian Maritimes in 1985, we were thrilled to visit Prince Edward Island, the setting for Anne of Green Gables, which the province plays up as a major tourist attraction. We saw the Anne of Green Gables musical in Charlottetown and visited the “house of Anne of Green Gables” in the countryside, which is to say the real house, belonging to cousins of author Lucy Maud Montgomery, that became the inspiration and fictional setting for the books.

I thought it would have been a challenge to find a place to rent something quintessentially Canadian like Anne of Green Gables in North Carolina. I opened the yellow pages with the intention of calling every video rental store in the Triangle (Raleigh-Durham-Chapel Hill) until I found it. The very first place I called, a five-minute drive away, told me that they had it. I was somewhat disbelieving so I had to double-check, “Is it the 1985 *CANADIAN* television movie?!?” Watching Anne of Green Gables together again reminded us that Anne, who was so earnest and melodramatic, had some of the best one-liners that buoyed our spirits and kept us giggling.

I think back on this time fondly but Shauna’s lack of interest in watching anything she hadn’t seen before surprised me and also kind of scared me. Worse was that she could no longer play the word game Boggle. We tried but it was too challenging for her and she gave up. Shauna had encephalopathy, impaired mental function, caused by her liver failure. Her inability to play a simple game like Boggle seemed far past an acceptable

threshold of deterioration. I couldn't have imagined that things could, and would, get way worse.

Waiting was difficult for me, only a minor fraction of how difficult it was for Shauna who was experiencing physical pain/inability to manage pain, loss of appetite, fatigue, mental impairment, gastrointestinal symptoms, and sleep disturbances. I could take daily walks around Duke University's east campus, which was a few short blocks from Shauna's house. This was a vague gesture at fitness and "self care," though in reality more an expression of the growing weight of boredom, tedium and frustration. I felt like a nervous and anxious horse circling a pen, running the fence line of a jumble of days that blended together with something like the taste of gum left in the mouth too long or coffee gone cold. On my walks, I listened to Shauna's discman. Always the same Lucinda Williams's CD. The repetition was indicative of the temporal dimensions of waiting, and the feeling that time was not progressing and advancing in any meaningful way. I think the encore presentations of Hugh Grant romantic comedies were also an expression of being "on hold" and the constraints of waiting. Time was stuck and we weren't getting anywhere. The movies were the same and the music wasn't changing. Every time that I drove Shauna's old Honda Civic with manual transmission, the same cassette played, The Best of the Velvet Underground. Like many old car cassette decks, it had "auto reverse" and switched automatically from side A to B. This tape would soon become the soundtrack for all the accumulated time in a dazed search for a spot in the visitor's parking structure across the street from the hospital (*It's so cold in Alaska, It's so cold in Alaska, It's so cold in Alaska*).

After a couple of weeks of waiting at home for “the call,” Shauna’s sodium level dropped lower than it had ever been. She was sleeping almost all the time, and in a feeble mental state any time she was awake. Shauna was readmitted to the hospital directly to the ICU. When Shauna was feeling well enough to get out of bed, I would put her in a wheelchair and take her, and the IV tree, for a walk around the hospital. She was often cold so I bundled her up in several layers of hospital blankets before heading down in the elevator to the atrium area in the lobby for sunlight and artificial greenery. We once ran into a resident who we had seen many times during her earlier hospitalizations. He stopped for a brief chat and it was like I witnessed through his perspective how much Shauna’s health had declined in a short time. Notably she was speaking very slowly, a change I was already adjusted to, but it was like I was hearing it for the first time. The resident wished us well and rushed off. I continued wheeling her around the hospital assuring myself that it wasn’t so bad, Shauna’s strong spirit was intact. But crossing paths with that resident made me realize that I was partially bluffing.

I had a similar feeling of faking a sense of normalcy when I ran into a hospital orderly who had once transported Shauna from her hospital room to radiology for an ultrasound (to get the sharpie X for the resident). Shauna had been in a friendly mood with him and they chatted all the way. When I saw him, he was pushing another patient in a hospital bed but in passing asked, “Hey how’s your sister?” I told him she was in the ICU. He repeated incredulously, “She’s in IC?” We continued on our respective paths, out of each other’s trajectory, but something about his puzzlement, and the expression on his face, came washing over me: *how is this happening?* There was disbelief and unreality to how events were unfolding.

Shauna's liver was failing her completely: it was hardened, scarred, inflamed and leaking. Her breathing was becoming more severely impacted by her water retention and she was incapable of filling her lungs to capacity. This conflicted not only with her comfort but also her practice of mindful meditation, which was a recommended strategy for dealing with the stress of waiting for a transplant. Her workaround, she told me, was to practice her meditative breathing while pretending she was a fish, with gills not lungs, and imagining that she was doing a kind of aquatic respiration that extracted oxygen from water.

I always stayed overnight with Shauna in the hospital. Her nights were difficult and sleepless. The night shift was when I was useful by simply being there, whether we could find a silly thing to laugh about or were snapping at each other without any daytime decorum. It was unfettered and sometimes very peaceful. I could also be a bleary-eyed presence for early morning rounds, and even semi-alert if I managed to trek down to the hospital coffee shop the moment it opened, joining a long line of customers that moved according to the relaxed pace of Southern service. When I had a coffee in my hand, it felt like my first mini accomplishment of the day, especially if the timing worked that I could consume the coffee before the doctors came.

One night Shauna and I decided to start her online journal. Over a year before, she had created a personal page on the CaringBridge website, a digital venue intended for individuals on "personal health journeys." Shauna's intention was to document and share her transplant story with family, friends, and her on-line support group for people with

Primary Sclerosing Cholangitis (PSC). The first journal entry is a transcription of her words that she dictated to me, an attempt to express what she was going through. Shauna could not type, or use a pen, even with the grippy foam cylinders provided by the OT. The loss of her handwriting was like she was robbed of an ability that was an intrinsic part of who she was. Her once beautiful handwriting had become hopelessly shaky.

The first journal entry is dated November 16, 2004, and time-stamped 3:20 AM. It's an account of Shauna's distress in her own words:

I would like to share with you a few things about the past few days, not sure how much I should reveal. But with that as my caveat as one of my surgical team doctors said this evening, "I am fighting for my life with my back up against the wall." I would also like to share this with you because I need your help in whatever form that might be. This past weekend in the ICU was very strange. I found myself quite unrecognizable and quite scared. Because my liver is so on the edge at the moment they have eliminated all pain killers and sleep aids that are metabolized through the liver or the kidneys and I find myself in more physical and mental anguish than I have ever known. I continue to hold all of my doctors in trust and realize just how much their hands are tied as well, as they acknowledge with all variety of bedside manner, good and bad, how they are asking incredible, perhaps too incredible, things from me. I trust them as they prepare for the still very much hoped for transplant surgery which will be a very complicated and more risky surgery than some liver transplants. By strange and unrecognizable I meant both literally and figuratively. The only thing coming through my IV aside from occasional vitamins and mineral supplements is saline solution and after fine tuning different doses

of diuretics I find myself with more ascites and edema swelling than I have ever known to the point where I have leaking sores all over my body. The only thing that offers a blessed drop of relief is to sit in steam and it is the only thing my doctors will agree to. So over the weekend I was lucky enough that the residents let me use their shower in ICU since there are no patient showers in ICU and this afternoon in another effort to make me more comfortable they took me out of ICU and moved me to the transplant wing where I would have access to a private patient shower. My appetite is very poor and about all that I have been able to eat is fresh watermelon unfortunately nearing the end of its peak season or already past. I would drink strawberry Boost if not for the fact that that counts as part of my half litre per 24 hour fluid restriction. If anyone has any suggestions of what I might eat at this time that would not add to my water weight I would greatly appreciate a note in the guestbook about these items also any tips on combatting dehydration in a way that also will not add water weight or would not need to exceed my fluid restriction, I would love to know of these as well. Sleep as such is not possible due to the pain and my goal instead of sleep is relaxation and rest. Again steam helps here as well. Whatever suggestions for non drug ways of dealing with pain would also be helpful at this time."

A few days later, I wrote: *"I have been attempting over the past few days to get a chance to write another journal entry with Shauna. We have sat down together with this intent but it has been too hard --- too many physical, environmental and perhaps emotional distractions. A large factor is Shauna's fatigue. Shauna misses her old self as much as we do. I think the first journal entry, which I have reread to her several times, reminds her that she hasn't lost the ability to express herself to the extent that she thinks she has."*

There was no time and energy for reflection, and the effort to make experience intelligible seemed impossible and overwhelming. I asked everyone to “*settle for my own observations,*” which encapsulates the inadequacy I felt, and still feel, trying to describe what happened.

Shauna and I spent much time perfecting the ritual of sitting in steam, which was the only thing that brought her comfort. We figured out how to make a serviceable steam room in the patient bathroom, made possible primarily because the hospital has an unlimited supply of hot water. I also discovered an abundant towel supply in a hallway closet. I could help myself to a huge stack of towels without anybody minding (I didn’t ask). Hospital towels are unfortunately quite thin so I used several layers to carpet the bathroom floor. They prevented the floor from becoming wet and slippery and blocked steam from escaping under the door. They also made the cold and sterile institutional bathroom feel surprisingly lush and cozy. Once the floor was prepped, I turned the hot water in the shower on full blast, spritzed rose water in the air, and shut the door.

While the bathroom filled up with thick steam, I got Shauna ready. I unhooked her IV, separating the line from the catheter, furtively and nervously, which annoyed Shauna because she thought I made it too big of a deal. I wore latex gloves and used plenty of disinfecting alcohol wipes on all the components but I was paranoid I would do something wrong and kill her. I was also certain we would get in trouble as it felt illicit like something a hospital “visitor” shouldn’t be doing. Free of her IV, I helped Shauna out of bed and into the bathroom/steam room. She would sit down in a motionless, drooped posture on a chair in the shower until most of the steam cleared away. I

contemplated her disproportional body and the outward signs of advanced liver failure. The upper part of her body, including her face, was becoming gaunt while her abdomen and bottom half was extremely swollen. The size of her lower legs compared to the size of her arms made her look like a badly executed oil painting, or somehow deliberately distorted. Staring at her form, enveloped by the steam, she looked like a blundered work of art more than a living human creature.

I continued to communicate to a growing audience through the online journal. I reiterated the issue of pain management and sleeplessness, referred to Shauna's "strange little hallucinations," caused by encephalopathy, and raged a little bit too about the doctor's concern for her nutrition. I wrote, "*Shauna's appetite is minimal, her mouth is completely dried out, parched, and often bleeding from weeks of thirst yet her doctors have the expectation/recommendation that she should eat like a horse to prepare herself for surgery.*" Shauna was so depleted and in a dire state of weakness and exhaustion that a feeding tube was ordered. Feeding tubes are threaded through the nose, down the throat and the esophagus and into the stomach. Shauna, struggling to hang on to last little shreds of comfort, thought it would be beyond unbearable to have the constant sensation of a tube in her nose and throat. She refused and the doctors relented but insisted she drink the prescribed 4 cans of Nutrihep a day.

Nutrihep is not even food. It's "tube feed." There was something dehumanizing about having to drink *feed* (to be fair, the Nutrihep website calls it "a medical food") Whether it's tube feed or "a medical food," Nutrihep is disgusting, a thick beige liquid. A friend found out that the manufacturer of Nutrihep provides "flavour packets" (banana-

strawberry or citrus sunrise) but the hospital didn't have any. The doctors were okay with my DIY plan to take the cans home and figure out a way to make Nutrihep more palatable with whatever I could find in the kitchen. I simmered it on the stove with several split vanilla beans and some expensive looking black tea that someone had recently given as a gift. The vanilla and the tea had strong enough flavours to mask some of the vileness of the Nutrihep. Shauna was able to drink this concoction chilled over ice. It helped that it looked like an iced coffee drink from Starbucks. I had the greenlight to make the same formula the following day, but Shauna crashed overnight and was rushed to the ICU to be rescued.

The reign of hope

I knew things were going badly but I was still in denial. The rhetoric of hope and fantasy of recovery mitigates the difficulty of dealing with the uncertainty and open-endedness of waiting, but it also suppresses the possibility of dying (or positions it as a “turn of events”). However more manageable waiting is when coupled to a tidy shored-up transplant ending, retrospectively I see it as profoundly stupid not to come to terms with the fact that this ending is in no way guaranteed especially when the circumstances shifted in a way that increased Shauna's likelihood of dying. Hope predominated, repressing the urge to contemplate death or negative outcomes with “positive thinking.” At the time, I wasn't concerned that it masked a failure to accept things as they really are. I was steeped in what Arthur Frank calls the “language of survival.” The imputed ending of a successful transplantation was the framework for waiting, tightly bound to a fantasy of recovery, ignoring that waiting could veer into a downward spiral ending in loss.

“Staying hopeful” is associated with fortitude and determination. There is also an inextricable bind between hope and waiting drilled into daily patient experience. Anthropologist Sharon Kaufman points out that waiting is an integral part of hospital life and it pervades patient and family experience. In the hospital, every soul is waiting for something - “for interventions, [a transplant], procedures, consultations, results, decisions, a change in condition.” Kaufman defines waiting as “anticipation mingled with hope and dread.” Waiting is always distinguished by hope, and both are perpetual in hospital experience.¹⁷

The treatment goal in the ICU was to keep Shauna stable until transplant surgery. The significant problem was finding a balance between preventing her blood pressure from dropping and managing her difficulty breathing and poor oxygenation due to pulmonary edema and fluid in her abdomen compressing her lungs. There wasn't really much to do, however, because any additional fluid to improve her blood pressure would escape out of her vascular system and collect in her abdomen, worsening her breathing. Shauna was put on a ventilator and to maximize its efficiency, the doctors induced chemical paralysis. I explained: “*The chemical paralysis means that Shauna is not really with us. She is not responsive at all, and the machines have basically taken over all her functions. She cannot be moved, which means she has been in the same position now for quite some time, and that her gown and linens aren't able to be changed and so have become damp from her edema and ascites.*”

¹⁷ Kaufman, *And a Time to Die*, 148.

There were other problems with blood gases, an unbalanced Ph, and blood in her ascitic fluid, indicative of an internal bleed. Then her kidneys went south too. I wrote vaguely that “*There is concern right now that her kidneys have been compromised by this ordeal.*” The “compromised” kidneys was a condition called hepatorenal syndrome. From the way I wrote this, it’s clear that I failed to register how serious it was. Hope and Morrison describe hepatorenal syndrome as an “ominous sign” that “usually portends death in days to weeks,” especially if renal failure is rapidly progressing.¹⁸ Shauna’s kidneys had failed her to the point that she was put on dialysis, which I explained as a “gentle” continuous dialysis not “*full-fledged hemo-dialysis*” because her blood pressure was so low. The dialysis machine was now a permanent fixture by her bed, tethered to Shauna by a thin blood-filled tube, a conspicuous stream of colour in a room with predominantly neutral tones: white, beige, grayish blue. She had to take anticoagulants in order for the dialysis machine to run properly and the doctors acknowledged that this was a risky move, potentially making transplant surgery even more dangerous. The other horrid possibility, we were informed, was neurological damage, which couldn’t be evaluated while Shauna was in a state of chemical paralysis and heavily sedated all the time.

I admit I had generalized about liver transplantation from stories of individual good luck and happy endings, the cases where prognosis is good. I had all the optimism in the world that this would apply to Shauna. Even at this point, the negative outcomes weren’t worth

¹⁸ Hope and Morrison, “Integrating Palliative Care.”

considering. There was no external impetus to question my optimism either. The imperative to be positive and hopeful runs deep in transplantation. Health researchers Sanders et al. argue that hope is more than just “positive thinking” it is also a kind of “moral pressure” because positivity in the face of illness is a “normative moral requirement.”¹⁹

Optimism was a mainstay of our communication with the wider social network through the online journal. The maintenance of hope often referenced God and prayers. The medical context that promotes being strong, brave and having courage wove together seamlessly with a religious narrative that God was somehow watching over Shauna with wisdom and love. In the guestbook comments on the CaringBridge website it was common to see well wishes phrased as “hope and prayers.” We were comforted by thinking that the volume of people hoping and praying could make a difference, as though the more people praying for you, the more likely it is that there would be “good news.” At the time, it almost seemed logical. Reading back through the abundant guestbook comments on the online journal, it’s like we were all participants in a sham that a transplant would inevitably happen.

The bulk of CaringBridge guestbook comments and the overall mood at the time was about expressing an unshakeable belief in Shauna’s secure future. Most people’s response to Shauna’s situation was to voice certainty and confidence - *I know* you will do well, I don’t have any doubt, as though we could keep her going with this positive “attitude,”

¹⁹ Caroline Sanders et al., “Planning for end-of-life care with lay-led chronic illness self-management training: The significance of ‘death awareness’ and biographical context in participants’ accounts,” *Social Science and Medicine* 66, no. 4 (2008), 990.

that we actually exert control over her fate and alter the outcome through a group investment in the happy ending and reiterations of Shauna's strength and determination. Lumby, in her research on patient experience of waiting, found that this degree of hope was the "majority attitude." One participant in her study said, "I knew that I was going to recover, I was going to be the quickest to recover . . . I had no intention of dying." Patients recall staying consistently positive; and Lumby writes the "possibility of negative outcomes was rarely mentioned."²⁰

No doctor ever discouraged optimism either. This would have contradicted the central place that hope has in the cultural/moral system of dealing with human adversity. Having a hopeful optimistic outlook, as I did, seemed like an asset in the situation. In a journal entry, my father wrote: "One of the Doctors has counseled us to park our fears and anxieties at Shauna's door and carry hope into her room." According to Larson and Curtis, "the therapeutic value of hope is well-established." There are several studies that determine that "hope helps patients emotionally endure crisis, and hopeful patients are better able to follow treatment recommendations and tolerate discomfort." Larson and Curtis write, "the challenge for physicians is to balance supporting hope while finding ways to provide patients with comprehensible and accurate prognostic information."²¹ It is not clear that such a "balance" is easy to be found, especially when the "comprehensible and accurate prognostic information" is not what patients or families want to hear.

²⁰ Lumby, "Liver transplantation."

²¹ Larson and Curtis, "Integrating Palliative Care."

No one was dishonest about a transplant being Shauna's only way out, but I can't help but think that the transplant team must have known that Shauna's situation was worse than we thought it was. Doctors tend to be very careful about what they say and measured in the way that they respond to questions, often being vague because definitive answers could be misleading. They communicated what their "concerns" were but overall strived to be calming, reassuring, and stressing caution, which was easy enough to "reframe" to "allow hope back in."²²

Two days before Shauna died, in the CaringBridge journal I was still stressing the "many reasons to be hopeful." I wrote: "*Even through our frustration and desperation we are holding on to hope and praying for Shauna. There are still many reasons to hope, not least among them that continuous monitoring has not discovered any infection. And thanks to Shauna's strength as a fighter, the surgeons still have margins to work with in her life support system and haven't maxed out.*" The reasons for hope were thinning- no fatal infection, margins in her life support system, and Shauna's strength/character. This journal entry represents a chain of soft-pedalled communication and wishful thinking- from the doctors, to the family and friends on the scene, to those we communicated to on the internet. The "reasons to hope" now seem like a subtle form of censorship. Hope can strangle out lucidity even while we insisted that it was reasonable to be optimistic. I wanted to think that I had balance and clarity, like Shauna who always showed so much

²² The idea that communication with doctors reframing to allow hope back in comes from David Rieff's memoir of his mother's death: *Swimming in a Sea of Death* (New York: Simon and Schuster, 2008).

composure, equanimity and moderation. But my perspective was so one-sided. In retrospect it seems fanatical.

As the end neared, I seemed to get more and more superlative about hope. Another journal entry says, *“Shauna's Dr. S came by late this afternoon. He assured us that no matter what the risks are they will proceed with the transplant when a liver is available. This is Shauna's only hope. But it is a tremendous hope, worth praying for endlessly and fervently. . . . We can only hope that . . . Shauna is comfortable and getting ready to tap into even more reserves of strength and endurance she didn't even know she had.”*

Shauna had become a high-risk patient for a transplant, perhaps not likely to survive surgery or recover, but this didn't seem to matter anymore. The effort to save her life was full steam ahead without much regard for the possible futility of it all. The irrational part of it indicated high emotional investment and heroicized the transplant team in my mind. I regarded them as extraordinarily compassionate and caring. Trying to save Shauna's life from the precipice of death at all costs was the crescendoing of emotion and irrationality that waiting for a transplant had become. I embraced the willingness to be irrational as a form of love, determination and betting against the odds. We say things like “I would cut off my arm for you” or “walk on burning coals” to convey passion and urgency. As I saw it, the more irrationality the better.

The emotional intensity was blindfolding. It amplified the ending we desired (a transplant) and almost completely nullified the other (dying). I also clung to a blinkered vision of post-transplant reality that made it seem like a state in which all problems go away. I don't think I registered the post-transplant reality/recovery with any depth.

Though after a meeting with the transplant team, I acknowledged that it wouldn't be easy when it was presented to me bluntly. I wrote in the journal:

“Dr. C. gave us reason to remain optimistic and hopeful even though we know that Shauna's battle for recovery will be extremely arduous and difficult. We all feel daunted and afraid about the post-transplant reality, particularly the knowledge that Shauna's suffering and struggling will be intensified and extended indefinitely into the future. Post-transplant, we can expect Shauna to remain on dialysis for some time, though they are hopeful her kidneys will bounce back once a well functioning liver is in place. If another system were to fail (heart, brain, lungs) this would disqualify her for transplant. Her lungs are certainly under a great deal of stress right now. A ventilator works by pushing air into the lungs, which is opposed to the way the lungs normally work, which is through muscle contraction creating a vacuum to draw in air. Ventilation certainly has detrimental effects on the lungs, and this in addition to the fluid pressure and accumulation is significantly stressing Shauna's lungs. Still, Dr. C. wasn't yet worried about lung damage from the ventilator. Paralysis is helping her to conserve energy and reduces the amount of damage the ventilator does to her lungs. The other development that would disqualify Shauna for transplant is a new infection. Dr. C. said that infection is his biggest fear at this time.”

The risk of another SBP infection was high and required constant monitoring. There seemed to be a clear message from the doctors that barring infection, a successful transplant was possible though I don't recall asking for a “successful transplant” to be defined, or what the chances for that really were. I did reveal in the journal, “A recovery

to something like a normal life is more likely the sooner a healthy organ appears, but her transplant surgery and recovery process will certainly be difficult the longer she spends on life support.” I am alarmed at the vagueness of “*something like a normal life*” and I wonder what it meant to me at the time. I still think I thought everything was reversible, all the damage would be undone, and things would go back to how they were or even better than before.

Czech playwright Vaclav Havel writes, “Hope is not prognostication.” But this is definitely how I saw it. Hope represented a narrow unambiguous positive outcome (a “new liver”), something to thoughtlessly cling to. Havel instead argues that “hope is an orientation of the spirit, an orientation of the heart; it transcends the world that is immediately experienced and is anchored somewhere beyond its horizons.”²³ Hope isn’t tightly bound to a specific ending and doesn’t just apply to a future where good things happen. I think I have some appreciation for what this means now. But at the time, not at all.

The dying days

Shauna had faith in God. We did not talk much about God and religion (I am not a religious person myself) but I know she took comfort in the idea that God had a “plan” for her even though she didn’t know what that was. Shauna participated in an on-line support group for people with Primary Sclerosing Cholangitis. It was only after we

²³ Vaclav Havel, “An Orientation of the Heart” in *The Impossible Will Take a Little While: Perseverance and Hope in Troubled Times*, ed. Paul Rogat Loeb (New York: Basic Books, 2014), #.

initiated the CaringBridge journal that I really became aware of how involved Shauna was in this community and the meaningful relationships she had formed, particularly with individuals with whom she explored the topic of religion. Her health had made her more religious in her thinking than I had realized. One support group friend posted a message reminding Shauna of a passage she had shared with her from the late Christian minister Oswald Chambers on the topic of “gracious uncertainty.” He wrote: “Our natural inclination is to be so precise - trying always to forecast accurately what will happen next - that we look upon uncertainty as a bad thing. We think that we must reach some predetermined goal, but that is not the nature of the spiritual life. The nature of the spiritual life is that we are certain in our uncertainty. Consequently, we do not put down roots. Our common sense says ‘Well, what if I were in that circumstance?’ We cannot presume to see ourselves in any circumstance in which we have never been.” For Shauna, this was a reminder to not imagine herself in future scenarios but instead live with the reality that the future is unknown. You can fortify yourself not with the knowledge of a secure future but with trust in God.

If Shauna had that kind of equanimity in her faith, it wasn’t mirrored in what I was going through. By the time the American presidential election was over, and John Kerry had lost, and that American Thanksgiving came and went, I was spending the entire day and all night at the hospital in a bubble. It was like my whole life had retracted into the hospital and the “real world” was an obsolete and unfamiliar place. It was even difficult to relate to other families in the ICU waiting room. I once accepted an invitation to join them in an impromptu prayer circle, out of politeness I think, or a when-in-Rome

attitude. I was raised Catholic, a decorous and solemn religious tradition, a far cry from this prayer circle, which was raw, almost primal, with lots of tears, trembling and pleading to Jesus. We were all in the same boat though, waiting for our names to be called on the intercom that connected the waiting room with the nurses' stations, letting us know that we were allowed in to see our loved ones. We wanted the best for each other, I think, but only in a superficial way. Maybe we were too submerged in our personal disasters, frantic about who would get out of this place alive and desperate over what good news or bad news was coming our way. Maybe it made us all very distracted, almost to the point of oblivion.

I didn't want to be around other people. I had no energy to search for commonalities with others who were not connected to my private drama. There was a conference room adjacent to the waiting room, a small windowless room with a big table surrounded by about a dozen chairs. It was used during the daytime for meetings but we (anyone affiliated with Shauna's group) took it over in the evenings and on weekends. The conference room was where I stayed overnight. It felt like my privileged quarters, a tiny corner in a massive institution where I had privacy and solitude. I slept on the floor in pitch blackness. I am not sure I really slept. It was something between sleep and merely lying motionless out of fear and numbness. Shauna's ICU nurses knew I squatted in the conference room overnight (technically, as a visitor, I am sure I was out of bounds). The doctors and residents knew I was there too because a team would arrive around 6 AM and flip on the fluorescent lights. Jarred awake, I would gather my things and leave them to their business. I am sure it was awkward to encounter me there but I felt so far out of the realm of social normalcy that it didn't faze me at all. Only once did the nurse come and

get me in the night because Shauna's heart rate lowered significantly and her blood pressure skyrocketed then quickly went into freefall. Eventually her heart rhythms restabilized.

We used this conference room and not the waiting room as our hospital base camp whenever we could. Demarcating our own territory felt like a considerable exploit, like we had discovered a secret place to claim and to populate only with family and friends. People came. Most of the time we did nothing. A friend taught a new (to me) version of solitaire, passed down from his grandmother, that I played frequently at that conference room table as well as in the years following Shauna's death. Even now I play solitaire to feel connected to that time. It's a small, trivial and oddly comforting source of continuity. But it also reminds me that there was no plan, just a run of cards.

Late one night when I was by myself in the conference room, I read the tragic obituary of Iris Chang in a copy of *The Economist* that a visiting friend had left behind. Chang was the author of a book called *The Rape of Nanking* about the mass killings and brutal torture and raping of tens of thousands of Chinese girls and women, perpetrated by the Japanese in WWII. Chang committed suicide while she was researching another book on torture. She shot herself in the head. Normally I read nothing yet something drew me to read, out of all the possibilities, a piece that was harrowing, bleak and hopeless. It must have been the depletion I felt after all the strenuous exertion to drum up optimism each day. A pendulum swing.

I had lost all contact with Shauna since she had been in the ICU. There were only two occasions that she was conscious and alert and was able to produce two shaky notes and hand them to the nurse. One asked, “new liver?” and the other note, attesting to our close bond, said “Sister can I see her?” (this is actually the very last thing Shauna ever wrote/said). Ventilation and sedation were required components of her care but this also meant not knowing whether she was really okay. She appeared to be comfortable but she was also alone most of the time. This ICU was a locked ward and there were only certain times that we were allowed to see her. Each patient had their own nurse so she was constantly monitored but we were no longer involved in her care and had no meaningful way to intervene or make anything better for her. I wrote, *“They were not letting us back to visit her very much today, as she is getting more delicate and is in need of vast amounts of medical attention. Doctors and nurses can do so much more for her than we can at this point. We are all still very hopeful that a liver is on the immediate horizon. And we are still very confident that Shauna will make it through.”*

When family and friends were allowed in to see her, we would stand around her bed. Sitting was too awkward because at chair level you couldn’t even see over the side of it. Standing was the only way to stare at her face and hold her small bony hand. The bed seemed very large, not like a bed at all but a commanding piece of equipment that absorbed Shauna into a non-human apparatus. Her body was unified with the bed itself and adjoined to other intensive care paraphernalia through a central line in her neck, and the ventilation tube down her throat. We were grateful that Shauna was getting what my father called the *“best possible maintenance care.”* That phrase itself drives home that

she was more like an object at this point, a piece of machinery. The sounds in the room were also inhuman - a hushed buzz, rhythmic beeps, and the clicking of the dialysis machine.

At her bedside, I typically tried to make Shauna aware of my presence by talking to her. Admittedly, it was hard to find supportive, loving and uplifting things to say without veering towards nervous babble, or sounding like a broken record, going over and over again through the utterances of I-love-yous and stay-strongs, we are here, we are going to do this, you are amazing, the best, totally awesome you. I wish I could say that I walked in there, held her hand, felt connected and offered reassurance; but I fear my words sounded more like pleas tinged with uncertainty. I don't think I realized just how strained, difficult and terribly sad this was until once when our friend Katy and I were about to leave. Coming to the end of the litany of goodbyes and well-wishes, Katy threw in, "Okay Shauna, keep it real," an expression that was common in the aughts, a kind of urban slang, associated with hip hop culture, that meant sticking to your roots and representing yourself in an authentic manner. Saying this to Shauna, under these circumstances, was so out of place and patently wrong that I burst out in laughter. The laughter broke through the illusion that we were anything other than completely helpless and lost in this effort to stave off death and save Shauna's life. It was as far from authentic and "real" as you could get.

Speaking to Shauna was meant to bring her comfort because allegedly she could still hear. I also wonder if whatever awareness she had was more a source of emotional or

psychological distress than of solace. I used to think mechanical ventilation was a benign experience. Before patients are ventilated, they are sedated so that they are totally unaware and their airways are numbed so that intubation is painless. Then I had a nightmare about intubation and ever since it's been on my mind that ventilation has the potential to be traumatic, something that never occurred to me at the time even though we were told on many occasions that Shauna struggled against the ventilator, which was the rationale for chemically paralyzing her. The fact that she was breathing out of synch with the ventilator and experiencing respiratory distress might mean that Shauna was really suffering, possibly feeling alone, scared, or like she was suffocating. We constantly described her as being "courageous" and "determined" but there is no truth in claiming that these were her actual feelings, it was more of our wishful thinking that we imposed on her. I once revealed the nurse told me, "*Shauna becomes agitated with any kind of stimulation.*" She couldn't be moved at all, which suggests that she was not in the state of peace and comfort we hoped she was but rather in a state of confusion, disorientation and possibly fear. I minimized this because I thought that a transplant was just around the corner.

Only recently did I consider more critically what the experience of chemical paralysis might have been like for Shauna. The use of Neuromuscular Blocking Agents have the possible side effect of unpleasant awareness so it's recommended that they are used with sedatives and analgesics.²⁴ This raises doubts I have about whether she felt comfortable

²⁴ Nancy Ballard et al., "Patients' recollections of therapeutic paralysis in the intensive care unit," *American Journal of Critical Care* 15, no. 1 (2015): 86-94.

or tortured. My gut, and some recurring bad dreams I have, tells me that she did go through some horrible experiences. I have a chronic worry that perhaps, under the circumstances, Shauna would have preferred to die. There was one night in the ICU, standing by Shauna's bed, that I was overcome with a strong sensation that Shauna was trying to tell me something. I imagined that we had special powers that would allow her to say something to me through invisible channels of communication. Trying to summon this message, I "heard" her saying that she wanted to die. But, of course, I talked myself out of this. Of course she doesn't want to die. The suffering was worth it because she was going to be saved.

After an earlier stay in the ICU Shauna wrote to friends, "*I must admit that I am also very scared. I think that this past weekend I may have also experienced some of the infamous ICU psychosis or perhaps that is the same as being scared and desperate.*" ICU psychosis is medically defined as severe anxiety, paranoia, disorientation and delirium. Margaret Lock explains that ICU psychosis may be the result of patients being overstimulated. She writes, "patients suffer a complete loss of control; their bodies are penetrated in almost every available orifice and pierced in numerous places. They are subjected to a ceaseless overload of noxious stimulants, among which light and sound appear to be the most troubling."²⁵ At the time, I wasn't consciously considering what Shauna's experiences were really like. There was no visible evidence of Shauna's

²⁵ Margaret Lock, *Twice Dead: Organ Transplantation and the Reinvention of Death* (Berkeley: University of California Press, 2001), 63.

sentient self. I saw her in a nonconcrete way, like an ethereal being with a tenacious grip on the fine thread of life. It fooled me into believing she could transcend her suffering.

In an article in *The Atlantic*, writer Jennie Dear quotes palliative care physician James Hallenbeck who describes death like a blackhole. As death nears, our senses fade away but it's very hard to know the level of awareness or sensory experiences a dying person has, especially when they are sedated or comatose. Dear writes, "Being at the bedside of an unresponsive dying person can feel like trying to find out whether someone is home by looking through thick-curtained windows."²⁶ In Shauna's case it wasn't just these thick curtains but also our fixation on a liver transplant that left her in a void. It was okay if my connection to Shauna was extinguished, as long as transplant was still possible. The lack of attention I paid to her seems more callous given that these were in fact precious dying moments. My dad wrote in the journal: "*We have been given another day. Shauna remains at death's door but is clinging to life on life support. The medical team feels that Shauna's life can be supported for a few more days and that a successful transplant is still possible.*" This message sums up how Shauna's few remaining days were measured in terms of the viability of a future transplant. This is what it means to "die waiting."

²⁶ Jennie Dear, "What It Feels Like To Die," *The Atlantic* (September 9, 2016).

4 The Role of MELD

The problem of allocation

Factors like luck, timing, serendipity, and other vagaries of being in the right place and the right time that we have no control over meant that neither Shauna's death nor a transplant was a foreordained ending. The promise of survival in feel-good narratives of transplantation dominated the waiting experience and (mindlessly) oriented us to the happy ending. The configuration of the waitlist tells a different story. Allocation policy played a significant role in Shauna's misfortune. It is the structuring context for waitlist death and paints a grimmer reality that is incongruous with the hope and belief that everything would work out okay.

Thomas Starzl (1992) explains that "Kidney transplantation burst onto the scene so unexpectedly in the early 1960s that little forethought had been given to its impact on society. Nor had its relation to existing legal, philosophic or religious systems been considered."¹ One of the issues that stemmed from this lack of "forethought" was determining who would have priority access to transplantation, given the scarcity of available organs, and what mechanisms could ensure that access was fair and equitable. Furthermore, whose responsibility is it to make these decisions? And what kind of oversight would there be?

¹ Thomas Starzl, *The Puzzle People: Memoirs of a Transplant Surgeon*. (Pittsburgh: University of Pittsburgh Press, 1992), 175.

In the early 1960s, the dialysis and kidney transplantation program at the University of Washington formed a novel screening committee to select which patients would become transplant recipients. This Seattle Screening Committee gained the public spotlight when the *Life* issue of November 9, 1962, published an article titled “They Decide Who Lives and Who Dies.” The article explains that the committee was composed of seven “ordinary people with no moral or ethical guidelines save their own consciences.” They met regularly to vet candidates for the kidney program. The sensational headline insinuates that the committee was in the business of “playing God.” One committee member saw their role more specifically as addressing the “central problem . . . that medicine has moved forward so rapidly it has advanced beyond the community’s support.” He explained the committee was trying to “bridge [the] gap” between “medicine” and “community support.” They did so by comparing candidates according to middle-class values and social worth and excluding those deemed socially inferior.² Physicians first “weed out the medically or psychologically unsuitable candidates” and put together a group of candidates considered to be equal in terms of medical need. The committee’s job was to determine who was the most deserving among them. The rationing criteria the committee came up with were age, sex, marital status, number of dependents, income, net worth, emotional stability, education, occupation, and future potential.³

² George Annas, “The Prostitute, The Playboy and the Poet: rationing schemes for organ transplantation,” *American Journal of Public Health* 75, no. 2 (1985).

³ Shana Alexander, “They Decide Who Lives, Who Dies,” *Life* (November 9, 1962): 102-125.

In the *Life* interview, the members on the committee reflect on the hardship of their role. Not having much information about each candidate's individual situation made the decisions hard. Based on the rationing criteria, quality of life was difficult to measure, and much was left to speculation about who would benefit the most from kidney transplantation. On top of it there were layers of philosophical questioning about the value and meaning of life. One committee member is quoted as saying "death itself is not the worst thing that can happen to a man, and just to live is not the greatest blessing."

The Seattle example is an anomaly (and it disbanded by the end of the 1960s) because in most transplant programs, allocation decisions were locally managed with no formal guidelines. Starzl explains, "procedures and policies were largely left to the conscience and common sense of transplant physicians and surgeons involved,"⁴ which is how transplant centers operated up until the early 1980s. In 1984, the US Congress passed the National Organ Transplantation Act (NOTA) which established the Organ Procurement and Transplantation Network (OPTN). The goal was to centralize the administration of a single national system. The OPTN created a task force to determine how to distribute organs efficiently and effectively, banning discrimination based on race, sex and class. It discouraged giving weight to social criteria like age and lifestyle, and also prohibited the buying and selling of organs.⁵

⁴ Starzl, *The Puzzle People*, 175.

⁵ Richard Rettig, "The politics of organ transplantation: a parable of our time," *Journal of Health, Policy, Politics and Law* 14, no. 1; see also the Summary of NOTA <https://www.congress.gov/bill/98th-congress/senate-bill/2048?r=5>

In the mid-1980s, the “organization of the procurement system” emerged as a central concern given that the growth of the organ transplantation industry was creating an increasing gap between “supply” and “demand.” The final report from the Task Force on Organ Transplantation (1986) also stipulated routine request practices. This meant that 1. health professionals had the responsibility to identify prospective donors, 2. acute care units require affiliation with organ procurement agencies and 3. hospitals need to develop formal request policies.⁶

In 1986, the United Network of Organ Sharing (UNOS), a non-profit private organization, was given the contract to establish a national organ distribution network and oversee allocation. For the allocation of organs for liver transplantation, priority was based on the level and location of care required the patient. Hospitalized patients in the intensive care unit had the highest priority, followed by hospitalized patients on the regular floor, and further down the list were those receiving outpatient care. In 1996, the liver transplant community questioned the fairness and efficacy of this system of liver allocation and wanted a more rigorous way of determining the medical status of waitlisted patients. There was concern about the potentially arbitrary nature of ranking patients by the location of care. Specifically, it could be manipulated by physicians to give some patients more priority over others by hospitalizing patients, or keeping them in ICU, in order to be transplanted first.⁷

⁶ Rettig, “The politics of organ transplantation,” 205-209.

⁷ Richard B. Freeman, “MELD: the holy grail of organ allocation?.” *Journal of Hepatology* 42, no. 1 (January 2005):16-20.; Eunice Lee, Chris J.C. Johnston, Gabriel C. Oniscu, “The trials and tribulations of liver allocation,” *Transplant International* 33, no. 11 (July 2020): 1343-1352; Russell Wiesner et al.,

In 1996, a consensus conference mandated the use of the Child–Pugh–Turcotte (CTP) score along with the location of care for liver allocation. The CTP score is based on 3 objective parameters (serum albumin, serum bilirubin, and prothrombin time) and 2 subjective criteria (the severity of ascites and encephalopathy).⁸ It was up to individual physicians to assess the severity of ascites (the accumulation of fluid in the abdomen) and encephalopathy (mental confusion). Some in the liver transplant community were concerned about this because “it is very difficult to standardize measurements of ascites and encephalopathy across observer groups” and questioned the use of subjective criteria, which were only “indirect measures” of disease severity.⁹

Seeking more rigorous standardization in the method of allocation, in the late 1990s, there was a new regulatory mandate to determine the status of individual patients on a national transplant list according to uniform countrywide criteria, not according to their evaluation by physicians in individual transplant centers.¹⁰ The goal was to give priority to patients with the highest medical urgency, based only on objective medical criteria. The Final Rule of 1998 (Thursday April 2, Federal Regulations, volume 63, no. 3) states that the development of national allocation policies should follow the principles of

“Model for end-stage liver disease (MELD) and allocation of donor livers,” *Gastroenterology* 124, no. 1 (January 2003): 91-96.

⁸ Evangelos Cholongitas and Andrew K. Burroughs, “The evolution in the prioritization for liver transplantation,” *Annals of Gastroenterology* 25, no. 1 (2012): 6-13.

⁹ Freeman, “MELD: the holy grail,” 17.

¹⁰ Nicholas Tilney, *Transplant: From Myth to Reality* (New Haven: Yale University Press, 2002), 262.

uniformity and standardization. The problem, as stated in the Final Rule, was, “The criteria used in listing those who need transplantation vary from one transplantation center to another, also the criteria used to determine the medical status of a patient. This lack of uniform medically objective criteria make it difficult to compare the medical needs of patients in different centers.”¹¹ The national system of allocation was meant to correct variation in wait times and create the opportunity for more organ sharing between regions. Ultimately, the goal was to create a system that responds to the fact that the “demand” for organs exceeds the “supply” by ensuring that available organs are distributed to those who need them the most.

Mortality risk as an ordering tool

In 1999, the OPTN formed the Liver Disease Severity Score Committee, tasked with developing a model to assess disease severity using only “biochemical derangements from liver failure.”¹² Rather than reinvent the wheel, they looked to the Model for End-stage Liver Disease (MELD) that was originally developed at the Mayo Clinic as a predictor of 3-month mortality risk after transjugular intrahepatic portosystemic shunt for variceal bleeding or refractory ascites. MELD is an algorithm that calculates a patient’s INR (international normalization ratio for prothrombin time, or how long it takes your blood to clot), serum creatinine (a measurement kidney function) and serum bilirubin (a measurement of liver function), and results in a score between 0-40. Researchers tested

¹¹ For the text of the Final Rule, go here: <https://www.govinfo.gov/content/pkg/FR-1998-04-02/pdf/98-8191.pdf>

¹² Freeman, “MELD: the holy grail.”

MELD using 5 data sets and validated that MELD is effective at predicting waiting list mortality for transplant candidates with chronic liver disease, and that it is generalizable to a heterogeneous group of patients (those who were hospitalized or ambulatory and had cholestatic or non-cholestatic liver disease).¹³ The MELD score was adopted on February 28, 2002 as the liver allocation tool for chronic liver disease candidates (MELD was adopted in Canada in 2004). This was perceived as a data-driven policy change that ensured livers were distributed to the “sickest first.” The consensus in the liver transplant community is that MELD scores indicate which patients have a more medically urgent need for transplantation using “readily available, reproducible and objective data.”¹⁴

Since 2002, the MELD system sorts patients into the order of priority and largely determines who does or doesn’t get transplanted. The significant change of MELD is that it eliminates time-based criteria for waitlist priority and uses only metrics to determine the patient’s likelihood of dying within the next three months. The time spent waiting for a transplant is no longer a relevant criterion in determining priority for a transplant. You move up the list as your MELD score worsens. Candidates’ lab results are reported on a set schedule and the list is configured accordingly (patients with MELD above 25 report every 7 days, patients with MELD between 19-24 report monthly, and those with MELD between 11-18 report every 3 months). Candidates can move both up or down based on

¹³ Wiesner et al., “Model for end stage liver-disease.” See also Kamath et al. “A model to predict survival in patients with end-stage liver disease,” *Hepatology* 33, no. 2 (December 2003): 464-470. For the Canadian context, see Burak et al., “Validation of the Model of End-Stage Liver Disease for Liver Transplantation Allocation in Alberta: Implications for Future Directions in Canada,” *Canadian Journal of Gastroenterology and Hepatology* (2016).

¹⁴ Wiesner et al., “Model for end stage liver disease.”

the variations of their own scores and the scores of other candidates, and on how many candidates were transplanted, delisted or died. The “top of the list” is no longer fixed; and there is no “waiting” to get there.

During the time that Shauna was waiting, her MELD score fluctuated. It decreased from 23 (when she was called as a backup candidate) to only 16, too low for transplant to be a realistic possibility. Effectively at this point she wasn’t waiting for a transplant but waiting to get sicker. For this reason, her low MELD score wasn’t reassuring. It just created anxiety about what “getting sicker” would mean. We knew that time accumulated on the list would have no bearing on her chances.

In the old system of Child-Turcotte-Pugh and location of care, wait time was used as an ordering tool for candidates with similar medical status, and often served as the “tie breaker.” In fact, because of the volume of patients on the list, wait times ended up becoming the major determinant of priority.¹⁵ The longer you were on the list meant you were higher up. The “first come, first serve logic” was flawed, however, because “patients enter the system at various stages in the severity of their liver disease” and because “different diagnoses progress at different rates.”¹⁶ For example, in 1994 the average wait time until transplantation was 225 days. This ballooned to 1811 days in 1999, a reflection of the fact that patients were being added much earlier to the waitlist, giving a significant advantage to patients who had higher access to medical care. In this context, waiting time was an insufficient and inferior criterion for defining “need.” It’s

¹⁵ Freeman, “MELD: the holy grail,” 17.

¹⁶ Ibid.

more equitable to rank patients by “disease severity,” especially as determined by an evidence-based analysis to define disease severity systematically and allocate livers according to greatest need. In this regard, MELD is widely considered to be an improvement.¹⁷

In the MELD system, need is defined entirely in terms of *mortality risk*. Not only is mortality risk deemed the most appropriate measure of need, it also frames need as something objectively measurable. The MELD score makes mortality risk a “specific and quantifiable determination of need”¹⁸ and a rankable prognostic score. Mortality is the proxy for disease severity because it is an easily measured outcome and facilitates systematic objective decision-making in line with transplant medicines’s aim to save lives. The logic of MELD is simple - livers should go to the patients who are most likely to die.

Allotting livers according to mortality risk is conceptually compatible with modern medicine’s (and society’s) orientation towards death. As sociologist Zygmunt Bauman argues, “we are offended by death.” According to Bauman, the development of a “death defiant culture is feature of modernity, evident in the way that modern medicine “battle diseases.”¹⁹ Drawing from Bauman, Margaret Lock argues that “In effect, to medicine all

¹⁷ Ibid.

¹⁸ Ibid.

¹⁹ Bauman in Margaret Lock, *Twice Dead: Organ Transplants and the Reinvention of Death* (Berkeley: University of California Press, 2001), 200-201.

deaths have become ‘bad’ and untimely.”²⁰ This mentality (death is bad) means that mortality risk as the basis for liver allocation is sound and logical because we take it for granted that any instance of evading death is a good thing. As Lock writes, “we moderns have become, thanks to medicine, preoccupied with life,”²¹ a preoccupation that dominates the field of transplantation as a whole.

To reiterate the statement of a member of the Seattle Committee from the Life Magazine article, “death itself is not the worst thing that can happen to a man, and just to live is not the greatest blessing.” Using mortality risk as the only allocation criteria assumes that death is the worst thing that can happen. MELD does not predict the outcome of liver transplantation or the likelihood that a transplant will be successful. It doesn’t engage with the intricacies of which candidate should have more priority because it circumvents social criteria and avoids the complicated question of utility. By contrast, the Seattle Committee in the 1960s was engaging in the matter of *utility* and the benefit to the recipient as well as society. In this regard, MELD is far simpler. An orientation to utility, on the other hand, could become rapidly embroiled in issues of social determinants of health as “unfavourable demographic characteristics” are associated with poor transplant outcomes.²² The danger of allocating according to utility is the likelihood that it would give rise to discrimination. The “best” candidates for transplantation could favour those

²⁰ Lock, *Twice Dead*, 203.

²¹ Ibid.

²² Freeman, “MELD: the holy grail.”

who have a higher quality of life to begin with, which is often related to socio-structural factors that are beyond individual patients' control.²³

A shortcoming of MELD may be that a “balance between medical urgency and transplant benefit is still to be defined.”²⁴ Given the scarcity of organs, allocation policy could evaluate not just who is the “sickest” but who would receive the “most benefit.” In such a system, “less ill candidates might have more priority” if expected transplant outcomes are also taken into consideration.²⁵ Some countries have gone in this direction. For example, both Switzerland and the United Kingdom (but not the US and Canada), have moved beyond exclusive consideration of the risk of death on the waiting list. Since 2018, the UK calculates a “transplant benefit score” and applies it to potential recipients.²⁶ The purpose of this liver offering scheme is to increase the number of life-years gained from transplanted livers, as well as decreasing the number of people who die waiting (a two-fold goal). The transplant benefit score uses an algorithm with 21 criteria that considers both waitlist survival and post-transplant 5-year survival. It also pays more attention to

²³ The social determinants of health refer to “non-medical and non-behavioral precursors of health and illness,” for an overview see M. Mofizul Islam, “Social Determinants of Health and Related Inequalities: Confusion and Implications,” *Frontiers in Public Health* 7 (2019) and Paula Braveman and Laura Gottlieb, “The Social Determinants of Health: It’s Time to Consider the Causes of the Causes,” *Public Health Reports* 129 (2014).

²⁴ Martin et al, “Over of the MELD Score and the UNOS Adult Liver Allocation System,” *Transplantation Proceedings* 39, no. 10 (December 2007), 3167.

²⁵ Freeman, “MELD: the holy grail,” 18.

²⁶ See <https://transplantbenefit.org/>

patient-recipient matching, and organs are allocated to a named recipient (rather than to an anonymous score).²⁷

Evidence-based medicine and the objectivity of fairness

Utility is more difficult to measure objectively than mortality. In our current health policy context, objective measures are vastly preferred. Shauna, given her training in economics, was partial to objective measures and believed that the MELD policy was a good thing. We had conversations about it back when she was first listed for a transplant. She saw it as an improvement over the previous system because it was more objective, and it eliminated the subjective judgement of physicians in the prioritization of liver transplant candidates. I remember her explaining to me that the MELD system was designed to create universality and equality for all candidates precisely because it only compares lab scores. Using only objective criteria, like lab scores, generates a system that allocates livers fairly and ethically and eliminates discrimination. Since the early days of transplantation, fair, equitable and universal access to transplantation was a key component in securing public support and trust in organ donation and transplantation.²⁸ To allay concerns that the wealthy, well-connected and white population have better access to transplantation than everybody else, Shauna agreed that it was better to have the MELD system, which standardized the way patients are ranked on the waitlist and applied it universally across the board.

²⁷ Lee, Johnston and Oniscu, “The trials and tribulations.”

²⁸ Renee Fox and Judith Swazey, *The Courage to Fail: A Social View of Transplantation and Dialysis* (Chicago: University of Chicago Press, 1974).

Studies have shown that the rates of African Americans receiving liver transplants have increased under the MELD system.²⁹ While this is a positive outcome, MELD doesn't take into account the many other ways that health disparities are perpetuated along racial lines and affect access to transplantation as well as transplant outcomes. Though MELD promotes equality in access to liver transplantation, this "equal access" is superficial given the profound unevenness of healthcare in the U.S. that make African Americans, especially poor African Americans, dramatically worse off than their wealthy white counterparts.³⁰ While "objective criteria" may prevent discrimination, it doesn't address racism on a broader systemic scale. It perpetuates the idea that racism is a product of individual personal bias, without recognizing that racism is embedded in the healthcare system itself. There is no "level playing field."

The perception that MELD promotes fairness and equality demonstrates the influence of liberalism in public institutions like health care. Political theorist Iris Marion Young (1989) described this as "equality conceived as sameness" reflecting the liberal idea that commonalities can transcend particularities and differences and give rise to universal standards - like basic human rights or simply the idea that everybody should be treated

²⁹ Nyingi Kemmer, "Ethnic Disparities in Liver Transplantation," *Gastroenterology and Hepatology* 7, no. 5 (May 2011); Cynthia A. Moylan et al., "Disparities in Liver Transplantation Before and After Introduction of the MELD Score," *JAMA* 300, no. 20 (November 2008).

³⁰ These disparities are systemic but are especially dire in the area of maternal health see the following report from the National Partnership for Women and Families: <https://www.nationalpartnership.org/our-work/health/reports/black-womens-maternal-health.htm>

the same.³¹ Treating all patients the same is a pillar of evidence-based medicine (EBM), the current Western paradigm for determining the “highest standards” of health care. MELD is an example of a policy that implements standardized measurable data as a means of improving system efficiency and fairness. This approach is consistent with the ethos of EBM, i.e., decision-making based on generalizable and universal research evidence, not clinical or patient experience.³² MELD only takes into consideration what is understood to be common and can be applied to all patients and ignores everything else. It is premised on the idea that there is a standardized experience of end-stage-liver disease that renders all patients the same and comparable, excluding all non-quantifiable and contextual factors.

In liver transplantation there is an assumption that an “evidence-based” approach will “make the wisest use of the available, scarce, organs “and make it possible to “rationally” allocate organs.³³ EBM assumes that evidence that applies to a large sample can be applied in each individual case. It assumes that the best evidence comes from the medical literature that analyses and reviews quantitative data from randomized trials. EBM is now the standard approach in not just clinical practice but also in policy, programming and administration. With its emphasis on standardization and controlled comparisons, EBM is especially appealing to managers, insurance companies, statisticians, and

³¹ Iris Marion Young, “Polity and Group Difference: A Critique of the Idea of Universal Citizenship,” *Ethics* 99, no. 2 (1989), 250.

³² Helen Lambert, “Accounting for EBM: Notions of evidence in medicine,” *Social Science and Medicine* 62 (2006): 2633-2645.

³³ Robert M. Merion et al. Evidence-based development of liver allocation: a review,” *Transplant International* 24 (2011): 965-972.

pharmaceutical companies, and in all institutional and bureaucratic contexts that call for standards and a system, and the application of rational technical rules.³⁴

Lambert, Gordon and Brodgan-Lovis argue that EBM produces “apparently robust recommendations” but that these are “based on knowledge that is actually partial and incomplete [because it] excludes the qualitative knowledge produced by much social science scholarship” as well as patient knowledge and experience.³⁵ Critics of EBM see its preoccupation with quantification, efficiency and effectiveness as geared towards managerialism and “audit culture” and not towards understanding contextual issues, complex social realities and the lived experiences of patients. While supposedly increasing transparency and accountability in medicine, the increased use of quantification, statistics, systems of measurement and ranking mean that more complex experiences are reduced to simple numerical indicators that are easier for management and control but are highly decontextualized.³⁶ Nonetheless, EBM is widely seen as providing effective and efficient care and for informing “best practices” and policies with transparency, clarity and accountability. According to Lambert, Gordon, Brodgan-Lovis, “it holds out the promise of providing a reliable objective means of informing decision-making.”³⁷ The philosophy and commitment to EBM is so entrenched that even though

³⁴ Lambert, “Accounting for EBM.”

³⁵ Helen Lambert, Elisa J. Gordon and Elizabeth A. Brodgan-Lovis, “Introduction: Gift horse or Trojan horse? Social science perspectives on evidence-based health care,” *Social Science and Medicine* 62 (2006), 2620.

³⁶ Ibid; Trisha Greenhalgh et al. “Six ‘biases’ against patients and carers in evidence-based medicine,” *BMC Medicine* 13, no. 200 (2015).

³⁷ Lambert, Gordon, Brodgan-Lovis, “Introduction: Gift horse or Trojan horse,” 2614.

some are critical of the MELD allocation system, they acknowledge that “the system is not about to change.”³⁸

Being an impersonal statistic

Greenhalgh et al. suggest that there should be a way of combining the evidence-based “assigned risk” with a consideration of the experience of illness. In a more patient-centered approach to medicine, “people rather than biomedical variables [would] have salience.” It would mean that “particularities, not mean values or generalizable truths . . . matter,” recognizing that “illness as lived” can differ from “the disease or risk state in the evidence-based guideline.” They write, “Personally significant evidence from a particular patient in the here and now should be systematically captured and treated as complementary to ‘statistically significant evidence’ from distant research populations.” They argue that “The EBM literature tends to depict the patient’s illness as a fixed entity with more or less stable properties.”³⁹ Surgeon Pauline Chen notes something similar in her memoir *Final Exam*, acknowledging that physicians often concentrate on “the treatment algorithm for their disease process” not on patient experience and discuss them as “cases in the context of objective data” rather than as patients in the here and now.⁴⁰

Shauna’s trajectory towards waitlist death was forged by the values and priorities of MELD (and the policy context that spawned it) that gave no consideration to her personal

³⁸ Joshua Mezrich, *When Death Becomes Life: Notes from a Transplant Surgeon* (New York: Harper Perennial, 2014), 247.

³⁹ Greenhalgh et al., “Six ‘biases.’” 2-5.

⁴⁰ Pauline Chen, *Final Exam: A Surgeon’s Reflections on Mortality* (New York: Vintage Books, 2007), 94.

experience. The privileging of objective data in medical decision-making means that all patients are ranked according to the same measures that *predict* mortality, even if a patient's health status means they are much closer to death than the score suggests. The evidence-based paradigm prioritizes "calculative practices of measurement"⁴¹ and the individuality of the patient is excluded - their experiences, views, knowledge and narratives are far less relevant than the seemingly sophisticated algorithmic formula that reduces them to an impersonal statistic. Interestingly, Brown et al. note that while the liver transplant patients in their study talked extensively about MELD, none had a clear understanding of it.⁴² I didn't understand it either, especially not the extent to which it orchestrated Shauna's demise.

In the MELD system, each patient is depersonalized and represented by a prognostic score that corresponds to a statistic of mortality risk. For instance, a MELD of 30 means a 90-day mortality rate of 65%. While this may be statistically reliable, for individual patient experience, it predicts very little. You might be one of the 35% who will still be alive beyond 90 days or like Shauna with a MELD of 30, you might be ventilated in the ICU and die 12 days later. This open-endedness makes MELD rather useless when it comes to understanding the varied lived realities that patients experience. As Ann Jurecic writes, "Even when we know the chances in general, we cannot know what will happen

⁴¹ C. Shore and S. Wright, "Audit culture and anthropology: Neo-liberalism in British higher education," *Journal of the Royal Anthropological Institute* 5 (1999), 557-575.

⁴² Jill Brown et al., "Waiting for a Liver Transplant," *Qualitative Health Research* 16, no. 1 (February 2006)

in individual cases”; she refers to Stephen J. Gould’s point that a “central tendency is not indicative of a hard reality. Variation is the hard reality.”⁴³

Jurecic argues that, from the patient’s perspective, a statistic or a central tendency (like 65% mortality risk) isn’t much to go on. A measure of probability based on aggregated data is “not a representation of one’s future.” She writes, “while general populations can be described with probabilities, the life of an individual cannot.”⁴⁴ For patients facing any kind of risk, statistics and probabilities provide little meaning especially when they are starkly out of synch with lived experiences. Even generally, Charles Rosenberg explains, “Likelihoods and multifactorial complexes of causation do not easily fit into most people’s way of thinking about themselves and family members . . . men and women want to know what is to happen next in their own lives or that of family members, not that of a statistical aggregate.”⁴⁵

In Shauna’s final ICU days, everyone knew her time was running out. No one referred to her MELD score of 40 meaning a 3-month mortality risk of 71.3%. On the ground, this abstract probability was irrelevant. It was obvious, in her case, there wasn’t a 28.7% chance of survival. Shauna’s personal story and “personally significant evidence” was insignificant compared to an abstract picture of the quantitative whole.

⁴³ Ann Jurecic, *Illness as Narrative* (Pittsburgh: University of Pittsburgh Press, 2012), 26.

⁴⁴ *Ibid.*, 22.

⁴⁵ *Ibid.*, 22.

On New Year's Eve the year that Shauna died, I went out for dinner at a Thai restaurant with a small group of friends. I was tired and subdued so I took a taxi home early. The driver asked about my year and I told him that my sister died. He was truly sorry. We went on to talk about the Indian Ocean tsunami that had happened a few days earlier and lamented the staggering death toll and the scale of the tragedy. The cab driver added "and your sister was forgotten just like that." I was in mourning, so his words stung. It was insensitive to imply that the memory of my sister had been wiped out. But, this tactless taxi driver also voiced an uncomfortable truth - the insignificance of a single human life. For me personally, Shauna's death was the *worst thing that ever happened*. The dimensions of a personal tragedy don't factor in the intellection that in the grand scheme of things a single death doesn't matter or have significance beyond intimate meanings and the personal pain of encountering loss. The result is feeling lonely, alienated and diminished.

These feelings were exacerbated as I thought about the *over-reliance* on quantitative measures in medical decision-making. In eliminating any "subjective criteria," MELD doesn't always capture a true picture of mortality risk, nor does it consider the impact of ESLD on an individual's life. In fact, quality of life for liver transplant candidates is not considered to be a valid issue for allocation policy; it is only concerned with mortality endpoints.⁴⁶ Biochemical predictors of mortality are deemed to be superior "evidence" than anything that might require human judgement. This truncated view signals a fantasy

⁴⁶ Richard B. Freeman, "MELD and the quality of life," *Liver Transplantation* 11, no. 2 (January 2005): 134-136.

that there can be a rational and efficient means to solve complex problems, as though the data itself can make the best decisions.

The introduction of MELD in the US brought about a 12% reduction in waiting list registrations and a 3.5- 4 % reduction in waiting list mortality. Overall, MELD has a C-statistic (a measure of goodness of fit for binary outcomes) of 0.8-0.85, meaning that MELD accurately predicts mortality 80-85% of the time and is inaccurate in 15-20% of cases.⁴⁷ In 2004, the year Shauna died, in the region where Shauna resided, there were 448 liver transplants and 168 deaths on the waitlist. Eleven of those deaths were patients between the ages of 18 and 34. Shauna is one of these eleven people.⁴⁸ I used to perceive this as unluckiness (and to an extent I still do). Yet in learning about MELD, how patient priority is determined, and how livers are distributed, Shauna's death seems far likelier than I imagined. At the time, Shauna's death was a shock, but as I was sifting through the details of MELD, I actually found myself thinking that it is not surprising that Shauna died, that what she endured was essentially unyoked from the happy ending all along, even though we fervently saw it otherwise. What I saw was Shauna traversing a precarious and harrowing patch of "mortality risk" on her journey to recovery, in keeping with the dominant transplant narrative. Meanwhile, MELD laid the groundwork for a different outcome.

⁴⁷ Sumeet K. Asrani and Patrick S. Kamath, "Model for end-stage liver disease score and MELD exceptions: 15 years later," *Hepatology International* 9 (2015): 346-354; Wiesner et al. "Model for end-stage liver disease."

⁴⁸ OPTN data reports are searchable: <https://optn.transplant.hrsa.gov/data/view-data-reports/regional-data/>

MELD is colloquially referred to as the “sickest first” policy, a designation that suggests that Shauna was somehow not sick enough to get a transplant. In fact, her experience of waitlist death is a product of the MELD system that necessitates finding an elusive middle ground of being “sick enough” yet not “too sick.” For many patients, this means they will become critically ill before a transplant is available. I hated Shauna’s growing frailty and wanted her to hold steady, but this would mean she would never make gains on the list. The more critically ill she became was favourable for this system of liver allocation, a strange type of advantage because it also meant she was nearing total disaster.⁴⁹

One of the consequences of the narrow focus on mortality risk is that liver transplant patients must compete to become the sickest and most moribund of all. I found a journal of Shauna’s in which she had been meticulously recording the waitlist of Type A transplant patients at the two local transplant centers. She did this each week when the list was updated from January 2 to April 30, 2004 (the period during which she had “improved” and her MELD score was low). Shauna’s lists record the number of patients listed by MELD ranges. She herself is somewhere in those anonymous lists, bleakly among the dozens of patients in the 11-18 range. I see her tracking all the other anonymous patients ahead of her, confirming each week that she was falling short, reminding herself that she was “not sick enough” with dehumanizing objectivity. Those lists reflect that some will make it and some will not with cold and uncaring neutrality.

⁴⁹ Surgeon Joshua in his memoir, *When Death Becomes Life*, notes that current allocation policy means “our patients have to be so much sicker to get these precious organs. I suppose that’s fair, but it sure has made my job harder” (390) – referring to the fact that sicker patients make surgery trickier.

Figure 4: Below are scanned pages from Shauna's journal

Jan 2/2004 OPTN Stats

At Duke 274 currently listed

Type A	
MELD <10 = 133	40
MELD 11-18 = 83	39 → 28 ♂
MELD 19-24 = 6	2 → 11 ♀
MELD 25+ = 3	2 → ♂ (35-64 y.o.)
(Inactive = 59)	1 → ♂ (50-64 y.o.)

At UNC (149 Type A)

MELD <10 = 70

MELD 11-18 = 56

MELD 19-24 = 0

MELD 25+ = 0

(Inactive = 23)

Tuesday, Jan 27
@ 11AM

Jan. 9/2004 OPTN Stats

At Duke 269 currently listed

Type A	
MELD <10 = 122	39
MELD 11-18 = 83	39
MELD 19-24 = 5	2
MELD 25+ = 4	1
(Inactive = 55)	18

At UNC (148 Type A) | Jan. 16 @ UNC (148 Type A)

MELD <10 = 71 | 70

MELD 11-18 = 55 | 56

MELD 19-24 = 0 | 1 - ♂ (50-64 y.o.)

MELD 25+ = 0 | 0

Inactive = (22) | 21

Jan. 16/2004

At Duke 269 currently listed

Type A (100)	
MELD <10 = 121	40 → 28 ♂
MELD 11-18 = 83	39 → 29 ♂
MELD 19-24 = 5	2 → 10 ♀
MELD 25+ = 2	1 → ♂ (35-64 y.o.)
(Inactive) = 56	1 → ♂ (50-64 y.o.)
Status 1 = 2	0

Jan 23, 2004

At Duke 269 currently listed

Type A (100)	
MELD <10	121
MELD 11-18	83
MELD 19-24	5
MELD 25	2
Inactive	56
Status 1	2

Jan. 30 @ UNC (147 Type A)

MELD <10 = 70 = 75⁴⁷⁶ (193) Total

MELD 11-18 = 56 = 49³¹⁰ (114) (18-34) = 4 (35-49) = 13 (50-64) = 20 (65+) = 2

MELD 19-24 = 1 = 3¹¹⁰ (11) (50-64) = 2 (65+) = 1

MELD 25 = 0 = 0 (4)

Inactive = 21 = 20 (63)

Status 1 = 0 = 0

(A=0 = 395; O=193; A=147; B=23; AB=8)

Jan 30, 2004

At Duke 265 currently listed

Type A (98)	
MELD <10	120
MELD 11-18	79
MELD 19-24	3
MELD 25	2
Inactive	61
Status 1	0

(O=143, A=98, B=23, AB=1)

Ubel PA, Loewenstein G.

Distributing scarce lives: The moral reasoning of the general public.

Soc Sci Med 1996; 42: 1049-1055.

February 6th, 2004

At Duke 267 currently listed

Type A	
MELD <10	122
MELD 11-18	79
MELD 19-24	5
MELD 25+	1
Inactive	60
Status 1	0

(O = 146, A = 97, B = 23, AB = 1)

At UNC (147 Type A)

MELD <10 = 73 (116-34) = 5 (50-64) = 33 (18-34) = 25 (65+ = 4)

MELD 11-18 = 50 (118-34) = 4 (50-64) = 28 (35-49) = 16 (65+ = 2)

MELD 19-24 = 1 (18) (35-49) = 1

MELD 25+ = 1 (18) (65+) = 1

Inactive = 22 (18)

Status 1 = 0

(O = 193, A = 147, B = 33, AB = 8, ABO = 386)

Transplants since 1988 (National)

PSC/Crohn's 546
PSC/no bowel disease 1085
PSC/other 1017
PSC/UC 1609

Waiting List Removals (1995-2003)

	PSC/Crohn's	PSC/noIBD	PSC/other	PSC/UC
2323) Cad Tx	390	718	130	1085
(186) LDTx	20	57	12	97
2509 Emer Tx	0	1	0	0
1st Ed MO	0	0	0	0
(2888) Death during Tx	0	0	0	0
3rd Medicaly Refused	0	1	1	1
(2176) Transplant	4	7	0	2
Transferred	26	64	10	88
Died	91	141	31	209
other	20	29	8	65
Cond. Improved	29	39	11	36
Too Sick	25	41	15	65
Tx @ other Ctr.	27	53	14	50

Waiting List Additions (1995-2003)

	PSC/Crohn's	PSC/noIBD	PSC/other	PSC/UC
4342	740	1351	231	2012

February 20, 2004

@ Duke 266 currently listed (97 type A)

MELD <10	120	41
MELD 11-18	78	35
MELD 19-24	6	3
MELD 25+	0	0
In Active	62	18
Status 1	0	0

(O = 145, A = 97, B = 23, AB = 1)

February 27 @ UNC

@ UNC (148 Type A) (148 Type A)

MELD <10 =	67	71
MELD 11-18 =	52	46
MELD 19-24 =	4	6
MELD 25+ =	1	1
In Active =	24	24
Status 1 =	0	0

February 27, 2004

@ Duke 268 currently listed (99 Type A)

	Type A	
MELD <10	121	41 (260) - no change from 02/13
MELD 11-18	75	34 (278) (18-30)=1 (50-64)=12
MELD 19-24	7	4 (28) (35-44)=13 (62+)=2
MELD 25+	3	2 (28) (35-44)=2
In Active	62	18 (35)
Status 1	0	0

(O = 145, A = 99, B = 23, AB = 1)

Questions

- ① Post TX exacerbation of IBD?
- ② Cholecystectomy (gallbladder removal) at TX?
- roux-en-y procedure?
- ③ Statistical significance of the difference between MELD scores -- is the supposed "continuity" of the model an illusion?

Duke Transplants (Cadaveric) - Type A

Jan-Nov '03	2002	2001	2000
10	14	18	13
average = 15/year			
365 = 24.3 days between transplants			
15 = (type A) on average.			
=> (24.3) * (spot on list) = average waiting time			
if 9th -> 219 days (~7 months)			

UNC Transplants (Cadaveric) - Type A

Jan-Nov '03	2002	2001	2000
17	20	16	26
average = 20.6/year			
365 = 17.7 days between transplants			
20.6 =			

Combined Duke/UNC Type A transplants

15 + 20.6 = 35.6 transplants (A) / year

$\frac{365}{35.6} = 10.25$ days between transplants on average.

=> if 20th on combined list
(10.25) x 20 = 205 days average waiting time.

Region 11 Data (Transplants Type A) Cadaveric

Status	Jan-Nov '03	Compare w/ Duke/UNC	UNC
Status 1	5 (13%)	0	11 (16%)
MELD < 10	8 (5.4%)	0	10
MELD 11-18	41 (27.5%)	11 (10%)	0
MELD 19-24	45 (30.2%)	4 (40%)	5 (29.4%)
MELD 25+	50 (33.6%)	5 (50%)	11 (65%)
	149	10	17

At Georgetown (Type O Cadaveric)

Jan-Nov '03	2002	2001	2000
14	16	8	14
13.25/year			
365 = 27.55 days			
13.25 =			

2003 Type O transplants (14)

Status 1 = 2 (14.3%)
MELD < 10 = 1 (7%)
MELD 19-24 = 1 (7%)
MELD + 25 = 10 (71.4%)

Waiting List (02/27/04) Type O

Status 1 = 1
Status 7 = 18
MELD < 10 = 79
MELD 11-18 = 48
MELD 19-24 = 9
MELD 25+ = 8

National Statistics (Cadaveric - Type A) Jan-Nov

Total	North Carolina (45)
Status 1: 155 (8.5%)	11 (24.4%)
MELD < 10: 122 (6.7%)	6 (13.3%) (6)
MELD 11-18: 416 (22.8%)	6 (13.3%) (5)
MELD 19-24: 499 (27.4%)	12 (26.7%) (3)
MELD 25+: 630 (34.5%)	18 (40%) (2)

Cadaveric (Type O)

Total: 2181
Status 1: 234 (10.7%)
MELD < 10: 110 (5%)
MELD 11-18: 433 (19.9%)
MELD 19-24: 545 (25%)
MELD 25+ 857 (39.3%)

Deceased Donors (Livers) Jan-Nov '03

National	Carolina Donor Services
O = 2,575 (49.4%)	O = 46/55 = 50.5 (49.8%)
A = 1,914 (36.7%)	A = 37/35 = 36 (35.5%)
B = 560 (10.7%)	B = 8/16 = 12 (11.8%)
AB = 167 (3.2%)	AB = 6/10 = 3 (3%)
5216	97/110
Wash. Reg Tx Consortium	203

O = 25/30
A = 8/30
B = 8/10
AB = 3/3
63/30

National Wait List	Carolina Donor Services
O = 8,646	= 334 (51.4%)
A = 6,243	= 246 (37.8%)
B = 1,355	= 61 (9.4%)
AB = 460	= 9 (1.4%)
<u>17,304</u>	<u>650</u>
Wash. Reg	
O = 207 (52.1%)	
A = 138 (34.8%)	
B = 43 (10.8%)	
AB = 9 (2.3%)	
<u>397</u>	

March 19, 2004	
@ Duke	266 currently listed (99 Type A)
Type A	
MELD < 10	= 127 43 (29%)
MELD 11-18	= 67 32 (29%)
MELD 19-24	= 6 3 (2%)
MELD 25+	= 2 1 (1%)
In Active	= 64 (20%)
Status 1	* yes, * yes (region 11)
	(O = 144, A = 99, B = 22, AB = 1)
@ UNC	(376 currently listed, 143 Type A)
Type A	
MELD < 10	= 64
MELD 11-18	= 49
MELD 19-24	= 4
MELD 25+	= 3
In Active	= 23
Status 1	= * yes
	(O = 186, A = 143, B = 39, AB = 8)

A closer look at MELD

At the time, I thought everyone was waiting fair and square. To a large extent the shortcomings and inconsistencies of MELD reveal why Shauna died and explain why other candidates on the list had more priority. Shauna was disadvantaged because in her case it's questionable that MELD accurately captured disease severity. It's not that she wasn't gravely ill, it was that her MELD score wasn't high enough despite the evidence that she was spiralling downward. Shauna really didn't have much opportunity for transplantation, except probably a few small windows during which we can assume nobody eligible died, consented to donation, or was a suitable donor for Shauna. Perhaps on paper the allocation system seems fair, rational and objective but it operates on the ground unevenly, almost like a crapshoot.

Despite being considered the best way to rank liver transplant candidates, a MELD score is not applied to *all* patients. One group of patients not ranked with a MELD score are given default priority. They are called Status 1, a classification that has carried over from the previous (pre-MELD) allocation policy. To qualify as Status 1 you have to meet the criteria of “fulminant liver failure,” defined as “the onset of hepatic encephalopathy within 56 days of the first signs or symptoms of liver disease.” A Status 1 patient cannot have a pre-existing diagnosis of liver disease, or else must be a recent recipient of a (failed) transplant experiencing “primary non-function of a transplanted whole liver within 7 days of transplant.” Status 1 patients also must be in ICU, either on a ventilator or on continuous veno-venous dialysis.⁵⁰ Shauna, who was in the rapidly terminal phase of her chronic illness could not qualify as a Status 1 patient and was always ranked lower than anyone who was, though death was imminent for her as much as it was for any Status 1 patient.

Shauna always referred to Status 1 patients somewhat wryly as “people who take too much Tylenol” either intentionally or accidentally, by not reading the labels correctly, or at all, or misinterpreting the dosage. This is true insofar as almost a quarter of Status 1 patients have acetaminophen toxicity; it is the most common cause of fulminant liver failure (most other Status 1 patients are in the category of non-acetaminophen toxicity or

⁵⁰ See Policy 9: Allocation of Liver, 9.1 A. Adult Status 1A Requirements
https://optn.transplant.hrsa.gov/media/eavh5bf3/optn_policies.pdf

have immediate post-graft failure).⁵¹ Finding out from the transplant coordinator nurse about whether there were any Status 1 patients on the list was something that we did daily when Shauna was in critical condition; it was akin to finding out whether or not someone was usurping Shauna's spot at the top. The transplant coordinator nurse was highly involved in Shauna's plight, compassionate, trustworthy, and available. Most days, she was able to reassure us that there weren't any Status 1 patients, but the day before Shauna died she told us otherwise, that there were not one but two Status 1 patients in the region. Effectively, it made Shauna third on the list, which might as well have been the very bottom. It was devastating.

At that point, we knew Shauna's MELD was 40 but MELD score calculations can go beyond 40. According to Safwan et. Al., MELD is capped at 40 for no reason.⁵² One study found that patients with MELD scores higher than 40 have twice the waitlist mortality of Status-1 patients. Patients with MELDs between 36-40 have no difference in waitlist mortality despite Status 1 patients having higher priority. Status 1 patients also benefit from the broader sharing of organs (having priority access to any available organ in the region).⁵³ Another study found that 11% of Status 1 patients "are not as critically ill as imagined" and recommended that Status 1 patients be stratified into high-risk and

⁵¹ Robert J. Fontana, "Acute Liver Failure including Acetaminophen Overdose," *Medical Clinics of North America* 92, no. 4 (2008): 761-794

⁵² Mohamed Safwan et al., "Should All Status 1A Patients Be Prioritized Over High MELD Patients? Concept of Risk Stratification in Extremely Ill Liver Transplant Recipients," *Transplantation* 103, no. 10 (2019): 2121-2129.

⁵³ Pratima Sharma et al., "End-stage liver disease candidates at the highest model for end-stage disease scores have higher wait-list mortality than status-1A candidates," *Hepatology* 55, vol. 1 (2011): 192-198.

low-risk classes.⁵⁴ For all these reasons (including the possibility that Shauna's MELD was in fact higher than 40) it seems like cruel unfairness that Shauna slid down the list when she needed a transplant the most. To this day, even the designation "Status 1" antagonizes me with all its insinuations of privilege. I couldn't (can't) get past feeling like Shauna was entitled too - she had waited and suffered for so long.

Another group of patients - those with hepatocellular carcinoma (HCC) have *allocated* (not calculated) MELD scores. From the start, one of the challenges for implementing MELD was how to include HCC patients. MELD measures risk of mortality from liver disease whereas HCC patients are at risk of dying from the "progression of their malignancy."⁵⁵ For this reason, the liver transplant community agreed that a MELD score would not accurately predict mortality risk for HCC patients. A policy was adopted to allocate "exception points" for HCC candidates. These exception points were initially far too high and HCC patients were overprioritized for transplantation. Patients with stage T1 liver cancer (1 lesion <2 cm) were all allotted 24 MELD points and patients with stage T2 liver cancer (1 lesion 2–5 cm or 2–3 nodules all <3 cm) were all allotted 29 points, with an additional increase every three months. The number of MELD points were reduced in 2003 to 22 (for stage T1) and 24 (for stage T2). In early 2005 (just after Shauna died) this was reduced even further to no exception points at all for stage T1 and 22 points for T2. Ten years later, in 2015, the HCC exception points were reduced even more because HCC patients were still overprioritized. The new guidelines are that HCC

⁵⁴ Joseph Ahn et al., "End-stage liver disease patients with MELD > 40 have higher waitlist mortality compared to Status 1A patients," *Hepatology International* 10 (2016): 838-846.

⁵⁵ Freeman, "MELD: the holy grail," 19.

patients are listed with their “native MELD” for the first 6 months, then they are allotted 28 points, increasing every 3 months for a maximum of 34.⁵⁶

The excessive priority for HCC liver transplant candidates was a disadvantage for ESLD patients waiting for a transplant, especially in the early years of MELD (2002-2005) when Shauna was waitlisted. When MELD was first introduced, nearly three quarters of HCC patients received transplants within the first three months of being listed. They had a significantly decreased risk of waitlist mortality and increased odds of transplantation compared to patients with end-stage liver disease (and “native MELD scores”).⁵⁷ Some have argued this is “not surprising” given that the policies surrounding exception points were not “evidence based” and “no clinical data from actual transplant candidates were used to make these decisions” at the time.⁵⁸ It turned out not to be consistent with MELD’s “sickest first” standards.

Exception points are not just used for HCC candidates. Nearly one-third of transplant patients in the US have MELD exception points. Two thirds of these are for HCC and the other third are patients who have received non-standardized exception points, which are allotted on a case-by-case basis by a regional review board.⁵⁹ Shauna had non-

⁵⁶ David S. Goldberg and Kim M. Olthoff, “Standardizing MELD Exceptions: Current Challenges and Future Directions,” *Current Transplantation Reports* 1 (2014): 232-237; Saleh Elwir and John Lake, “Current Status of Liver Allocation in the United States,” *Gastroenterology and Hepatology* 12, vol. 3 (2016): 166-170.

⁵⁷ Patrick Grant Northrup, “Excess mortality in the liver transplant waiting list: Unintended policy consequences and model for End-Stage Liver Disease (MELD) inflation,” *Hepatology* 61, no. 1 (285-291).

⁵⁸ Goldberg and Olthoff, “Standardizing MELD Exceptions,” 18.

⁵⁹ Goldberg and Olthoff, “Standardizing MELD Exceptions.”

standardized exception points on account of her low serum sodium levels (hyponatremia), a clear sign of decompensation. Shauna's hepatologist and the liver transplant team were concerned that Shauna's MELD did not accurately represent the severity of her sickness and her risk of mortality. They applied for exception points from the UNOS regional board and a few extra points were granted.

Some of the flaws in the MELD system have resulted in policy changes since it was first implemented. The MELD system today is different than it was at the time that Shauna died. Notably, in 2016, the MELD score officially changed to include serum sodium in the calculation for all transplant patients. MELD is now MELD-Na. This change resulted from studies that showed that low serum sodium, or hyponatremia, was an independent predictor of mortality in liver transplant patients as well as that sodium scores improved MELD's accuracy in predicting mortality (and reducing its C-statistic).⁶⁰ In 2004, Shauna fell through the cracks of an un-tested system of allocation that didn't yet take into consideration hyponatremia's strong link to pre-transplant mortality. More studies have pointed to other severe effects of end-stage-liver-disease that are underweighted by MELD for determining mortality risk- portal hypertension, refractory ascites and hepatorenal syndrome.⁶¹ These are all symptoms Shauna had.

⁶⁰ Andres E. Ruf et al., Addition of Serum Sodium into MELD Score Predicts Waiting List Mortality Better than MELD Alone," *Liver Transplantation* 11, no. 3 (March 2005): 336-343; Shunji Nagai et al., "Effects of Allocating Livers for Transplantation Based on Model for End-Stage Liver Disease – Sodium Scores on Patient Outcomes," *Gastroenterology* 155, no. 5 (November 2018): 1451-1462.

⁶¹ Mauro Bernardi, Stefano Gitto and Maurizio Biselli, "The MELD score in patients awaiting liver transplant: Strengths and weaknesses," *Journal of Hepatology* 54, no. 6 (2011): 1297-1306

It is not just that the particularities of Shauna's illness (plus bad luck and bad timing) worked against her in the MELD system, recent research has shown that there is a systemic gender bias at play. MELD has increased a gender disparity amongst liver transplant recipients- more men are getting a liver transplant than women. In fact, MELD has produced an increase in waitlist mortality for female liver transplant candidates.⁶² The issues that contribute to this disparity are not well-understood but possibly include body size, MELD's incorrect assessment of disease severity, and gender bias in the selection process of transplant candidates.⁶³

More men suffer from end-stage liver disease than women and the prevalence of diseases for which transplantation may be indicated is not equally distributed between women and men. Cirrhosis is more common in men than in women. Hepatitis C more prevalent in men than women.⁶⁴ Overall, fewer women are listed for transplant - they represent about 36.1% of patients waiting.⁶⁵

⁶² Alina Allen et al., "Reduced Access to Liver Transplantation in Women: Role of Height, MELD Exception Scores and Renal Function Underestimation," *Transplantation* 102, no. 10 (October 2018): 1710-1716; Jayme E. Locke et al., "Quantifying Sex-Based Disparities in Liver Allocation," *JAMA Surgery* 155, no. 7 (May 2020); Monica Sarker et al., "Outcomes in liver transplantation: Does sex matter?" *Journal of Hepatology* 62, no. 4 (April 2015) 946-955.

⁶³ Omobonike O. Oloruntoba and Cynthia A. Moylan, "Gender-based disparities in access to and outcomes of liver transplantation," *World Journal of Hepatology* 7, no. 3 (2015): 460-467.

⁶⁴ Jennifer Guy and Marion G. Peters, "Liver Disease in Women: The Influence of Gender on Epidemiology, Natural History and Patient Outcomes," *Gastroenterology and Hepatology* 9, no. 19 (2013): 633-639.

⁶⁵ Locke et al., "Quantifying Sex-Based Disparities."

The concerning issue is that the introduction of MELD has reduced waitlist mortality for men and increased it for women.⁶⁶ The first study that looked at the impact of race and gender on waitlist mortality in the MELD era, using data from 2002-2007 found that women had a higher waitlist mortality - 23.7% of women die on waitlist vs. 21.9% of men.⁶⁷ More recent studies, have found this gap has widened. A study in 2018, found the difference to be 22% waitlist mortality for women and 18% for men.⁶⁸ A 2020 study using data from 2013-2018 found that 41% of patients who die on waitlist are female and 59% are men, when these percentages are adjusted to reflect the distribution of men and women on the waitlist, this represents an 8.6% greater risk of waitlist mortality for women. The same study found that women are 14.4% less likely to receive a deceased donation.⁶⁹ Studies have also found that women have a higher mortality compared to men with the same MELD scores, specifically a 19% higher risk of waitlist mortality for female patients compared to male patients with the same MELD scores.⁷⁰ Despite the fact that MELD was developed to be unbiased, 20 years of data show there *is* a consistent bias against women, but no policy changes have occurred, no doubt reflecting that transplantation is a male-dominated field.

⁶⁶ Sarker et al., “Outcomes in liver transplantation.”

⁶⁷ Moylan et al., “Disparities in Liver Transplantation

⁶⁸ Allen et al., “Reduced Access to Liver Transplantation.”

⁶⁹ Locke et al., “Quantifying Sex-Based Disparities.”

⁷⁰ Jennifer C. Lai et al., Height Contributes to Gender Difference in Waitlist Mortality Under the MELD-Based Liver Allocation System,” *American Journal of Transplantation* 10, vol. 12 (2010): 2658-2664.

The initial study that validated MELD as a predictor of mortality overrepresented men, particularly white men with Hepatitis C. Of the sample of 3437 individuals, 67.8% were men, 70% were white, and 36.4% had Hepatitis C.⁷¹ The influence of disease diagnosis in the MELD score may contribute to the gender disparity. Men are nearly twice as likely as women to have Hepatitis C.⁷² MELD may not represent disease severity accurately across different liver disease diagnoses. MELD's indicators may not be applicable to liver failure in a broad universal one-size-fits-all category of end-stage-liver disease. It is possible they are more specific to liver failure in male patients with Hepatitis C. Dureja and Lacey argue that Hepatitis C is more likely to lead to renal impairment than cholestatic and autoimmune liver diseases, which more women have,⁷³ including Shauna whose renal function was good. Her serum creatinine was the main reason why her MELD score was so low (that is until she developed hepatorenal syndrome, which entails acute kidney injury).

At the outset, there was no consideration of the influence of gender in MELD score calculations. Since then, many researchers have questioned the weighting of serum creatinine in the MELD formula and whether this systematically disadvantages female candidates.⁷⁴ Serum creatinine may be “relatively insensitive to determining renal failure

⁷¹ Wiesner et al. “Model for end-stage liver disease.”

⁷² Allen et al., “Reduced Access to Liver Transplantation.”

⁷³ Parul Dureja and Michael R. Lucey, “Disparities in liver transplantation in the post-model for end-stage liver disease era: Are we there yet? *Hepatology* 50, no.3 (2009): 981-984.

⁷⁴ E. Cholangitas et al., “Female liver transplant recipients with the same GFR as male recipients have lower MELD scores – a systemic bias,” *American Journal of Transplantation* 7 (2007): 685-692; SC Huo, “Is the corrected-creatinine model for end-stage liver disease a feasible strategy to adjust gender difference

in women.”⁷⁵ Studies using eGFR (estimated glomerular filtration ratio) found that many women have worse renal function than their MELD score suggests. In fact, correcting creatinine values using eGFR would increase the MELD score for a majority of women by 2-3 points. As things stand now, women receive fewer MELD score points for the same renal function as men.⁷⁶ Cholongitas et al. argue that using creatinine in the MELD formula means women are not given equal priority as men and amounts to systemic discrimination against women. Nothing has changed, however, because one study found that adjusted creatinine levels for women did not elevate the “predictive accuracy” of MELD for determining three-month mortality.⁷⁷

Creatinine is affected by body mass, which is why the need for a more accurate measure of renal function is required.⁷⁸ Women, due to body size and muscle mass, tend to have lower serum creatinine than men, and this could be why MELD underestimate the severity of liver disease in small patients (who disproportionately tend to be female, like

in organ allocation for liver transplantation” *Transplantation* 84 (2007): 1406-1412; AL Mindikoglu et al. “Gender disparity in liver transplant waiting-list mortality: the importance of kidney function,” *Liver Transplantation* 16 (2010): 1147-1157; RP Myers, “Gender, renal function, and outcomes on the liver transplant waiting list: assessment of revised MELD including estimated glomerular filtration rate,” *Journal of Hepatology* 54 (2011): 462-470.

⁷⁵ Guilherme Mariante-Neto et al., “Impact of creatinine values on MELD scores in male and female candidates for liver transplantation,” *Annals of Hepatology* 12, no. 3 (2013): 434-9.

⁷⁶ Lai et al. “Height Contributes to Gender Difference,”; Allen et al., “Reduced Access to Liver Transplantation.”

⁷⁷ Mariante-Neto et al., “Impact of creatinine values.”

⁷⁸ Claire Francoz et al., Inaccuracies of creatinine and creatinine-based equations in candidates for liver disease with low creatinine: Impact on the model for end-stage liver disease score,” *Liver Transplantation* 16, no. 10 (2010): 1169-1177.

Shauna who was only 4'11" tall) However, a MELD score deficit in women because of creatinine alone did not “substantially explain” higher risk of waitlist mortality for women across the board.⁷⁹ The inclusion of body size was not shown to improve the “predictive accuracy” of MELD either.⁸⁰

Height and abdominal cavity size play a role in whether or not liver offers are suitable for smaller female candidates. Access to small livers is limited as smaller organs are preferentially offered to pediatric patients; and large organs cannot be successfully used in small patients because of “body surface area discordance.”⁸¹ A contributing factor to the gender disparity may be the fact that it is not always the patients at the top of the list receiving the transplant. A surprising fact is that 30% of livers are not allocated to candidates within the top 3 positions on any given match run.⁸² The reasons for this are not well understood, although body size is one of them, and also that liver transplant patients can experience events that lead to temporary deactivation on the list, or temporarily be deemed unsuitable for transplant.

Because events that lead to deactivation can also lead to sudden deterioration, periods of deactivation may be a significant disadvantage, as it was for Shauna who experienced the rapid progression of liver disease. A recent study experimented with a MELD alternative

⁷⁹ Lai et al., “Height Contributes to Gender Difference.”

⁸⁰ Patrick S. Kamath et al., “A Model to Predict Survival in Patients With End-Stage Liver Disease,” *Hepatology* 33., no. 2 (2001).

⁸¹ Lauren D. Nephew et al., Exception Points and Body Size Contribute to Gender Disparity in Liver Transplantation, *Clinical Gastroenterology and Hepatology* 15, no. 8 (2017): 1286-1293; Lai et al. “Height Contributes to Gender Difference.”

⁸² Locke, “Quantifying Sex-based Disparities.”

called the OPOM model (Optimized predictor of mortality). It takes into consideration “the trajectory of change in lab values” and accounts for the increasing mortality risk for patients who are in rapid decline, which MELD does not capture. The study notes that MELD is actually the least effective when it comes to the sickest population, meaning it loses predictive qualities with increasing disease severity. The study found that if livers were allocated using the OPOM model there would be fewer waitlist deaths, especially among women.⁸³

The story of declined livers

Another area that hasn't been thoroughly investigated is the role of declined livers in waitlist mortality. This may be, according to Lai et al. another clue for understanding the gender disparity. Of people who die on waitlist, 84% receive one or more liver offers. Lai et al. found that women are more likely to have donor livers declined. While most (68%) declined offers are refused for donor quality/age, 9% are declined for size mismatch, which very likely affects women more than it does men.⁸⁴ In Shauna's case, there were at least three declined livers (possibly more). We heard a rumour that Shauna

⁸³ Dimitris Bertsimas et al., “Development and validation of an optimized prediction of mortality for candidates awaiting liver transplantation,” *American Journal of Transplantation* 19, no. 4 (2018): 1109-1118.

⁸⁴ Jennifer Lai, Sandy Feng and John Paul Roberts, “An Examination of Liver Offers to Candidates on the Liver Transplant Waitlist,” *Gastroenterology* 143, no. 5 (2012): 1261-1265.

was once passed over for a transplant (for the reason that she was too sick). Two other declined livers figured prominently in the waiting drama.

The first organ offer happened early one morning after a chaotic and sleepless night on the regular hospital ward. For most of the night, Shauna had been frantic and delirious. She thought we were on a boat. Gradually she became less agitated, but her heart rate was irregular and she was losing consciousness. I don't even know if Shauna heard the transplant surgeon calling out her name as she was running down the hall. The surgeon burst into Shauna's room and announced with a rush of excitement that there was a potential liver. The energy shifted when she saw the state Shauna was in. She immediately ordered Shauna to the ICU and her bed was whisked out of the room so fast that there was time to communicate with me. The situation was incoherent owing to the mix of good news (a liver! A transplant!) and bad news (slipping into a coma?). I just stood there, stunned, in the suddenly empty room.

My job was to clear out Shauna's room. The nurse gave me a large plastic bag that said "Patient's Belongings" and in a daze, I stuffed everything in: tokens of comfort like aromatherapeutic room sprays, lotions and lip balm, and small electronics like a bedside lamp and a cd player. The surgeon came back to give me a hug. I carried the bulky conspicuous bag of Shauna's belongings to the car. I posted a tentative update on the online journal we were keeping that stated, "*events were hopefully underway,*" explaining that Shauna was transferred to the ICU for "*surgery prep.*" Then we waited in the ICU waiting room, as we had been instructed, until it was okay to see her. It was hardly how I

imagined the send-off moment of Shauna's liver transplant. She was now intubated, with a central line in her neck, and under heavy sedation. There was nothing to do but pray.

The transplant surgery was estimated to take place at 4 in the afternoon. The surgeon herself had gone to recover the liver to save time. It was in a nearby city, only one hour away. Dr. T. needed to make a judgement about whether the liver could be used. It was explained to us that a "marginal liver" was being considered because as I wrote in the online journal: "*Shauna truly has no other option at this time. Since this morning she has been in a decline. She had a sudden drop in blood pressure, combined with a racing heart.*" I am not sure I succeeded at conveying that Shauna had plummeted into a critical state because I used a simple dichotomy of "great" and "not great" to explain the situation. The liver was "*apparently not great,*" Shauna was "*not in great shape for surgery*" but her heart, kidneys and lungs were in "*great shape*" as was her strength, endurance and fighting spirit. We shortly found out that the potential liver had tumours in it so the surgeon had to reject it. She assured us she was going to put out an "urgent call" in the region and there would be another organ offer soon.

Six excruciating days later, the second organ offer came late one evening. There was joy and excitement, yet we were guarded because the liver would need to be evaluated to see if it was "suitable for transplantation." Also, I wrote in the journal, "*Shauna will have to survive the considerable stress of a trip downstairs for a CAT scan, which will tell us whether she might have swelling and brain damage. This would make a transplant impossible. The scan itself is a very risky proposition in the eyes of her doctors, who don't want the trauma of going through all this movement to jeopardize Shauna's stability and*

thus the opportunity for her transplant, but there is no other option at this point. The anesthesiologist and all of her life support--with the exception of her dialysis machine--will travel with her for the CAT scan."

Our guts were in knots. The possibility that the liver wasn't good, the spectre of brain damage, the onerous trip to radiology, how fragile she was, how easily her stability could be compromised - these were all the reasons to feel uncertain. But by midnight we had "Good news!!!" The CT scan showed no brain damage. I wrote, "*Pray now that the liver will be okay. This is Shauna's big chance!!*" The journal guestbook was flooded with supportive messages, and we were slowly elevating our hopes and expectations that the transplant was really going to happen soon. A couple of hours later we reported a delay due to the family gathering to pay last respects to the donor. This wasn't received as a setback. My father wrote, "*We stand with grateful and humble hearts in solidarity with the Donor Family as they express their grief and say their final good bye to their loved one.*" We prayed for the donor family, those anonymous people determining the course of Shauna's future. The donor was already poised in the story as her savior, bringing about Shauna's re-birth, which was now scheduled for the very next day.

We were gearing up for what some transplant recipients call their miracle day. My father, especially, was the thick of it, heavily imbued with religious overtones. He wrote in the online journal: "*This is the day the Lord has made; we rejoice and are glad in it. Liberation from a diseased liver is dawning for Shauna. For now we wait in hope for the GO. We are excited about the new possibilities that today can bring.*" We waited all

morning and afternoon to hear about the status of the liver. In the evening we found out it was a “fatty liver” and the surgeon was not going to use it. A fatty liver is an actual medical condition though it sounds less like a disease than a description of a piece of meat. It was a tremendous blow but I sent a message about the bright side too, writing, *“The good thing is that she remained stable throughout the day. We also know from her CT scan yesterday that her neurological function is not impaired. Shauna is still there beneath her unconscious state. Let's hope the next offer is imminent!!! We are so hopeful that Shauna will pull through.”* I also expressed gratitude, once again, to the donor family, the strangers who are part of this story.

We most often referred to a possible transplant as a “new liver” for Shauna as though it had no previous “owner” or donor to speak of. But these two donors with the tumours and the fatty liver are real people. One of them might have been the turning point in the transplant story, the critical element of a successful transplant narrative. A glitch, I think, in the fantasy version of this story is thinking that healthy people “die anyway.” I knew in my mind that I didn’t exactly want someone to die (it is very difficult or perhaps impossible to think this). The notion that people “die anyway” seems like a middle ground. But it does not take into account that such people are likely not well. Most dying people are not eligible donors for this reason. Expanding the donor pool means considering borderline cases, as in Shauna’s experience, donors with tumours and hepatic steatosis that don’t make for good “new livers.”

In her book, *Strange Harvest: Organ Transplants, Denatured Bodies and Transformed Selves*, anthropologist Lesley Sharp describes organ procurement as a form of body

commodification that transforms organs into depersonalized (and scarce) “coveted goods.” She sees that transplant patients/recipients are encouraged to depersonalize organ donation and imagine waiting for a disembodied organ. Meanwhile, on the donation side, the family of the donor is encouraged to see organ donation as a highly personal act, a way for their loved one to “live on.” She frames this as an “ideological disjuncture” between donation and transplantation where competing messages and euphemistic devices are used to describe the same processes. In her analysis, body commodification is couched in “Gift of Life” discourse that stresses lofty values like generosity and altruism and does not acknowledge that organ transplantation is shaped by a utilitarian ethos and “technocratic approach to healing.”

The asymmetry in how the concept of the gift of life plays out for the donor families and for the transplant recipients, stems from a denial that donated organs are, at the of the day, treated as goods or resources that are either good and valuable or bad and worthless. Sharp’s ethnographic research found that donor kin are “encouraged to humanize and personify loved one through donation” and organ donation is positioned as a way of “making a loved one feel real again,” which starkly contrasts with the medical/utilitarian discourse about the organ supply that not only objectifies organs but can sometimes even denigrate them. Sharp writes that over the course of her fieldwork she sometimes heard surgeons say such things as “I don’t want these shitty kidneys.”⁸⁵ Gift of life discourse, on the other hand, is exclusively about saving lives. It can’t acknowledge the agony and

⁸⁵ Lesley Sharp, *Strange Harvest: Organ Transplants, Denatured Bodies and the Transformed Self* (Berkeley: University of California Press), 15, 83.

letdown when organs have to be discarded because they are essentially objects of no merit and medically unsuitable for transplantation.

The fact is most donated livers are not “high quality”; and the number of high quality organs is decreasing. In Lai’s study, only 29% of livers qualified as “high quality.”⁸⁶ John Edgar Wideman writes, “Any story, sad or happy, is always precariously close to being other than what it was . . . We carry forward these fictions because what might have been is part of what gives shape to our stories.”⁸⁷ A waitlist death or a successful transplant may come down to the difference between a “good liver” and a “declined liver.” No one talks about declined livers though because it ruins the narrative for both donors and recipients. Declined livers are also a wild card in a method of allocation set on being “systematic,” rational and fair. The factor of declined livers ruins that too.

Tweaking the distribution system

The flaw in the allocation system that’s received the most priority and attention is regional disparities. According to the United Network of Organ Sharing (UNOS), the current median MELD at the time of transplantation is 32 but it’s widely known that there are significant regional variations. MELD determines priority for allocation (the candidate ordering system), but *distribution* is done according to geographical units and

⁸⁶ Lai, “An examination of liver offers.”

⁸⁷ John Edgar Wideman, “Looking at Emmett Till” in *In Fact: The Best of Creative Nonfiction*, ed. Lee Gutkind (New York: WW Norton, 2005), 30.

tiers.⁸⁸ For the purposes of matching donated organs to transplant candidates, UNOS sectioned the United States into 11 regions. Shauna, for example, was in region 11, comprising five states - North Carolina, South Carolina, Tennessee, Virginia and Kentucky. Patients with the same MELD scores will experience divergent wait time depending on the geographic region they are listed in. This creates the perception that the liver allocation system is inequitable, and some have voiced the critique that in a rational equitable system, access to transplantation shouldn't be affected by the place of listing.⁸⁹

There are three tiers in the distribution system - local, regional and national. Typically, organs are offered to local candidates with the highest MELD rather than being offered to the patients with the highest MELDs in the entire region. The distribution policy of offering livers first to local candidates over regional candidates with higher MELD scores, according to some, "an apparent distortion of the MELD-based system's intent to offer donor livers to those at highest risk of waiting list death."⁹⁰ MELD is supposed to support rational decision-making in liver allocation but the distribution system it's attached to creates random irregularities (think of it as the Model of Erratic Liver Distribution). The distribution system can mean that some patients are luckily transplanted with a low MELD score, while for others there is almost no chance of this happening at all. In this regard, MELD is highly unpredictable and unstandardized.

⁸⁸ Elvir and Lake, "Current State of Liver Transplantation."

⁸⁹ Merion et al., "Evidence-based developments."

⁹⁰ David. A. Goldberg, Richard Gilroy and Michael Charlton, "New organ allocation policy in liver transplantation in the United States," *Clinical Liver Disease* 8, vol. 4 (2016): 108-112/

In 2015, UNOS implemented new “sharing” rules to make the MELD system better aligned with its goal of providing livers to the patients with the greatest medical urgency. This included a new policy called Regional Share 35. It mandates that livers are offered to candidates with a MELD score greater than or equal to 35 in the region before being considered for local candidates with a MELD score below 35. It also included the National Share 15 policy, which means if the priority local candidate has a MELD of 15 or lower (which generally means not very sick), the organ must be offered nationally, to eliminate the use of organs in low-urgency patients. An analysis performed 1 year after the implementation of these new share policies revealed a 30% lower waitlist mortality in patients with a MELD score greater than 30.⁹¹ The Regional Share 35 rule also increased median transplant MELD scores and “increase[d] . . . the proportion of patients undergoing transplants while in the intensive care unit or on life-support devices.”⁹² When Shauna died, no such sharing rules existed.

The rationale for using regions for distribution is reducing cold ischemia time (the time an organ spends on ice in a cooler once it’s been removed from the donor), which improves the quality of transplant organs. It also lowers transportation costs. But these carved up UNOS regions represent arbitrary boundaries, not the distance between the patient and the donor. In 2020, UNOS changed the distribution policy to abolish the transplant regions and to calculate proximity by nautical miles. Allocation rules are now

⁹¹ Elwir and Lake, “Current state of liver transplantation.”

⁹² *Ibid.*, 166.

established by progressive distance from the donor - 150 NM, 250 NM and 500 NM.⁹³

This more “rational” allocation policy might have an impact on the reduction of regional disparities and possibly waitlist mortality. The focus on “fairness,” however, skirts the issue that a lot of patients *will* die, and it seems impossible to determine whether any of these deaths could ever be perceived as *fair*.

Taking it personally

A couple weeks after Shauna died, our friend Katy and I took a short trip to New York City. We stayed with friends in Brooklyn but spent our days wandering Manhattan briskly and aimlessly, wrapped up in scarves and wearing gloves. (I also stayed in bed quite a bit - smoked marijuana in bed, drank beer in bed, and looked at a pile of Life magazines from the 1930s and 1940s in bed). As I remember it, the sky was fiercely blue and the air was crisp, cold and refreshing, and hit the right notes in me. I was temporarily buoyed by blending in with the flow and the fullness of New York, a contrast to the idleness of the previous months in Durham spent waiting in the hospital. It was a fortifying trip.

To get to New York, Katy and I drove from Durham to Richmond, VA and took the Amtrak. We were running late and nearly missed the train. As we barreled through Richmond to get to the station, from the car window, I saw a large single-story building with a sign on the lawn: UNOS (the United Network of Organ Sharing), the organization that manages the entire organ transplant system in the United States. I knew they had

⁹³ Lee, Johnston, Oniscu, “The trials and tribulations.”

their national headquarters in Richmond, and here it was. In retrospect, it's doubtful that I really did see UNOS. Googling shows that the UNOS headquarters in Richmond looks nothing like the building I saw from the car window. The real UNOS is a four-story building with extensive landscaping, surrounded by a memorial garden. But, according to a little internet digging, that UNOS building was only constructed in 2003, and the memorial garden completed in 2005. I still think it's possible that day in December 2004, I saw an *old* UNOS headquarters, an abandoned building, an empty piece of real estate. An old empty deserted UNOS fits with how I thought of UNOS at the time: a sham, a scam, *caveat emptor*. If there had been more time I would have wanted to stop and throw a brick at UNOS in fury.

While I don't blame UNOS for Shauna's death, I can still relate to the urge to throw a brick at UNOS. In fact, throwing a brick at UNOS is a bit like what I am doing through my writing (not directed at UNOS specifically but at the practice of liver transplantation as a whole). The magnitude of cultural, social, medical and institutional validation that liver transplantation has makes me feel like my critical voice is but a small projectile hurled against a behemoth enterprise. It's like an act of vandalism in that it's an attempt to seize a little bit of power and exert a little bit of destruction toward a practice that mostly seems unwilling or unable to admit its own harms and the shortcomings of its policies. While many lives have been saved, other lives have been ruined by transplantation - from "the greedy spell of waiting" (as Shauna once put it) to actually dying, being eluded by a prognostic score and omitted from the dominant transplant story.

One main source of my frustration is that the dominant transplant narrative and MELD are united in a future orientation, whether a “happy *ending*” or a *prediction* of mortality. Neither effectively deals with the here and now for transplant patients, yet both of these imagined futures have a profound structuring influence on the experience of waiting. The symptom burden of end-stage-liver-disease (ESLD) is distorted by the perpetual spotlight on a potentially curative liver transplant in the dominant transplant narrative. Likewise, the suffering and symptom burden of patients is not something the MELD system cares about at all and is not even designed to determine.⁹⁴ MELD doesn’t measure functional decline, pain, distress and other factors that erode ESLD patients’ quality of life. Walling and Wenger write, “although these predictive models [MELD] are useful for predicting long-term outcomes in ESLD and guiding treatment decisions, they do not always align with a patient’s reported functional status and sense of well-being.”⁹⁵ In Shauna’s case this was especially true because MELD does not take into consideration clinical markers like ascites, portal hypertension, varices, hepatorenal syndrome, and hyponatremia. All of these are recognized as poor prognostic indicators and causes of substantial suffering, but this was never brought sufficiently into focus. Instead, Shauna disappeared into a fairy tale or vanished in a depersonalized abstract algorithm of mortality risk. And neither recognize what happened to Shauna at all.

⁹⁴ Freeman, “MELD and the quality of life.”

⁹⁵ Anne. M. Walling and Neil S. Wenger, “Palliative Care and End Stage Liver Disease,” *Clinical Gastroenterology and Hepatology* 12, vol. 4 (2014)

5 The Erasure of Death

The tragedy of organ donation

Anthropologist Margaret Lock argues that when we perceive the shortage of organs as a “crisis” or “waste” we are not acknowledging where organs come from. She writes, “In North America, we proclaim a shortage of organs, even as we wring our hands at increasing suicide rates and drug overdose deaths among youth. But we do not make associations between these disparate ‘facts.’”¹ In her opinion, “we have become so enamored of the idea of saving lives through organ transplantation” that we “studiously [avoid] reflection on how exactly those organs are procured.”² According to Lock, the “gift of life” is a “seductive metaphor” because it “glosses over the source of . . . organs.”³ Similarly, Margrit Shildrick thinks the “gift of life” is a “ubiquitous slogan” because “It is precisely the kind of good news rhetoric that recipients, donor families, transplant teams and the wider public alike feel unconstrained in using insofar as it appears to offer a wholly positive take.” Shildrick argues it “buffers . . . against the more disturbing aspects of transplantation.”⁴

¹ Margaret Lock, *Twice Dead: Organ Transplantation and the Reinvention of Death* (Berkeley: University of California Press, 2001), 371.

² *Ibid.*, 206.

³ *Ibid.*, 4.

⁴ Margrit Shildrick, “Staying Alive: Affect, Identity and Anxiety in Organ Transplantation,” *Body and Society* 21, vol. 3 (20015), 25.

One of the disturbing aspects of organ transplantation is the transformation of human organs into depersonalized body parts. Lock interprets this in terms of the Marxist notion of the fetishization of the commodity. The basis of commodity fetishism is that it renders social relations invisible. Lock explains, “The commodity- the object - is decontextualized in a capitalist system, and consumers know little or nothing about the social relations of production or of exchange.” In the case of organ transplantation, human organs are “transformed into decontextualized objects. Their previous social history is erased, and their value assessed solely in terms of their quality as organs for transplant: are they vital and healthy, have they been well cared for during procurement?”⁵ It’s almost as though the death of the donor isn’t part of organ procurement, a kind of tricky thinking that results, as Locks sees it, in the sense that there should be enough organs to go around to everyone who needs them.⁶

When Shauna was waiting, we hoped for organ offers as though somehow a disembodied liver would magically appear, to “surface” out of nowhere. Though it’s obvious what we were waiting for - a suitable donor to die. In an email a couple months before she died, Shauna announced to family, friends and colleagues that she had improved and was discharged from the hospital but added a note acknowledging that her life now depended on someone else’s death. “*We humbly ask now,*” she writes, “*that you might turn your thoughts to an unknown, grieving family that they might be guided through their time of grief and with incredible generosity, faith and love consider organ donation.*” The

⁵ Lock, *Twice Dead*, 48-49.

⁶ *Ibid.* 372.

indebtedness and gratitude for organ donors is part of what makes waiting for a transplant emotionally taxing. There are tragedies folded into the hoped-for transplant, which despite good intentions, is something that I could very rarely bring myself to think about.

Once I was with Shauna for her appointment at the outpatient liver clinic at the hospital. We were in the doctor's office; the door was open and we were waiting. One of the transplant surgeons was rushing down the hallway but stopped when she noticed Shauna sitting there, a favourite patient. After Shauna introduced me, the surgeon first lamented that I, so young and healthy, couldn't be a potential living donor for Shauna because we had incompatible blood types. "We want," she said, "to get the best possible liver for you." This was nice to hear. "Gunshot wound to the head" were her parting words. Shauna and I sort of giggled.

Of course, all transplant patients need to grapple with the idea that all deceased organ donation is derived from someone else's misfortune. But there is more than this.

"Gunshot wound to the head" is either murder or suicide. Optimal donors are young and often die violent deaths and there is no escaping recognizing that this is connected to a system of economic and social injustice, racism, and also mental illness. The idea that a good outcome for Shauna would have involved someone's life tragically ending with a gunshot wound to the head suggests a bigger, murky picture not really being acknowledged.

Rebecca Solnit argues that our society goes to great length to ignore the suffering of others. She writes, "We come up with elaborate means of not knowing about the

suffering of others and of blaming them when we do . . . to be impervious to suffering you have to convince yourself that people deserve what they're getting, that their suffering has nothing to do with you."⁷ While I didn't feel that others deserved to die, I felt no responsibility for the circumstances that would result in someone dying in such a way that they would be an "optimal" donor. The "it has nothing to do with me" attitude is the kind of individualistic thinking that excludes the suffering from others from one's own comfort, safety and happiness. It also shields us from having to think about the dynamics of race and racism and how the norms and standards of individualism are damaging to people of color especially because individualism, along with competition, perfectionism and progress, perpetuate regimes of white supremacy.⁸

In those days leading up to Shauna's death had there been a fatal car crash, a gunshot wound, a suicide, I would have been very glad about it, glad that someone else died. The doctors would come to us with "good news." The message wouldn't be about someone else's life, but a body part - a liver, what we were waiting for. Jeffrey Prottas writes: "if it appears that the organ procurement agency is 'waiting for someone to die,' it's because they are. But this is quite different from wanting someone to die, and painful as the thought must be, organ transplantation depends on death."⁹ That painful part is well shielded though largely because the practice is immersed in euphemistic language.

⁷ Rebecca Solnit, "The Separating Sickness," *Harper's Magazine* (June 2013).

⁸ See Kenneth Jones and Tema Okun, *Dismantling Racism: A Workbook for Social Change Groups*, ChangeWork, 2001.

⁹ Quoted in Renee Fox and Judith Swazey, *Spare Parts: Organ Replacement in American Society* (Toronto: Oxford University Press, 1994), 69.

“Availability” is a prime example of a euphemism in organ transplantation. Will there be a liver available in time? Availability is a word that is used freely and easily. The availability of a “new liver” submerges the death of the donor in a narrative of redemption.

The tendency to see organ transplantation exclusively as a life-saving enterprise masks the donor’s death and little is done to acknowledge the tragedy of organ donation - the focus is all on the benefit and the “good part” of saving lives. The blindness to loss and mortality is a form of denial and is supported by the idea that death can be imbued with “more meaning” if it can be endowed with life-giving legacy.¹⁰ This win-win version of organ donation and transplantation has salience (and is persuasive) because it merges moral philosophy (altruism) and the rational language of economics (to maximize life-saving organ recovery).¹¹ It gels with our value system. The naysayers who don’t see it as pragmatic and humanitarian are dismissed as superstitious, irrational, mistrustful and paranoid. The normative view is to see organ donation as a life-saving act of kindness and an opportunity to “create something of value out of senseless, bad deaths.”¹² With a focus of turning losses into “positive things,” organ donation and transplantation represents “hopes for transcendence [and] for continuity” and can seamlessly become a narrative of conquering and transcending death for both donors and recipients.¹³

¹⁰ Fox and Swazey, *The Courage to Fail: A Social View of Transplantation and Dialysis* (Chicago: University of Chicago Press, 1974), 28.

¹¹ Fox and Swazey, *Spare Parts*, 69.

¹² Lock, *Twice Dead*, 206-207.

¹³ *Ibid.*, 196.

The blurry state of dying

The innovative life-saving technology of organ transplantation “forced a reconsideration of the boundaries between life and death.”¹⁴ Namely, the category of brain death opened discussions that made “the very concept of death . . . increasingly complex, both physically and philosophically.”¹⁵ Medically, brain death was defined by an ad-hoc committee at Harvard Medical School in 1968 as the irreversible cessation of all brain function. Brain death is only possible in the realm of life support technologies so that an individual can be “kept alive” with machines even when they have lost all brain function. This has made the distinction between life and death less clear cut and discernible. For an individual who has suffered brain death, signs of life are a “technical artifact”; the machines are doing “the work.” Attesting to this ambiguous state, Lock notes brain dead patients were sometimes called “living cadavers.”¹⁶

In her fieldwork, Lesley Sharp observes the way people grapple with the concept of brain death. Technically, it may be difficult to grasp, but Sharp argues it gels with compatible lay understandings of loss of subjectivity. People relate to the *feeling* that their loved one is no longer thinking, sensing or present; she argues the notion of brain death corresponds to “intimate understandings of the selfhood of the beloved” and the sense “that the social being they know and love is irrevocably lost.” Organ donation can be a way to make a

¹⁴ Ibid. 2.

¹⁵ Nicholas Tilney, *Transplantation: From Myth to Reality* (New Haven: Yale University Press, 2002), 158.

¹⁶ Lock, *Twice Dead*.

someone feel real again. It's seen as a transcendent and regenerative process infused with hope, renewal and transformation.¹⁷

A narrative of transcending or overcoming death is echoed throughout the culture of Western biomedicine. Fighting death, thwarting death, keeping death at bay can also be interpreted as a form of denial and the inability to accept human limitations and mortality. Surgeon Atul Gawande describes medicine's tendency to deny mortality in his insightful book *Being Mortal*. Part of the issue, he argues, is that doctors have difficulty openly acknowledging death with their patients. Instead, they have a tendency to talk about "treatment options" rather than dying, even when death is on the immediate horizon. Gawande admits that "discussing a fantasy was easier - less emotional, less explosive, less prone to misunderstanding than discussing what was happening before my eyes."¹⁸ Anthropologist Sharon Kaufman also notes the predominance of ICU terminology like "code status," which veils death in language about "resuscitation efforts."¹⁹ No one talks about it head on.

As Shauna was dying, it wasn't obvious how to contend with the possibility of death when the fantasy of recovery was continually reinforced. The experience of waiting for a transplant is a particular form of dying that is heavily (*heavily*) steeped in the denial of mortality. Dying was thoroughly off-script. No one even uttered the words waitlist death.

¹⁷ Lesley Sharp, *Strange Harvest: Organ Transplants, Denatured Bodies and the Transformed Self* (Berkeley: University of California Press, 2006), 83-100.

¹⁸ Atul Gawande, *Being Mortal: Medicine and What Matters in the End* (Toronto: Doubleday, 2014), #.

¹⁹ Sharon Kaufman, *And a Time to Die: How American Hospitals Shape the End of Life* (New York: Scribner, 2005).

We were anxious about her being “delisted,” a technical or bureaucratic term that stood in for dying. We continually describe Shauna’s situation as a “closing window.” We used the word “stable” to describe her ambiguous place on the spectrum between life and death. The moment of death would be a decision to “withdraw support.”

Gawande writes, “I knew theoretically that my patients could die, of course, but every instance seemed like a violation, as if the rules we were playing by were broken. I don’t know what game I thought this was, but in it we always win.”²⁰ This mentality positions death as a rule infraction or a Game Play Error. The medical system is built around the possibility of “winning” against the odds and it fails to prepare patients for outcomes that are “vastly more probable.” Gawande writes, “We’ve created a multitrillion-dollar edifice for dispensing the medical equivalent of lottery tickets—and have only the rudiments of a system to prepare patients for the near-certainty that those tickets will not win.”²¹

The orientation towards “winning” means that more and more patients are dying in the ICU following withdrawal of life-sustaining treatments. According to Gawande, “Among patients with chronic diseases who die in the hospital, approximately half are cared for in the ICU in the three days before their death and a third pass at least 10 days in the ICU during the final period of their hospitalisation.”²² This is where patients find themselves in the gray zone between life and death.

²⁰ Gawande, *Being Mortal*, 7.

²¹ Ibid.

²² Ibid.

In the ICU, the distinction between “medical care” and dying is blurred. When on the “threshold of death,” medical technologies can effectively put you “on hold.”²³ We put Shauna “on hold” until the bitter end. There was no sense of “excess” treatment, or limits of acceptability around life-prolonging technology. We wanted to prolong Shauna’s life as much as we possibly could, using everything available to ward off death in the context of critical care.

The patient typically undergoes a lot in the ICU. *In Raising the Dead: A Doctor’s Encounter with His Own Mortality*, Richard Selzer explains, “the man in the bed is to be ventilated, dosed, defibrated, probed, suctioned, and infused. Most of his bodily functions will be taken over.” The result is a kind of dehumanized state - “No longer need he swallow, chew, inhale, or exhale, cough, urinate, defecate, clear his throat, maintain acid-base balance, cogitate, remember, sigh, weep, laugh, desire.”²⁴ Bodily functions and human agency are taken over by the machines to which patients are attached by possibly “more than a dozen lines, tubes, or leads.”²⁵ Patients are reduced to “prisoners of technical apparatus.”²⁶

While “medical technology” can serve “to eliminate suffering and control and manage the body’s disintegration,” people say they “don’t want the “overuse of drugs and

²³ Leo Pessini, “Life and death in the ICU: ethics on the razor’s edge,” *Revista Bioetica* (2016).

²⁴ Quoted in Lock, *Twice Dead*, 55.

²⁵ *Ibid*, 62.

²⁶ Pessini, “Life and death in the ICU.”

machines” when they are dying.²⁷ The ICU experience creates a conundrum because technology is an integral part of intensive care. Margaret Lock explains, “Technology is indispensable not only for supporting the respiration of critically ill patients but also for feeding them, administering medication, and monitoring body functions. Kaufman aptly describes “stability” as a state “produced and regulated by detailed and ongoing surveillance.” Intensive care specialists must have “an aptitude for technology” because knowledge about the patient’s status and condition is filtered through technology, which, Lock explains, is inherently objectifying and dehumanizing. She writes, “The numerous printouts, traces, films, X rays that result from the close monitoring of patients is a kind of ‘displacement’. The subjective experience of the patients - their ‘personhood’ - is unavoidably discounted and replaced by a medical narrative composed of graphs and traces.”²⁸

A seminal study in the mid-1990s found that being connected to tubes and machines and an excess of procedures are reasons why people report a lack of satisfaction with the way their loved ones died. Kaufman’s ethnographic study of ICU death was inspired by this finding.²⁹ In her research she is intrigued that despite the aversion to being “attached to machines,” families don’t refuse life-prolonging strategies when they are offered. In her fieldwork, she observed that when faced with the immediate threat of mortality, patients

²⁷ Kaufman, *And a Time to Die*, #.

²⁸ Lock, *Twice Dead*, 61-63/

²⁹ The study was part of SUPPORT (Study to understand Prognoses and Preferences for Outcomes and Risks of Treatments). See Alfred F. Connors et al., “A Controlled Trial to Improve Care for Critically Ill Hospitalized Patients,” *JAMA* 274, no. 20 (1995): 1591-1598.

and families continually choose life support and life-saving interventions. At the bedside, in a crisis, these measures aren't perceived as "artificial life."³⁰

Kaufman writes, "As long as life-sustaining techniques and pathways exist, they will be wanted and chosen."³¹ In her analysis, this is because fundamentally people don't want their loved one to die. The more *not dying* is pursued the more that a "good death" (characterized as being peaceful, easy, comfortable and without the "overuse" of technology) fades away. As Kaufman explains, there are powerful emotions attached to wanting cure, evading death, overcoming disease and frailty, all of which perpetuate our enthusiasm for medicine, and the drive for optimum health and longer life. Kaufman argues, it is "ironic" that "there is simultaneously a loud cry for a kind of dying in which medical intervention is minimized." Kaufman sees this as a paradox of wanting the "best" medical treatment and the "best" death at the same time.³²

A feature of the "good death" is awareness and facing death with courage. There are physical and communication barriers to achieving this when someone is on life support in the ICU. They are inaccessible. Lock writes, "To an outside observer the ICU, with its central monitoring station and beds ranged around the walls, all surrounded by machines quietly doing their work, appears calm."³³ But the appearance of calm is also related to the fact that many patients are drugged beyond the point of awareness or coherence.

³⁰ Kaufman, *And a Time to Die*, 319.

³¹ *Ibid.*, 319.

³² *Ibid.*, 323.

³³ Lock, *Twice Dead*, 62.

Anthropologist Robert Murphy sees heavy sedation as a form of isolation and a distancing mechanism that makes death a remote experience. He writes, “it is now common in our society for death to come during a drug-induced semi-coma.”³⁴ Dying has become more obscure and inscrutable. It’s alienating for loved ones. Lock explains, “New technologies have made death ‘invisible’ . . . an event that the family can neither fully participate in nor verify.” Death in the ICU has also been decentralized, in the sense that different body parts can die at different times.³⁵ In Shauna’s case we were told about multiple “systems” failure, one organ at a time. Though none of this was outwardly obvious.

In the ICU, death is not strictly a natural occurrence. It is actively managed and prolonged, and packaged as a “decision.” Kaufman argues that hospital ICU culture does not treat death like an inevitability or a fact, but as a “frame of interpretation,” leaving it to the patients to surmise and “choose” dying. Kaufman’s insight is that death in the hospital has become a “decision” about the “switch from life-prolonging moves to making preparations for death moves.”³⁶ Sometimes the choice is presented when the provision of a “good death” seems an important consideration. This was not the case with Shauna. At no point did we care about a “good death” because in our minds she wasn’t dying at all. With Shauna, the transition from “life prolonging moves” to “making

³⁴ Robert Murphy, *The Body Silent: The Different World of the Disabled* (New York: WW Norton, 1987), 64.

³⁵ Lock, *Twice Dead*, 71-72.

³⁶ Kaufman, *And a Time to Die*, 153.

preparations for death moves” was so abrupt. The gap between “staving off death” and the “vital existential moment of death”³⁷ was miniscule.

A “good death” involves the “acknowledgement of being on a terminal pathway” with ample time to talk about it and accept it.³⁸ But, modern medicine and healthcare is stacked against the acceptance of death. In a ground-breaking 1965 study by Barney Glaser and Anselm Strauss, they found that hospital staff will impede awareness of dying at the end-of-life by “maintaining a fiction” that survival is still possible. “Open awareness” of dying is preferred so patients and families have the opportunity to be “at peace” with death before it occurs.³⁹ But even today this is not always practiced. As Gawande suggests, there is perhaps the concern that no one (physicians, nurses, patients, families) really have the fortitude or the emotional equilibrium to confront death. It is avoided rather than addressed directly. As Gawande explains, “discussing a fantasy was easier.”

The acclaimed poet Mary Oliver writes, “when death comes like an iceberg between the shoulder blades, I want to step through that door full of curiosity, wondering: what is it going to be like that cottage of darkness?” This line in her poem *When Death Comes* exemplifies the courageousness and acceptance often lacking in a hospital context but it does so while portraying death in a disarming way as a quaint “cottage of darkness.” I’ve

³⁷ Jessica Nutik Zitter, *Extreme Measures: Finding a Better Path to the End of Life* (New York: Avery, 2017).

³⁸ Kaufman, *And a Time to Die*, 154.

³⁹ Tom Andrews and Alvita Nathaniel, “Awareness of Dying Remains Relevant after Fifty Years,” *Grounded Theory Review* 2, no. 1 (2015).

always recoiled from this pairing of mortality and quaintness, and the suggestion that we should endeavour to confront death full of wonder. It seems like a standard that is too high, certainly in Shauna's case, to leap from waiting for a transplant to ease with dying.

Strive, strive, strive

In her memoir, surgeon Pauline Chen acknowledges that physicians are reluctant to abandon treatment even if there is a “glimmer of hope” She writes that not treating or to stop treating is “the moral equivalent of giving up,” inextricably linked with a sense of failure and defeat. The result is pursuing “hope-driven treatment” at almost any cost.⁴⁰ Gawande also acknowledges that treatments are pursued regardless of only offering a “sliver's chance of benefit.”⁴¹ While science and medicine are systems of knowledge that privilege rationality, Gawande stresses that hanging on to that sliver's chance stands out as an irrational calculus that strangely has become the common thing to do. According to Gawande, doctors have a fear of doing too little, despite evidence that suggests that they routinely do too much. Doing too much has just become an accepted part of the medical system.

Our celebratory attitude about medicine's “power to cure” is apparent in the field of transplantation. We are not always aware of the high costs of the enterprise of “saving lives.” In Shauna's case, it led to aggressive attempts to repel death and pursue the

⁴⁰ Pauline Chen, *Final Exam: A Surgeon's Reflections on Mortality* (New York: Vintage, 2007), 148.

⁴¹ Gawande, *Being Mortal*, 9.

fantasy of a cure, even as the prospects of a transplant surgery became riskier and its success more remote and unlikely. The possibility of “saving her life” overrode the reality that she was dying. It thundered on despite the dismal truth that her chances were grim. My father wrote in the journal: “*We are encouraged by the postings of the happy stories about others who have been in similar straits and have recovered. Shauna’s situation is grim but there is time for our story to be a happy one too.*” It wasn’t supposed to end in death. There was going to be a happy ending. We refused to see it any other way.

From the patient’s perspective, the stakes of transplantation are high. Transplantation is a remedial treatment for liver disease that often represents a patient’s last and only hope. This is why even if failure was likely it seems like the superior option to just letting someone die. This mentality dominates transplantation. Even if the likelihood of survival was minimal, the other option was certain death. Any chance was better than no chance at all.

The idea that pursuing transplant is in the best interest of patients, when the alternative is certain death, is a Western way of thinking and not “universal.” Margaret Lock, who has examined transplantation in different cultural contexts, emphasizes that the unquestioned goodness of transplantation is a Western phenomenon. In *Twice Dead*, she recounts the story of a baby born in 1989 in a First Nations community of northern Alberta who was diagnosed in infancy with a serious liver disease and given a prognosis of a few months to live without a liver transplant, which would require that the family relocate and enrol at the transplant clinic in London, ON. According to Lock, the parents had the sense that

a transplant would be “unnatural” and “violate the baby’s physical and spiritual identity.” They refused to pursue transplant as a treatment for spiritual reasons as well as medical concerns about the side-effects of long-term use of immunosuppressants, including vulnerability to infections, kidney damage and increased risk of cancer. They moved instead to a reservation in Saskatchewan because the doctor in Edmonton threatened to refer their case to social services on the ground that they were refusing “essential care.” They were worried their baby would be taken away.

In Saskatchewan, the parents found a pediatrician in Saskatoon who agreed to care for their baby even though they did not want a liver transplant. Even still, social services got involved. There was a court hearing that included testimony from their doctor, Dr. Garth Bruce (who, coincidentally, was also Shauna’s pediatrician at the time), who validated the parents’ concerns that post-transplant prospects for the baby were unknown. He relayed another case of a 7-month-old baby who had a liver transplant and had been in a coma ever since. The court decided to uphold the position of the parents. The judge’s ruling stated, “There is considerable uncertainty as to the future quality of life for a ‘successful’ recipient. There is no real way to look into the future to determine what may be visited upon this child. The ‘successful’ candidate may be committed to a life of prolonged suffering.” The baby died at home at 11 months old; and the mother recounts, “my heart broke wide open and I experienced a love and a sense of inner peace that I had never known before.”⁴²

⁴² Lock, *Twice Dead*, 310-314.

The cultural and spiritual values that support approaching an infant's death with peace and courage vs. the imposition of the doctor to promote treatment in the name of the child's best interest demonstrate both the colonial structures of Canadian institutions, as well as the colonial mindset of saviourism and Eurocentric moral superiority that runs through transplantation. It is significant that the Indigenous parents had no autonomy to make a choice for their baby without the support of Western authority, in this case the doctor and the judge who validated the parents' choice to refuse transplantation on the grounds of the fallibility of the treatment and its uncertain outcomes. The misguided effort to "save" the baby reveals how the norms and standards of biomedicine and transplantation (and the self-appointed power to act in the "best interest" of others) has much in common with colonialism and imperialism – expansion (encroachment on the sovereignty of others, the extension of lives at all costs), resource extraction and "mastery" over the natural world. This is all part of the fantasy of transplantation, and what Thomas Starzl calls the "glory of striving."

In the early experimental years of transplantation, it was not obvious there was always a balance between providing care for the patient and pursuing treatments that realistically only had a small chance of success. Transplant pioneer Dr. Francis Moore asks:

Does the presence of a dying patient justify the doctor taking *any* conceivable step regardless of the degree of hopelessness? . . . it gives the impression that physicians and surgeons are adventurers rather than circumspect persons seeking to help the suffering and the dying by the use of hopeful measures. The dying person becomes the object of wildly speculative experiments when he is hopeless

and helpless rather than the recipients of discriminating measures carried out on his behalf.⁴³

Thomas Starzl thinks, on the other hand, that while a patient may be subject to aggressive treatments that are unlikely to work, they have at least been given a shot. With reference to pediatric patients, Starzl argues, “Those opposed to trying always claimed that these little creatures [pediatric patients] had been denied the dignity of dying. Their parents believed that they had been given the glory of striving.”⁴⁴

When Shauna died, I did not experience “the glory of striving”; instead I felt what anthropologist Ruth Behar calls “double sadness.” She explains, “grief stems not simply from the loss of one beloved but from a consciousness of defeat - the sense that more could have been done, that the struggle ended too soon.”⁴⁵ Shauna’s loss was compounded by grief about the liver transplant itself (that a liver transplant didn’t happen felt like a loss in its own right), which stung all the more because, by the standards of being a “good patient,” Shauna had tried so hard.

Robert Murphy writes that in rehabilitation patients are pressured to try hard and keep up courage. The prevailing mentality is that there will be payoff for substantial effort and maintaining motivation and determination, a pain equals gain mentality that urges patients to put on a mask of bravery and “whistle in the dark.”⁴⁶ The idea that the volition

⁴³ In Tilney, *Transplantation*, 193.

⁴⁴ Thomas Starzl, *The Puzzle People* (Pittsburgh: University of Pittsburgh Press, 1992), 165.

⁴⁵ Ruth Behar, *The Vulnerable Observer: Anthropology that Breaks Your Heart* (Boston: Beacon Press, 1996), 52.

⁴⁶ Murphy, *The Body Silent*, 52.

and determination of the patient will affect prognoses exists in other areas of medicine as well, like cancer. There is a tendency, according to Susan Sontag in *Illness as Metaphor*, to perceive illness as a “test of moral character,” a notion she critiques because doing so deflects attention from “the calamity of the disease” itself.⁴⁷

Sontag wrote *Illness as Metaphor* in the wake of her own experience with breast cancer but the book makes no mention of her personal struggles. This was a deliberate choice. She explains, “I wanted to be useful – to tell yet one more story in the first person of how someone learned that she or he had cancer, wept, struggled, was comforted, struggled, took courage . . . though mine was that story. A narrative, it seemed to me, would be less useful than an idea.”⁴⁸ Her key idea is that we always look to illness to contain “deeper truths” and social and political meanings rather than dealing with illness as illness itself. Recently, Sontag’s son David Rieff wrote a memoir about his mother’s death. He explains that despite Sontag’s critique of illness metaphors, in her own life she fiercely took on cancer as a “battle.”⁴⁹ She also viewed her chances of survival as dependent on her willingness to suffer and “her willingness to have the most radical, mutilating treatment.”⁵⁰ For her, force of will was a weapon against her dire prognosis. She wanted her entourage, doctors included, to rally around her survival even if it departed from a

⁴⁷ Susan Sontag, *Illness as Metaphor* (New York: Farrar, Strauss and Giroux, 1978), 41-42.

⁴⁸ Quoted in Lisa Diedrich, *Treatments: Language, Politics and the Culture of Illness* (Minneapolis: University of Minnesota Press), 32.

⁴⁹ David Rieff, *Swimming in a Sea of Death: A Son’s Memoir* (New York: Simon and Schuster, 2008).

⁵⁰ Ann Jurecic, *Illness as Narrative* (Pittsburgh: University of Pittsburgh Press, 2012), 25.

more “realistic” outlook. Rieff considers that in terminal diagnoses, “*There is such thing as too much reality.*”⁵¹

Rather than facing reality, Rieff explains that Sontag looked backward. Her history with cancer was extraordinary. She’d had two previous cancer diagnoses, including metastasized breast cancer in the 1970s that she overcame by seeking out a radical and aggressive therapy. In her experience, pursuing aggressive treatments was the reason why she survived. Thwarting her death on two occasions gave Sontag the sense of “being the author of . . . her own disease.” Rieff writes, “How, above all, if you struggled to find the right doctors, and braved the most gruesome treatments, can you really say to yourself that none of this really had much to do with why you are still walking on the earth.”⁵² In the end, despite her efforts, Sontag died, leaving Rieff to wonder whether the hubris and the suffering was worth it and whether it would have been better to face mortality with more humility and acceptance.

Rieff’s memoir resonated with me, particularly his exploration of how focusing exclusively on survival can create ambivalence and regret when death occurs. Part of me feels even foolish for not accepting what was obviously coming. I once watched a BBC nature documentary with my kids that featured a battle between a rattlesnake and a squirrel. The squirrel’s strategy was to outsmart and out-manuever the rattlesnake by rubbing some shed snakeskin it found into its fur to create a kind of olfactory defense that

⁵¹ Rieff, *Swimming in a Sea of Death*, 42.

⁵² *Ibid.*, 86.

would make the rattlesnake think a rival was nearby. It swished its bushy tail from side to side wafting the scent and creating the illusion of being bigger and more threatening. The ruse works. According to the narrator, the snake is “confused” and slithers away. The brave squirrel wins. This astounding glimpse at the natural world impressed my children but it was easy for me to imagine this scene ending with the snake striking and squirrel being devoured. In which case, the actions of the desperate squirrel wouldn’t look so clever and heroic. It would look like a stupid squirrel. We imagine that it is valiant to go down with a fight or a wild shot but, depending on the context, it also can signify failure to “accept” death and therefore naivete or lack of wisdom. Endings do matter, in the sense that they can detract from the “glory of striving.”

Coda

The night before Shauna died I hadn’t stayed at the hospital like I usually did. I was sent home for a night’s rest by the group of Shauna’s friends who had become my ad hoc support community. I was demented from exhaustion and traumatized the by news about the Status One patients. My mother decided to stay the night in my place. My mother had the reputation of being “frail” both in her physicality and her demeanor. She is a tiny person. Unlike the rest of the crowd, she wasn’t exuberant about the possibility of a victorious ending (she could not sustain this). She thought more about defeat than the rest of us, and says that as a result, she often felt silenced and marginalized. I think we saw her pessimism as a weakness and so we were dismissive of it. I don’t think I could distinguish between accepting that Shauna could die from wanting her to die. It almost

seemed like the same thing. My mom believes that she was “realistic” about death the whole time.

That night, my mother didn't stay in the conference room like I did but on a recliner in the ICU waiting room. There were two recliners in the waiting room, always in use. They were coveted because all the other chairs in the waiting room were lined up around the perimeter of the room and bolted to the ground, with thin padding, straight backs, and armrests that prevented stretching out or any other attempts at getting comfortable. We needed to stake out a recliner for my mother to spend the night on by watching for the rare occasion one was vacated. Someone was going to have to spring upon it as quickly as possible, and then make sure it was occupied by one of our group for the rest of the day. You had to be that vigilant if you wanted a recliner.

The ICU nurse was usually available first thing in the morning to let us know how Shauna's night had been and give updates on her “stability.” I arrived at the hospital early and was allowed in the ward to see Shauna right away. This is what I remember: I was in the hallway right outside Shauna's room putting on a gown and gloves and the nurse, a new one I had never met before, came up to me and said, “oh, you don't need to gown and glove. Shauna's been de-listed for transplant.”

The scene that followed could have been directed by John Cassavetes. As a filmmaker, Cassavetes is known for directing emotionally wrought performances, perhaps most notably the performance of Gena Rowlands in *A Woman Under The Influence* (1974),

which has been described as intense, vivid and chaotic portrayal of a character whose world is crumbling down.⁵³ I don't know exactly what happened. There was shouting. I know I accused the nurse of not having a *fucking clue* what she was talking about. The commotion was quickly regulated by the head nurse who immediately saw that the conflict between me and that "Shauna is de-listed" nurse was irreparable. She sent her away to the far end of the ward where we wouldn't cross paths (I wanted her to go to hell or worse) and switched in another nurse to replace her.

I called the transplant coordinator nurse. She assured me that she had heard nothing about Shauna being delisted, but later in the day there was going to be a family meeting. I requested the presence of the hepatologist Dr. S who was tied up in his clinic that day with appointments but available later in the afternoon. I needed him there because I trusted him the most. His opinion was the only one that mattered to me. The family meeting was with Dr. S., the transplant coordinator nurse and the rest of the transplant team, the ICU docs and the new nurse for the day. There were boxes of Kleenex on the table. I guess we knew what they were going to say. It was unanimous that life support should be withdrawn. Transplant was no longer possible.

We had been warned about other "systems" failing, and neither Shauna's heart (low pressure, erratic rhythms) nor lungs were in good shape anymore. Combined with her already failed liver and kidneys, this meant she had "multi system organ failure" (the

⁵³ See Sven Mikulee, "'A Woman Under the Influence': Cassavetes' Intense and Emotionally Exhausting Slice of Life." <https://cinephiliabeyond.org/a-woman-under-the-influence-cassavetes-intense-and-emotionally-exhausting-slice-of-life/>

cause of death on her death certificate). We also knew about the concerns of infection, given her overall weakened state and fragility, and she had an infection too. We gathered around her bed with the ICU nurse who was going to turn the ventilator off and remove the ventilator tube. There was no process of dying to witness. It was instantaneous. Without the ventilator, Shauna didn't take a single breath. There truly was no life left in her.

There was, though, a shocking sense of rupture. Maybe I was expecting more of a soothing letting go, or a drifting away. There was an ugliness and brutality to the suddenness of the break, like she had just been sucked out of an airplane at lightning speed, snapped into oblivion. Her fast disappearance felt empty to me. I wish death felt more lush or dense. Foundationally, I collapsed (a friend noted that part of me had died too). I yearned for something consoling like peace or transcendence, which I found a bit in the bone structure of her face that was so delicate, and in her clear smooth skin.

I felt hollow, like my central most inner part was suspended and had no essence, sensation or physicality. Feelings seared straight through me without sum or substance or landing on my body. I went blank. My mother wanted Shauna spared the indignity of being sent to the hospital morgue so we waited with her in her room for the funeral home to come with their black suits, formal demeanors and synthetic sympathy. In the meantime, another *persona non grata*, the attending ICU doctor, came in to “pronounce death” (a redundancy) and sign the death certificate, a bureaucratic intrusion and gesture of ordinariness that clashed with our monumental loss.

Everything about it felt wrong. Shauna's death was essentially a message received in a boardroom, a setting that is far too staid for the intensity of life and death matters. It's appropriate, though, for the delivery of grave news and making a logical case. Shauna's condition was being "managed" and "controlled" now it had become "unmanageable" and "out of control". The doctors were clear they had no more tools, tricks, and juju magic. Everyone at the table said so; and everything collapsed in that boardroom meeting into a meaningless gnarl of futility. Bob Dylan recorded a song in the late 1970s called "Senor (Tales of Yankee Power)." Dylan experts have grouped with song in with his "south-of-the-border adventure songs" but I think about that boardroom when I hear these last lines: *"Let's overturn these tables; Disconnect these cables; This place don't make sense to me no more; Can you tell me what we're waiting for, senor."* The idea of overturning tables is my fantasy version of what happened. In that boardroom I sat still and wept but it would have been preferable to stand up and flip the tables over. Willie Nelson's cover of the song is even better because his voice is a mournful and gentle counterpoint to my visions of trashing the boardroom. This death wasn't easy to accept. It made the end of Shauna's life seem like a charade.

A couple of hours before Shauna died, I announced in the online journal that Shauna "had spiralled and crashed." I began the journal post almost sheepishly with the quasi-disclaimer "we don't know how to say this." I wrote at 4PM on a Friday afternoon:

We don't know how to say this but Shauna has spiralled and crashed. Her blood pressure, her heart, and an infection. All of her doctors, even her beloved Dr. S, recommend that we withdraw support. We want her to die peacefully. We are

planning a funeral here in Durham. For those who can, you might want to start making travel arrangements.

We had no idea that things were coming to such a bad end.

Later I posted a message, with the help of the hospital chaplain, that Shauna had died at 6:15. It said (the chaplain's words): "*Shauna's suffering is over now and in the loving hands of God.*"

Shauna's funeral planning began the next morning. The funeral home director gently barrages you with logistical questions about what they should do with the body that is now in their care. So, out of obligation, we made decisions quickly. The funeral would be in a week's time, but without a casket and a body. We didn't want Shauna to be embalmed, looking stiff and waxy, and opted to cremate her the following day.

We had a small impromptu gathering at the funeral home right before she was cremated. We chose not to have Shauna dressed in her nicest clothes (one of the questions the previous day was undoubtedly about dressing instructions). She hadn't worn civilian clothes for months, let alone formal attire, and it seemed too odd and unfamiliar to picture her that way, too dissonant with the Shauna who died. Clothes would have implied continuity between her life and her death, not rupture. The hospital gown wasn't a dignified option so we decided to simply wrap her in a white cotton sheet. The simplicity was striking and suggested a mythical or spiritual state of being.

The funeral home ambience is generic and overly tame, dominated by muted tones, glossy wood, artificial plants, blandness and drabness (like the hospital). After the

gathering started, I had the idea to fill the casket with rose petals. Close friends rushed off to the florist to buy dozens of multi-colored roses and together we all tore rose petals from the stems and scattered them around her body. The spontaneity of it brought creative energy and it made this small makeshift ceremony feel like the least repressive and least numbing experience in months. The configuration of Shauna in the casket, the white sheet, the petals - all on the cusp of immolation - was sublime.

The funeral a week later was miserable. I wanted to give a eulogy but I couldn't write one. I just read from her journals, through tears. Theoretically, I understand that a funeral can be a "celebration of life" but in this instance it really wasn't. It was just too sad. Being "alive in memory" didn't feel like anything substantial, lame in fact. The mood was sombre. Guests sat. There were no trappings of celebration aside from champagne, which I drank quite a bit of. Like any funeral, there was lots of hugging but this was hardly the "tribute" she deserved. It was still sinking in that what had happened was irrevocable; we were no longer waiting for something to change.

I liked the idea of establishing a ritual of burning rose petals on the anniversary of Shauna's death to symbolize her cremation. I didn't succeed though. Fresh rose petals don't ignite easily and they don't incinerate completely. They burn down a little, and only with the help of butane. For the first-year anniversary of Shauna's death I went to Mount Royal Park and started a small illegal fire in the woods with my rose petals and almost an entire bottle of lighter fluid. Another year, I lit a fire in a kitchen pot on the balcony. Neither time evoked much sentiment, not as much as I hoped it would.

The idea of a designated day, like a death anniversary, is meant to be a recognition but it feels like a minimization, as though it was possible that a date (significant though it is) could predict and put boundaries around a day of year to feel the loss most acutely. The anniversary date doesn't miraculously conjure sadness and longing, and if I can summon those feelings they often come with anxiety and a sense of guilt and failure. As grief loses rawness it loses focus, becoming scattered throughout different aspects of daily life and other relationships, puncturing little voids.

For the 10th anniversary of Shauna's death, close friends and family planned a reunion in May in Ocracoke, NC, a tiny island off the Outer Banks. Though I was greatly looking forward to it, when I was there, I retreated inward and went to bed early each night while others stayed up late on the screened in porch. While I couldn't connect with others I did feel strongly that there is something inherently cathartic about the ocean. It induces an intense longing that seems to come from the sea itself - a vast expanse of generalized heartache, human troubles, fatality and loss. Standing on the ocean's shore makes death, loneliness and separation seem part of normal reality, just the way things are. The ocean has a way of making loss and grief generalizable without reducing its potency.

The repercussions of denial

It seems absurd to me that I ended the announcement of Shauna's death with the wide-eyed claim "we had no idea things were coming to such a bad end." Ironically, MELD is about the risk of mortality but the actual reality of dying on the waitlist remains unspoken. There is no discussion of the kind of death "waiting for a transplant" leads to. I was dramatically unprepared for Shauna's death. There is very little guidance for the

experience of the loss of a loved one on a transplant waitlist. Information on how to prepare for the transplant and what to expect afterward during recovery is readily available. The possibility of being de-listed or death is not explored. How death impacts waiting is a hidden experience, a lurking crisis.

The silence around death limits sensitivity to patient experience, including our sense of compassion, empathy and understanding. Ian Craib contends that contemporary society encourages us to “hide from disappointment” of all kinds. We bury our losses and our failures and parade our successes.⁵⁴ When I think back now, I can recognize many taboos around death that we actively kept in place (and are kept in place by the culture of biomedicine and transplantation). I think that Shauna was privately thinking about her mortality, and I am left with only little inklings of this. For instance, I see that on one occasion she wrote in her journal: *Who are the people who die waiting?* The question itself implies the people who die are invisible, unknown entities and also suggests that she was thinking: will it be me?

Recently, researchers have advocated for more palliative care for ESDL patients, including transplant candidates. As it stands, there is a “lack of palliative care focus” for transplant patients, based on a misperception that palliative care is only an option for patients who are certainly dying. Boyd et al. explain, “Palliative care may be viewed incorrectly as only applicable once the patient is in the final days of life and all other

⁵⁴ Ian Craib, *The Importance of Disappointment* (New York: Routledge, 1994).

treatment options have been exhausted.”⁵⁵ The purpose of palliative care is broader - to provide relief of suffering, support and improvement of quality of life. Walling and Wenger argue that palliative care should not be limited to end-of-life care and should be offered to patients who are waiting for a transplant, especially because pain management is complicated, symptoms like fatigue and lack of appetite are difficult to treat, and the possibility of dying is real.⁵⁶

Transplant patients receive aggressive care without any focus on their “palliative care needs.” According to Iredale, there is little literature on appropriate palliative care for ESLD and liver transplant patients. The model of palliative care has been developed with the disease paradigm of progressive cancer.⁵⁷ Walling and Wenger explains that care-planning is more complicated for liver transplant patients because the course of liver disease is often unpredictable. They write, “there are often periods of exacerbation, followed by stabilization or even improvement making prognostication and care-planning more challenging, especially among patients who remain hopeful for transplantation.” They propose a model of care where life-prolonging therapies and palliative care can occur concurrently.⁵⁸

⁵⁵ Boyd et al., “Living and dying well with end-stage liver disease: Time for palliative care?” *Hepatology* 55, no. 6 (2012).

⁵⁶ Anne M. Walling and Neil S. Wenger, “Palliative care and End Stage Liver Disease,” *Clinical Gastroenterology and Hepatology* 12, no. 4 (2015).

⁵⁷ John Iredale, “End-stage chronic liver disease: time to define a good death,” *Hepatology* 47, no. 6 (2008). See also Boyd et al., “Living and dying well.”

⁵⁸ Walling and Wenger, “Palliative Care and End Stage Liver Disease.”

Walling and Wenger explain, “It may seem counterintuitive to initiate palliative care for patients considered for transplant because of the potential for cure; however, the potential for adverse outcomes and significant symptom burden is also high. Therefore, it is appropriate to initiate palliative care, even while recognizing the possibility of long-term survival.”⁵⁹ The purpose of integrating palliative care with liver transplantation care is to improve symptom management and to address end-of-life wants and needs. As Baumann et al. explain, “the current standard of care is getting ESLD patients to transplant.”⁶⁰ This alone is insufficient.

Larson and Curtis argue that “care should be taken that patient advocacy or physician discomfort is not used to ignore or sublimate the issues raised by the risk of death.”⁶¹ There seemed to be an unspoken assumption that talking about waitlist death will detract from hope for a transplant. Ultimately this supposes that patients will be satisfied with what Shildrick aptly calls the “surface gloss of heroic medicine.”⁶² The surface gloss masks loss, grief and suffering and is not, as transplant surgeon Bud Shaw puts it, the “whole story.” Disregarding the experience of waitlist death affects all transplant patients because it denies a most painful part of the uncertainty of waiting. It also supports a relentless dualism regarding what constitutes “success” (transplant/life) and “failure”

⁵⁹ Ibid.

⁶⁰ Alexandra J. Baumann et al., Benefits of Early Palliative Care Intervention in End-Stage Liver Disease Patients Awaiting Liver Transplantation,” *Pain Symptom Management* 50, no. 6 (2015).

⁶¹ Anne M. Larson and J. Randall Curtis, “Integrating palliative care for liver transplant candidates: ‘too well for transplant, too sick for life,’” *JAMA* 295, no. 18 (2006).

⁶² Shildrick, “Staying Alive.”

(death). Palliative care is not synonymous with “giving up,” as though there are only two mutually exclusive options: hoping for a transplant and choosing death. It seems much better for patients to combine treatment plans for transplant and comfort measures for end-of-life, to the extent that this is possible, including addressing the issues of acceptance and denial.

The concurrent model of palliative care is a recognition that patients die while waiting; that for some patients, waiting will be end-of-life. These two experiences overlap (waiting and end-of-life occur concurrently). While some may hope to reduce waitlist death by addressing the organ shortage or tweaking the allocation policy, the reality is that waitlist death will never be eliminated, and the experience of waitlist death is negatively impacted by our culture of death avoidance.

A few years ago, a good friend suggested that I read the work of the psychologist Francis Weller to help me work through issues of grief and loss. Weller critiques the way we avoid grief and loss by suppressing it or turning it into something saccharine and redemptive. He argues that we should encounter grief and *embrace* it (what he calls *the wild edge of sorrow*).⁶³ By giving grief our attention, we can turn it into something vital and potent that will energize us. This was an epiphany-like realization that opened up a path for me. First, it seemed important for my personal sorrow, but it also struck what seemed like a much wider need to confront death in transplantation.

⁶³ Francis Weller, *The Wild Edge of Sorrow: Rituals of Renewal and the Sacred Work of Grief* (Berkeley: North Atlantic Books, 2015).

There are benefits to giving mortality more attention rather than leaving it unspoken (or obfuscating it as a “paradox”).⁶⁴ Weller argues that we need to explore the “low lying places” and acknowledge “what is hidden below, in the shadows” in order to express the “full measure” of all we are carrying.⁶⁵ The pervasiveness of death avoidance is disorienting and does not allow us to have a “safe encounter” with what is most vulnerable in us.⁶⁶ Ignoring death, or addressing it as a “paradox,” makes it seem unsafe. It also ensures that when death occurs it will be confusing and difficult for the loved ones left behind.

⁶⁴ The “paradox” refers to Judy Lumby’s “Liver transplantation: The death/life paradox,” *International Journal of Nursing Practice* 3 (1997).

⁶⁵ Tim McKee, “The Geography of Sorrow: an interview with Francis Weller on Navigating our Losses,” www.thesunmagazine.org.

⁶⁶ In the introduction of her book *Beyond Words: Illness and the Limits of Expression* (Albuquerque: University of New Mexico Press, 2013), Kathlyn Conway describes a passage of Christina Middlebrook’s book, *Seeing the Crab*: “she relates her story of a colleague who, consulted because the children in a nursery school were having nightmares, discovered that the teachers and parents ‘were editing out the evil characters and frightening endings from the fairy tales and nursery rhymes that they read aloud’ to the children. When the adults refrained from editing, the children’s nightmares stopped.”

6 Fixing a Broken Narrative

Sisters

After Shauna died, I often listened to “The Ballad of the Absent Mare,” one of Leonard Cohen’s more obscure songs from his 1979 album, Recent Songs. It’s about a cowboy mourning his runaway horse. Cohen’s distinctly raw and forlorn voice has gravitas well suited to mourning (like the deep and abrading voice of Patti Smith). Mostly I listened to it for the opening lyrics: *Say a prayer for the cowboy, his mare’s runaway. And he’ll walk til he finds her, his darling, his stray. But the river’s in flood, and the roads are awash, and the bridges break up, in the panic of loss. And there’s nothing to follow, there’s nowhere to go, she’s gone like the summer, gone like the snow, and the crickets are breaking his heart with their song as the day caves in and the night is all wrong.* The nuances of grief and mourning are familiar to me- the disaster, collapse and panic. The fragility of being human is heightened (*a heart broken by crickets*). The inevitable passing of the seasons is wrenching (*gone like the summer, gone like the snow*). Time moves on despite a sense of disorder (*all wrong*).

The metaphor of a cowboy grieving a horse suggests something that goes above and beyond the meaning we ascribe to human relationships. To lose a horse is to lose a strong bond and a sense of unison with another creature. I have learned this by adding “horse” rather than “sister” to my internet searches on “grief” and “loss.” People talk about attachment to horses with passion and clarity. Some explain that our profound connection

to horses comes from a primal recognition that we are both similar types of prey animals. Humans occupy the ambiguous position of predator and prey. Horses have a similar ambiguity - they are powerful and majestic, but ultimately a prey species. We are mutually vulnerable and dependent because of it. Vulnerability and dependency often connote neediness but this is nowhere near what comes across from accounts of the human-equine bond, rather it's defined by characteristics like mutual trust, respect, connection, interest, enthusiasm, energy, attention, cooperation, curiosity, caring and inspiration, everything that defined my sisterly relationship with Shauna.

Historian and literary theorist Hayden White notes that metaphors and other figures of speech connect concepts that are otherwise "thought not to be related." They are, what he calls, "swerves in locution"¹ that show us different ways of expressing ideas, new possibilities for thought, and cast familiar things in new light. Metaphors add dimensions of meaning that are derived from what literary scholar Eric Cheyfitz explains as the ability to "sustain the simultaneous perception of likeness and difference." This is, according to Cheyfitz, "the very special perception we give to metaphor."² Metaphors are particularly useful with experiences that are difficult to grasp or come to terms with psychologically. Sometimes we need a metaphoric re-naming or to create an association that makes feelings easier to comprehend. I found this to be true with regards to losing a horse as opposed to losing a sister.

¹ Hayden White, *Tropics of Discourse: Essays in Cultural Criticism* (Baltimore: Johns Hopkins University Press, 1978), 2.

² Eric Cheyfitz, *The Poetics of Imperialism: Translation and Colonization from the Tempest to Tarzan* (Philadelphia: University of Pennsylvania Press), 106.



Figure 5 Shauna in pink, me in blue

From the time we were little, Shauna and I were very close. She was my bossy older sister. I happily followed along with anything she said because to my mind she was the most important person in the world. Dressing up was our favourite game. We had a large blue wooden box for our dress up clothes - old dresses, scarves, shoes, hats, purses and jewelry - that served to costume a cast of witches, heroines and hobos in our made-up stories. We played typical make-believe games but tended to foreground misery like pretending to be orphans or indigents obliged to eke out a living and fend for ourselves in poverty and hardship. We also had a modest collection of Barbie dolls. We sacrificed one of the Barbies to be the villain who we distinguished by cutting off her long blond hair. The dolls all wore homemade clothes, sewn by our mother.

I was in awe of Shauna going off to kindergarten, one year ahead of me. Kindergarten felt entirely out of my league. I was much more comfortable in the sheltered care of our stay-at-home mom. I was timid by nature but Shauna wasn't. When she was around 4 years

old, she had her picture in the *Edmonton Journal*; it was a close-up of her face as she shook the hand of an alderman during a children's event at the public library. Shauna is wearing a paper hat with a big bow tied under her chin. The hat had something to do with Klondike Days, the big annual exhibition that commemorated the regional history associated with the 19thC Gold Rush. I was there too, probably in one of those hats, but clinging to our mother because I was afraid in a crowd and dependent on her for a feeling of safety.

As a child, Shauna had a propensity for piecing things together. She was sharp, perceptive and equipped to navigate new realms with ease. I was not quite adept at such things. She eavesdropped on adult conversation while I always tuned it out; and she grasped things about the world that I couldn't begin to comprehend. When we watched *Gone With the Wind* as a family when it aired on television over the course of several evenings, Shauna grappled with the heavy themes of civil war and slavery and found it disturbing and unsettling. But the movie did not penetrate my thick encasement of childhood oblivion. To my mind, it had no connection to the real world, which for me only consisted of my inner confabulations and everyday experiences in my small surroundings. Shauna's concept of reality was more expansive and she could reconfigure it according to new ideas and information. She was beginning to see that the world we live in was structured by history and politics much sooner than most other children, especially me. The older she got, the more curious she became about politics, global events and social and environmental problems. She honed her acuity for such things on the high school Debate Team. She took it upon herself to be informed, in a well-rounded

way, to the extent that she could in the pre-internet early 90s. A file cabinet in her bedroom had folders with newspaper clippings related to issues of the day: the destruction of the rainforest, nuclear disarmament, the Meech Lake Accord, women's rights and the hole in the ozone layer.

Until Shauna got sick, we shared a bedroom. It had twin beds with matching sheets and yellow comforters, metal bed frames that were plated in a fake shiny brass, and a yellow plastic dome-shaped lamp on the dresser. When Shauna no longer wanted to share a bedroom with me the so-called extra bedroom in our three-bedroom house (used as the piano room) became my bedroom. With me gone, Shauna painted the room powder blue and our mother sewed her a quilt in matching hues. I decorated my new room in pink and white. I would have wanted it to be frillier if our parents would have been willing to buy the accoutrements like a canopy bed, the gold star of frilliness, but that was out of the question. I had my own quarters, a typically hideous and tasteless girlhood bedroom, but I didn't really want it. This new boundary between me and Shauna made us separate entities in a way that I had never thought of us as separate before. It was a big change.

Shauna was diagnosed with autoimmune hepatitis when she was 11 years old. By that time, she had lost weight and her eyes and skin were yellow-tinged and without any luster, evidence that hepatitis had been present for a while and that probable cirrhosis is occurring. Once autoimmune hepatitis is set in motion there is no cure. The typical treatment is corticosteroids (prednisone) and immunosuppressants (Azathioprine). It was the side-effect of the prednisone that was the most dramatic, especially when prescribed

as a mega-dose, a term that was frequently used to describe Shauna's prescription. It causes water retention, fat redistribution and increased appetite which leads to weight gain and a distinct phenomenon known as moonface, or what we called a puffy face. It completely altered Shauna's appearance. The dose of prednisone was eventually tapered down but the long-term use had another side-effect that was revealed over time - growth suppression. Shauna's height was completely stunted at 4'11", what she measured at eleven years old.

The two of us, who had once looked so similar, were now radically different. In photos from our childhood, Shauna and I are often wearing matching outfits with tidily braided hair. We looked so similar as sisters that we could sometimes pass for identical twins. The differences between us were miniscule - her eyes were bluer; her blond hair was slightly darker and more reddish. Our proportions, shape and size that were once like cookie cutouts or paper dolls ended with her growth suppression and weight gain and me growing up tall and slim. The mutual effect on our body image was merciless, a combination of resentment, disdain, guilt and loathing. My body represented an injustice and betrayal to my sister. Comparisons were unavoidable and the conclusion was inevitable - how much easier it was to be me.



Soon after her diagnosis, Shauna was referred to see a specialist at the Children's Hospital in Calgary. We all drove there as a family and we stayed with an old friend of my father's who lived in a big house with many children, the youngest of whom were twin girls my age. On the day of Shauna's appointment at the hospital the wife of my dad's friend arranged for me to go to school with the twins. Shy and nervous about fending for myself in a strange school with twins I hardly knew, I would have rather stayed with Shauna and my parents and gone to the appointment too. But I never would have said so. I knew I was the lucky one who didn't have any need for doctors' appointments. In these circumstances, luck came with the uncertain feelings of being insignificant and superfluous, peripheral or lacking a distinct place. While not an entirely solid bedrock for my childhood development, my fortune proved to be easy enough to navigate. That day at the Calgary elementary school turned out fine. Everyone was nice

to me and the twins included me at recess. I relaxed into being anonymous and inconspicuous and caught sight of the freedom to be had by loosening the ties of belonging and becoming distant.

I can't explain what illness was like for Shauna. I didn't understand it. I didn't even spend much time visiting Shauna in the hospital when we were kids. Perhaps there was a prevailing attitude that children didn't really belong in hospitals as visitors, witnessing illness and suffering, bringing in germs, being noisy and disruptive. Even when I made brief visits, the unfamiliarity of the institution itself imposed a gulf between us. Shauna was inaccessible and removed while I carried on my life as normal. Even at home, Shauna's health problems were largely in a zone of exclusion. I didn't really know what it was like for her. I just saw from across a chasm that it required monitoring and management with regular doctors' appointments and blood tests, scopes and biopsies, when required. This was just the surface of things. It was alienating and impenetrable so I turned inward and brooded.

Even a cursory glance at research on the experience of siblings of chronically ill children suggests that I exhibited some of the common traits, especially as an adolescent: being anxious, depressed, withdrawn, loss of interest, rebelliousness and emotional suppression. There were other factors too, such as a beloved aunt that died of cancer, an uncle that died of suicide, glimpses of big unanswerable questions and overall disillusionment that contributed to my mopiness. I was unstimulated and uninspired by everything except the

music that I listened to, which was viscerally appealing to my sadness, or kind of loud, edgy and dissonant.

As a teenager, I was obsessed with the 1990s David Lynch television series *Twin Peaks*. Shauna and I both loved *Twin Peaks* because it was beyond anything we had seen on television, or anywhere: the aesthetic, the offbeat plot lines, the haunting music. Unlike other TV shows that were popular at the time, it was complex: both dark and uplifting, comedic and deeply stirring, romantic but also violent, sinister and cryptic. We recorded the show on blank VHS tapes and watched the episodes over and over. We both adored the show's protagonist Agent Cooper because we had never encountered anybody, real or fictitious, so singular and compelling. I think it made both of us realize how much our lives were isolated from anything or anybody intriguing. We had inklings of this too when we were little girls visiting our grandparents in Medicine Hat, Alberta. There we were awed by the priest at the Catholic church near their house. When attending weekly mass at home in Saskatoon I would sit quietly on the hard pew and tune out the old mumbling priest but the Medicine Hat priest was young and had a booming voice with the affectation of a Shakespearean stage actor (not that I had seen any Shakespeare) that made Shauna and I giggle. We thought he was very weird and liked to impersonate him when Mass was over. That priest brought a spark of curiosity and a touch of subversion to our bland and ordinary childhood.

Paul Ricoeur explains that one important function of plot is to fuse past, present and future. Accordingly, it requires us to "distend" our mind to contain both our memories

and our anticipations of the future and grasp everything together. This is how we construct our life stories, and these, in turn, become critical to our understanding of self-identity. According to Ricoeur, identity implies sameness, uniqueness, uninterrupted continuity, or “immutable substratum.” This coherence of identity is derived through the narratives we construct. As Ricoeur puts it, we locate the “durable properties of character” in narratives about ourselves.³

As a child, Shauna’s chronic liver disease made her an anomaly. She also didn’t “fit in” because of her determination to make something of herself. Mediocrity was the norm. Shauna was called an *overachiever*, a concept that reveals negative associations with striving, being ambitious, and having aspirations that are beyond what is considered to be normal. She cared about her grades and worked much harder than her average peers. Doing so was associated with a perceived lack of social skills, as though an excess of achievement (outside of sports) was compensation for being, by social standards, a loser. In Shauna’s case, the idea of overachievement also suggests a concern that, given her poor health, she was overextending herself, taking on too much. Working hard was a form of distraction from her liver disease and a way to deny her illness. Her accomplishments were good subterfuge, drawing attention elsewhere. It created the appearance of thriving that she couldn’t if she spent time in bed doing nothing.

³ Paul Ricoeur, “Narrative Identity” in *On Paul Ricoeur: Narrative and Interpretation*, ed. David Wood (New York: Routledge, 1991), 190-195.

I played a part in constructing a narrative that Shauna was thriving and always expected her to be strong, ambitious, and capable despite her illness. This particular way of seeing chronic illness and liver transplant colored the way I saw Shauna and constructed her identity. It also shaped how I saw myself and the way our identities are intertwined. I accentuated her “overachievement” by joining in with the apathetic crowd in high school and developing an identity that was shaped by early 1990s grunge, the heyday of messy appearances and teenage alienation. Later on we developed a dynamic of dependency as I relied on her to be my role model and guide as I entered into early adulthood with a skillset vastly less evolved than hers was. I admired Shauna for being so much more accomplished than I was, but I also see that she was encumbered with extraordinary expectations to tackle her obstacles, get on with life, and show me how to do it too. I imposed this on her.

Shauna moved to Toronto to go to university while I was stuck in Saskatoon living out my last miserable year in high school. Our letter-writing correspondence became a lifeline to me. We had been to Toronto on a family trip in 1985. We stayed with friends at a non-descript high-rise in the suburbs and visited tourist attractions like the CN Tower where we dined at the revolving restaurant at the top of the tower that offered a 360-degree view of the city. We also dropped in on our mother’s friend Sue who lived in a Victorian house in Cabbagetown, a formerly derelict neighbourhood in downtown Toronto in the throes of gentrification. The house was narrow, with high ceilings, dark wood detail, art on the walls, and pink paint in the dining room that cast a warm, pleasant glow. The dimensions of the house and the density of the neighbourhood were unlike

anything Shauna and I were familiar with and we instantly fantasized about living there. It was the cosmopolitan antithesis to the prairie towns we were used to.

In Toronto, Shauna had access to better specialized doctors. She went to her doctor's appointments with a binder in hand to take notes on her lab results, changes to her medications and any upcoming tests or procedures. She kept her own meticulous medical records and used the internet to research her conditions and become much more knowledgeable as a patient. At this point, she and I were communicating directly about her health, not mediated by our parents, and it felt like we were leaving a lot of the unknowns from childhood behind. In pre-internet days, patients and families had few resources to find disease information, discuss symptom management and treatment plans with other patients and consider options and alternatives. During the early years of Shauna's illness there was no one to talk to about these things. Our parents sought a little bit of peer support from the parents of a boy in Saskatoon who also had autoimmune hepatitis. That family decided to pursue holistic non-Western therapies, a decision that seems understandable to me. The Western medicine approach was limited and did not address the underlying causes of autoimmune hepatitis. Treatment could only slow down the development of cirrhosis and the scarring of the liver, staving off liver failure but the side-effects of treatment, especially prednisone, were not good.

Our parents conformed to the expectations from a previous era in medicine where patients didn't know much and didn't have preferences or opinions. They lacked the communication skills to speak openly with health professionals about uncertainties and

ask for clear information. Their tendency was to be silent and unquestioning around doctors. Where Shauna's health was concerned, our parents just took what was told and looked for evidence that everything would be fine, even if this was, at best, uneasy hopefulness, or a form of avoidance. This does not just apply to how they handled Shauna's illness, it is also evident in other events, like what happened to their baby that died before Shauna and I were born. Our mother never got to hold that baby. After she gave birth, the baby was taken away and pronounced dead. She regrets she didn't ask to see and touch the little lifeless body of the baby she had nurtured and cherished through pregnancy. Our parents also never requested an explanation for why the baby died. They were told she wasn't strong enough to live and this was just accepted in sorrow.

Our mother was a secretary, a fate determined early on in life by a school administrator who routed her into the vocational stream in high school on the day of her enrolment. Her parents, poor Polish farmers in Southern Alberta, had no particular ambition for my mother, and no money to board her at the dormitory so while she was in high school she earned her keep as a live-in maid for a well-off family in town.

Our mother's family history is harsh and somber. Her grandfather, on her father's side, emigrated from Poland to Buffalo, NY but got sick and died, leaving our great-grandmother rather destitute in Poland with seven children. Our grandfather, the second youngest of those children, fought as a soldier in WWI and then emigrated to Alberta in 1928 because he was recruited as an agricultural labourer and offered free passage and board, a reflection of how the development of agriculture on the "unused" land of the

prairies was central to colonial expansion in the western Canada.⁴ The Great Depression hit soon after he arrived and nobody knows what Grandpa did to survive in the first four years he was here. In 1932 Grandpa met and married our grandmother, the daughter of Polish immigrants who came to southern Alberta to homestead in the prairies in 1906. They started a small farm and lived in a tiny house dimly lit by a kerosene lamp. Our mother was born in 1934. Two baby brothers born after her died of pneumonia.

Both of our parents grew up on farms but our dad's family was better off financially, part of a hardworking, churchgoing settler colonial (or "pioneer") farming community in rural Saskatchewan.⁵ Our father was a Catholic priest when he met our mother. He left the priesthood and married her at Edmonton's City Hall in November of 1972. At the time, she was pregnant with the baby that died on the day that she was born.

Our father's side of the family manifested the farm life ethic. They embraced working hard, worshipping God, and demonstrating grace, humility and gratitude for what life has given you. Our father once told me that the most meaningful part of the Bible to him was the Beatitudes in the New Testament, the idea that "the meek shall inherit the earth." But being meek, quiet, unobtrusive and trusting was also repressive and led to harbouring

⁴ For a discussion of agriculture as a tool of colonization see Zoe Matties, "Unsettling Settler Food Movements: Food Sovereignty and Decolonization in Canada," *Cuizine: The Journal of Canadian Food Cultures* 7, no. 2 (2016).

⁵ Ibid. The status of "pioneers" negates Indigenous presence and denies the prior existence and values of Indigenous subsistence activities on the land. The European settler perspective only valued the conversion of land for agricultural use.

regrets and leaving too much unspoken. Silence and stoicism masked secrets and suffering, a family psychology so common that it is a cliché. This mentality defined the way that Shauna's health captured attention in the family, manufacturing guilt and loneliness for everyone. I felt guilty for being well while Shauna felt guilty for being sick and the hardship it caused. She once noticed our parents reading *Why Bad Things Happen to Good People*, a religious book about why God allows pain and suffering. In our minds, it cast Shauna's poor health as a form of punishment (God's punishment) and we also suspected our parents felt the same way about the death of their first baby. There were never any overt mentions of punishment and culpability, these were quiet undertones; yet Shauna's illness had a heavy presence in the family. It was a constant source of worry and concern and I believe Shauna privately felt responsible for it, and as a result treated it mostly as a private burden.

There are not many ways to counteract the pervasive *cultural* expectation to cope with illness as a private burden. This has been normalized and absorbed into the fabric of our social world that promotes the ethos of individual responsibility and self-sufficiency on so many levels. Discretion about illness is taken to be a sign of extraordinarily resilience. It also mirrors social values like independence and self-reliance, which we hold in high regard. Physician and author Arthur Kleinman, extols patients like Shauna who, in his words, represent the "best in our shared humanity." He writes, "To maintain one's aspirations in the face of grave adversity, to work hard to contend successfully with the daily assault of an impaired body on a robust spirit . . . these are lessons for us all,

examples of what is best in our shared humanity.”⁶ The “best in our shared humanity,” however, is something that people in good health have the fortune of admiring from afar. I bought into the idea that coping with illness just proved how strong Shauna was. I admired her for it. Robert Murphy suspects that putting sick people on a pedestal also relieves the guilt that others may have about being well. I put Shauna on a pedestal without thinking how it burdens those suffering from poor health with the task of assuring the wider social group that illness, however onerous, can be endured, overcome and survived.

Shauna’s ability to function so highly with her health hardships led me to easily believe that liver disease and eventually liver transplant could be integrated into her life with as minimal disruption as possible. Sociologist Anthony Giddens argues that “a person’s identity is . . . to be found . . . in the capacity to keep a particular narrative going.”⁷ The successful transplant narrative was part and parcel of a lineage of stories that constructed Shauna’s identity as someone who had the will and fortitude to manage her illness. Oliver Sacks writes, “When things fall apart, when our plans fall apart, it is by reference to storied projections of life and self.”⁸ The prospect of a transplant was met with already entrenched notions of Shauna-ness that made it seem like it was nothing she couldn’t

⁶ Arthur Kleinman, *The Illness Narratives: Suffering, Healing and the Human Condition* (New York: Basic Books, 1998), 137.

⁷ Anthony Giddens, *Modernity and Self-Identity: Self and Society in the Late Modern Age* (Palo Alto: Stanford University Press, 1991).

⁸ Quoted in John D. Engel et al., *Narrative in Health Care: Healing Patients, Practitioners, Profession and Community* (New York: Radcliff, 2008), 52.

handle. A sense of her identity was embedded in the “successful” transplant story. When that story fell apart, it felt like an undermining of her identity, an affront to the person that she was.

Ricoeur argues that the loss of a “narrative configuration” can amount to loss of “personal identity,” and that the disintegration of narrative can equate the disintegration of identity.⁹ Shauna’s death, under the circumstances, felt like such a profound erasure, an offense against an “immutable” aspect of who she was. She physically died, but on another level (the “lacking a narrative” level), she disintegrated.

In the spring of 2005, five months after Shauna died, I went back to Durham for the graduation ceremony at Duke University. The university decided to posthumously award Shauna her PhD. She hadn’t finished her dissertation before she died but her advisor and some of Shauna’s colleagues in the department stepped in to bring it to adequate completion. Shauna’s graduation felt like the culmination of the years that she spent absorbed in the competitiveness of the academic scene, vying for awards, scholarships, and other distinctions. While it was stressful and full of pressure, Shauna was in her element as a graduate student, both socially and academically. After the ceremony, there was a graduation party. In an odd way, it was like Shauna’s life could be celebrated and carried on without her, like she was in a state of limbo where she wasn’t fully gone and could still reach new milestones. A chapter of Shauna’s dissertation was published in a

⁹ Ricoeur, “Narrative Identity,” 196.

special issue of the journal *The History of Political Economy* journal on the theme of public support of the arts (Volume 37, number 3, Fall 2005). The volume was dedicated to Shauna's memory. The editor of the journal wrote, "The history of economics has lost a bright light and a warm colleague."

After graduation, we went to the Outer Banks in North Carolina to scatter some of Shauna's ashes in the Atlantic Ocean. May was typically warm in North Carolina but the day we scattered the ashes was cold. Katy swam out in a wetsuit to dump a small plastic bag of Shauna's remains while everyone watched her from the windy shore. Only a few of Shauna's ashes were scattered. One time Shauna mentioned in passing that she would like to be cremated when she died and scattered in the ocean. My mother couldn't stand the idea of letting her disappear into the sea like she'd never existed. Our family has a burial plot in Saskatoon's Woodlawn Cemetery. In the end, most of Shauna's cremated remains were buried there. My parents want to be buried next to Shauna in Saskatoon when they die. They have already pre-paid for their interment and bought their tombstone. I've kept a small amount of Shauna's ashes for myself in a tiny "keepsake" urn.

Eventually, I may dig up Shauna's ashes in the Woodlawn Cemetery and take her to the ocean like she wanted, maybe to the Bay of Fundy. I am torn about overriding my parents' wishes, but fundamentally I knew Shauna better than anyone. We had a depth of understanding that was mostly unspoken, an ineffable sibling bond rooted in the intertwining of our identities, our shared history and the central drama of Shauna's illness

that defined our childhoods. As young adults, we cultivated a desire to escape the past and the way we knew it stifled us. We both left Saskatoon with the conviction of never going back. Removing Shauna's box of ashes would be a symbolic gesture that restores some integrity to a story that otherwise crumbled.

The unraveling of grief

In the immediate days following Shauna's death, I was bedridden. There were tasks to do - the sorting and packing of things, choosing what of hers I would like to keep, engaging in the violation of privacy that comes after you die. I did these things outside my conscious recollection. For Christmas, my parents and I decided to visit Katy and her family at their beach house in North Carolina. We went to the local Episcopalian Church for a Christmas Eve mass but at the service I felt sick to my stomach. I called Katy's brother to come and take me home so I could go back to bed. The only other thing I remember is going to a hardware store to buy a fire pit to put on the deck. Katy and I liked the idea of sitting outside around a fire in the chilly nights. It didn't happen though. Katy's dad thought the fire pit was a fire hazard and wouldn't allow it. We went back to the hardware store to return it.

I eventually went home to the frigid winter of Montreal to re-enrol in graduate school and resume the courses I had dropped in the fall. I had maybe been home a week when I got a call that my 94-year-old grandmother in Edmonton was dying. I rushed straight from the

airport to the nursing home, arriving almost as she was taking her last breath. I just had time to touch her face and whisper “Grandma, it’s Anita.” I think she heard me say it.

Grandma wasn’t in a regular nursing home but was staying in the provincial motherhouse of the Grey Nuns and cared for by the sisters who lived there. This was arranged by her niece who had a decades-long career at the Grey Nuns’ Hospital in Edmonton, starting out as a nurse and climbing up into administrative and governance roles. The atmosphere was serene, impeccably clean and otherworldly. While we were waiting for the funeral home, there was a summon to the daily evening mass. I decided to go because Grandma, a devout Catholic, would want me to. I joined a flock of elderly nuns in their grey garb on their way to the chapel. One sister seemed quite perplexed by the presence of someone from outside their hermetic world. She gazed at my face and asked: “who are you?” I explained why I was there but to my own self, under the circumstances, I had no idea how to answer the question.

Grandma’s death meant that I unexpectedly found myself back at my childhood home in Saskatoon, where the funeral would be held. It also demolished the structure of the family, like the nucleus was ruptured, and not only temporarily, it was permanently dissolved. It was a change marked by swiftness, like the way Grandma was quickly buried in the white snow because no one no one could bear the January cold.

My mother wasn’t at Grandma’s funeral. She had stayed in Durham, meticulously organizing Shauna’s things, holding on to what she could, completely broken and unable

to face the death of her mother-in-law so quickly after Shauna's passing. My cousin Shannon wasn't there either. She had just gone back to England where she lived with her husband and daughter, having just been in North America for Shauna's funeral. Without Shauna, my grandmother, my mother, and Shannon, I felt unanchored. I had previously imagined that when Grandma died, Shauna, Shannon and I would spend time together going through Grandma's china, her extensive collection of costume jewelry, her clothes and hats, selecting keepsakes and mementos, and assuring some kind of continuity of the family matriarchy. In the end, it was just me, a lone person. I took all the costume jewelry and a year later it was stolen when my apartment was robbed. It didn't feel bad, it felt like being showered with numbness.

The theft of grandma's jewelry brought to mind the Elizabeth Bishop poem "One Art."¹⁰ The line repeated in each stanza is "the art of losing isn't hard to master." I see the art of losing in my life: my stolen computers, a vanished hard drive, my book of poems, all my CDs, my sister's pearl ring, another special necklace disappeared, all the things forgotten, misplaced, left behind in an irretrievable place, or accidentally deleted. We are surrounded by loss, the intent to be lost, but the tone of this poem implies a sense of detachment, even flippancy, because it also reiterates that loss is not a "disaster." From small losses to significant losses, there is no disaster.

¹⁰ <https://www.poetryfoundation.org/poems/47536/one-art>

Bishop's life was filled with tragic losses not mentioned in the poem. She lost both her father (to death) and her mother (to a mental asylum) when she was a baby, and a lover to suicide. I didn't know this about Bishop when I first read the poem. Afterward, the "art of losing" made sense to me differently. What started getting to me was the *guile* of the poem. The poem is not called "Loss" it is called "One Art." All the necessary parts of loss - letting go and acceptance - occur because they have to. You have no choice. But it also makes life a bit of a ruse, or a run-around.

For my own part, I reconfigured and rebuilt my life in a hurried and accelerated way to avoid lingering on what had happened. I steadied myself. I didn't have a breakdown. Carrying on with life seemed like the only way to prove to Shauna that I was okay. I imagined she had almost an omniscient awareness of what I was doing such that I believed I was fulfilling her expectations, and deliberately becoming more *like her*. At the same time that I applauded myself for marching to the "driving beat" of progress the best that I could, I felt deeply passive, as though my life was simply unfolding. As a coping strategy, I aligned myself with the idea that there must be a "grand design" - that everything was happening as it was meant to be, even if it felt all wrong.

A few weeks before Shauna died, I went home to Montreal for one weekend. I was conflicted about going because I knew how much Shauna needed me but I felt a definite pull home. I was scheduled to present a paper at a conference; and I knew it would feel good to see my close friends who would envelop me with care and support. Once I landed in Montreal, I felt like I had made a mistake. That weekend the doctors cut Shauna

off from pain meds and she had to contend with symptoms of opioid withdrawal, along with having no alternative methods of pain management available to her. No one had realized that Shauna had developed an addiction to Oxycontin, despite knowing that she took these pills daily for several weeks or months (the extent of her Oxycontin usage is unclear to me but I don't think she would have taken more than the prescribed dose and what was dispensed to her in the hospital). Even by the time I got back, Shauna wasn't herself. She was highly agitated, even furious, and demanded that if the attending physician came by I could not let him leave the room without giving her oxycontin. Worse was that she was told off by a resident who had no sympathy for her distress and lectured her about not understanding what was good for her own health.

That Montreal weekend in November was so cold. I wore several sweaters, scarves and boots but I couldn't find any warmth at all. I also couldn't get around a surge of guilt whenever I thought of what Shauna was going through. On Saturday night, I went to a party where I sat on the couch, got drunk, chain-smoked, and got into a shouting match with someone about whether there was such thing as "human nature." Shortly after Shauna died, a man I met at that party contacted me out of the blue. He sent a kind and genuine email that said he hoped he would see me again one day, which surprised me because I remembered myself at that party as a drunk charmless smoker (when we were in therapy right before our relationship ended, the therapist asked him what the first thing he'd noticed about me. He said that I had seemed very "real"). At the party, I had not disclosed anything about Shauna - it was the raw and painful reality I was trying to escape. With some hesitation, I replied to his email revealing that my sister had just died,

adding as a sidebar that I had started sleeping with stuffed animals. From that point onward, everything about us seemed fated.

I once blurted out to a small group of friends that if Shauna dies I was going to have a baby. In the end, I had three. Due to luck and favourable circumstances, it turned out that motherhood was a balm for me after Shauna died. It distracted me from a deep ambivalence I felt about everything in my life and eroded my foggy sense of purpose. Motherhood felt like a brightly lit pathway and an opportunity for something new, oriented towards belonging and attachment. It became all-consuming, as I wanted it to be, otherwise I felt lost and detached. Creating a family knits you in, not only to the family unit itself but also the wider social fabric and I found opportunities for place, community and belonging that otherwise wouldn't have existed.

Now that I can see a bigger picture, and that my relationship fell apart after 12 years, I can detect how little I did to integrate loss into my life, and how much I did to avoid grief. Loss was just part of my inner and private landscape, as I think it is for so many people. In an effort to keep up appearances, I maintained the delusion that I was inhabiting a "happy story" and that everything was working out even though this was far from the truth. Alternatives to progress stories are not obvious. No matter what dark and disquieting events take place, progress stories somehow prevail, urging us not to abandon the pursuit of success and happiness. We believe it is "healthy" to have an optimistic outlook on life and look for the silver linings. Shauna's death was a clear failure of a progress story but I couldn't readily exit the progress narrative; it clung around. I was

attempting to live out a version of “progress” that was inauthentic and mired in fantasies of re-birth that circumvented the actual ending of Shauna’s death and resembled the projected ending of the successful transplant story.

One of the most painful parts of the “art of losing,” as I experience it, is that maintaining my bond with Shauna has been harder than I expected. I seldom find significant ways to acknowledge her absence and meaningful ways to memorialize her. I have a vintage brown suitcase full of a few things that remind me of Shauna - the unfinished cross-stitches, a nearly empty bottle of lotion she wore in the hospital, a portion of her ashes in the keepsake urn (around three tablespoons) along with its pink velvet heart-shaped carrying case with her death certificate tucked in, two framed pictures of Shauna and two pictures of me and Shauna when we were girls, lots of scarves, two boxes of dried rose petals from Shauna’s funeral, a few scented candles - Mediterranean fig, ylang-ylang, marine moss, cedar, bergamot and tobacco, lots of packing paper, and also for some reason, my daughter’s birth story written by the doula. Some of these things are quite random and seem most poignant to me now because they have spent almost 20 years in a suitcase.

Mostly, I used up Shauna’s things rather than preserve them. I still use her small makeup bag and her Coach wallet. Both are looking battered and shabby. She would be appalled if she knew there are clothes of hers that I still wear - socks for instance, t-shirts that I use as pajamas, black seamless underwear made out of some kind of indestructible synthetic fabric, a turtleneck sweater. More precious than these mundane possessions are the cards,

letters and photographs that I have saved in boxes, stored in my front closet. On account of my messy habits over time the boxes have accumulated other documents, other unrelated threads, condensing paper trails of my life history in unedited bits and pieces that distinctly lacks the scaffolding of a narrative. *This is what loneliness is.*¹¹

The Bay of Fundy

Any kind of loss (death, disappointment, things going wrong) is difficult to express or represent as a cohesive story. The online journal we kept when Shauna was dying testifies to this: it is choppy, sporadic, inconsistent and obfuscating. Throughout her illness, Shauna was a fastidious note-taker and recorded precise information about her health and asked that others do the same when she was unable. So I tried. I was committed to posting updates in the online journal. I wanted to convey her “transplant story” like she wanted. But whatever information we received from the doctors mostly evaded me, even their dumbed-down glosses of her critical condition and their attempts to treat it. I only cared that she was “stable.” In total, there are 31 entries posted at intervals that varied between 30 minutes and 39 hours. The language I used in the posts deteriorated. I abandoned technical terminology and became more colloquial, even somewhat crude. I see the lack of clarity she would have hated. I once described Shauna’s lungs as having “*taken a hit*,” explaining “*They are increasingly filled with*

¹¹ “*it took me ages to realize that this is what loneliness is; it is the lack of a narrative*” – Ciara Kierans, “Narrating Kidney Disease: The Significance of Sensation and Time in the Emplotments of patient Experience,” *Culture, Medicine, Psychiatry* 29 (2005), 34.

fluid, junk, and gunk, and this evening Shauna has started coughing up blood.” I think I couldn’t get past what felt like the underlying *incoherence* of the situation. Events were profoundly out of sync with my expectations and therefore unintelligible and hard to describe.

The influence of narrative creates assumptions and expectations that a transplant will come as some kind of great revelation: a miracle, a re-birth. The record of Shauna’s demise (that was supposed to be the “transplant story”) comes to a blunt and empty finish. Hayden White (1980) argues that narrative gives reality “the mask of meaning, the completeness and fullness of which we can only *imagine*, never experience” For White, “coherence, integrity, fullness, and closure” are narrative characteristics of wishes, daydreams, and reveries. They “produce an image of life that is and can only be imaginary.”¹² Transplantation is not a linear story that always leads to a positive outcome. But most of our knowledge and understanding of organ transplantation is limited to this “imaginary” version that posits transplantation as a rebirth. The entire experience of waiting for Shauna’s liver transplant was conditioned for her heroic recovery - this is what would give it “coherence, integrity, fullness and closure.” It is only the “storybook version” that can come across as an adequate account and sufficiently explanatory. What happened (reality) is full of holes.

¹² Hayden White, “The Value of Narrativity in Representations of Reality,” *Critical Inquiry* 7, no.1 (1980), 24.

Richards observes, “relatively little personal writing has been done on kidney failure and transplantation. A possible reason for that is that we, too, are meant to fit into a happily-ever-after narrative we did not write.”¹³ I think this insight can apply to why there is little personal writing about loss, particularly when the wait for a transplant ends with death. It doesn’t fit into this narrative either; and it is difficult to locate alternatives when the one “we did not write” is so dominant and deeply embedded in the field of transplantation.

The conventions of the typical transplant narrative are incompatible with Shauna’s death; and I can’t easily offer another “story” in its place. I can only explain how my interpretive perspective changed over time and how the successful transplant story is no longer a useful model. Hindsight involves sifting and sorting through memories, finding patterns and causal links through many layers of reflection and a degree of critical detachment. It doesn’t lead to what “really happened” but it does reveal how my interpretive perspective on Shauna’s death has greatly evolved. Robinson and Hawpe point out that stories change through retrospection and undergo what they call “narrative repair.” We “repair” our narratives when after “testing the continued validity of life experience stories” they come up short.¹⁴ In Shauna’s case, a narrative shaped by the anticipated future of a successful transplant lacks continued validity. In the almost 20 years since she died, it is plain that there are obvious distinctions between an idealized narrative, what actually happened and everything that is ignored.

¹³ Rose Richards, “Writing the Othered Self: Autoethnography and the Problem of Objectification in Writing About Illness and Disability,” *Qualitative Health Research* 18, no. 12 (2008), 1725.

¹⁴ John A. Robinson and Linda Hawpe, “Narrative Thinking as a Heuristic Process” in *Narrative Psychology: The Storied Nature of Human Conduct*, ed. R. Sarbin (New York: Praeger, 1986), 123.

Frank Kermode argues that we “cannot abide the loathsomeness of contingency.”¹⁵ So we seek out a narrative logic of causality and interpret our life events unfolding according to a plot with a beginning, middle and the end. Ricoeur argues that plot is a way to organize “the multiple scattered events” of our lives. He writes, plot is “the operation that unifies into one whole and complete action the miscellany constituted by circumstances, ends and means, initiatives and interactions, the reversals of fortune, and all the unintended consequences issuing from human action.”¹⁶ In terms of plot, Freeman observes “Our pervasive tendency [is] to let endings determine beginnings,” and seeing the ending as a “final episode of an emerging pattern, an evolving story, integrally related to what has come before.”¹⁷ This is accomplished through a “backward temporal movement” that inverts “the so-called natural order of time. By reading the end in the beginning and the beginning in the end.”¹⁸

In the summer of 1985, our family embarked on a cross-Canada road trip. This trip was more ambitious than anything we had done as a family. The map of my childhood up until that point included only four places: Saskatoon, Edmonton, Yorkton, and Medicine

¹⁵ Quoted in Peter Goldie, “Life, Fiction, Narrative” in *Narrative, Emotion and Insight*, eds. Noel Carroll and John Gibson. (University Park, PA: The Pennsylvania State University Press, 2011).

¹⁶ Paul Ricoeur, *Time and Narrative Vol. 2*, trans. Kathleen Blamey and David Pellaver (Chicago: University of Chicago Press, 1984), x.

¹⁷ Mark Freeman, *Hindsight: The Promise and Peril of Looking Backward* (Toronto: Oxford University Press, 2010), 41.

¹⁸ Quoted in Mark Freeman, “Data are Everywhere: Narrative Criticism in the Literature of Experience” in *Narrative Analysis: Studying the Development of Individuals in Society*, eds. Colette Daiute and Cynthia Lightfoot (Thousand Oaks: Sage, 2004), 65.

Hat, a prairie universe. Of those four places, Edmonton was the best. It ranked higher than Saskatoon by a landslide. Not only did Edmonton greatly outsize Saskatoon it had the West Edmonton Mall, a conglomerate of attractions, unrivaled by anything else on the Canadian Prairie (in fact, it was the largest mall in the entire world).

Shauna and I were dazzled by Edmonton but didn't have much to compare it to but Yorkton and Medicine Hat. Yorkton, a city of about 15,000 three hours away from Saskatoon, was noteworthy because it was home to Shannon, our much-admired older cousin. Shannon was pretty and had the aura of the alpha female of a junior high. Her aesthetic echoed the pages of *YM* and *Seventeen*, which to our mind was the cutting edge. Shauna and I wore her hand-me-down clothes and tried our best to imitate her. Shannon was the reason we could go to Yorkton, Saskatchewan and come back feeling like we had just become much cooler. By contrast, Shauna and I were far less enthusiastic about going to Medicine Hat, Alberta to visit our maternal grandparents. Grandma spent most of the time sitting in a sunny chair by the back door looking over the garden. She took a dozen pills every day and wore the thickest glasses I had ever seen. Grandpa drank buttermilk. Their old house felt like it was from a different era - the furniture, the appliances, the small wooden cabinet in the exterior wall for milk delivery. Going to Medicine Hat was like going back to a time when life was dull and there was nothing interesting to do.

That summer of '85 we were very excited to drive from Saskatoon all the way to Newfoundland in our old white Ford LTD. Our mother borrowed a directory of bed and

breakfasts from the local public library to choose our accommodations. She had an aversion for motels and bed and breakfasts were a thrifty choice. They had quaint names like Old Oak Farm and Happy Apple Acres and the hosts were friendly and informative retired couples eager to share tidbits and suggestions about the region. Wanting an alternative to a standard chain motel room, and a more local experience, makes a lot of sense now but it certainly didn't to children in the 1980s. The idea of bed and breakfasts, staying in a stranger's home, was abnormal to me and Shauna. To us, ages 8 and 10, they just seemed like old houses, interesting only to old-fashioned people.



Figure 6 Flat tire, family road trip 1985

One of the final destinations of our trip was the Bay of Fundy in New Brunswick. The size and intensity of the tides at the Bay of Fundy are a so-called wonder of North America. High tide brings in 50 feet or 100 billion tonnes of seawater and low tide

exposes dramatic sculptural rock formations that loom high above the ground. During low tide, tourists can descend a staircase that leads down to the ocean floor and walk around temporarily until the four stories of seawater return.

At low tide, the Bay of Fundy evokes an uncanny feeling, the power of the ocean *in absentia*. It's like lying down on a train track even if you know that the freight train is miles off. It is only a matter of time. The geometry of the Bay, its vast size and depth, funnel shape, and the oscillation of deep waves in the continental shelf rock the sea with much more intensity than the ordinary gravitational pull of the Sun and the Moon. There are pictures of us there- me and Shauna - standing on the muddy ocean floor, rocky arches in the background, looking small and vulnerable. This is the origin of Shauna's ill-fated medical story.



Figure 7 Shauna, mom, me

After we visited the Bay of Fundy Shauna wasn't feeling well and developed a rash on her back and her chest. Our parents were worried enough that they took her to a walk-in medical clinic the next morning. The doctor thought it was an allergic reaction. Shauna had no known allergies so our mother found it strange. Other than our visit to the Bay of Fundy there had been nothing out of the ordinary about the previous day.

Shauna was fatigued for the rest of the trip but the rash eventually faded. I also wasn't sleeping well. On the ferry from Newfoundland I had watched *The Neverending Story*, a

movie based on a German fantasy novel that was the most terrifying and sad thing I had ever seen. There was a blood-thirsty pack of yellow-eyed wolves but the real antagonist in the film is a black swirling cloud called the Nothing, a mysterious entity that erases people and places. The lasting impact of the movie was something intangible that I really couldn't cope with. It also seemed to correspond to our mother's trepidation that something had happened at the Bay of Fundy and her intuition that things were not as they were before.

Over the course of the year, there was a drop in Shauna's energy. Our parents took her to the family doctor who had an office in a tiny strip mall on the closest busy street to our house. This doctor was elderly and odd. I didn't like him at all because he had once prescribed mysterious pills for my chronic bedwetting when I was only four years old (drugs are not often used for bedwetting). The only pills I had ever taken were the small pink children's chewable aspirin tablets with a pleasant powdery flavour. No one mentioned not to chew when I took my first bed-wetting pill one evening. The acrid taste made me cry inconsolably.

Shauna not only had fatigue but had started showing jaundice in the whites of her eyes when she saw that bizarre/quack family doctor. He was not that concerned about her symptoms though and like the doctor in New Brunswick, he thought they indicated allergies. His sketchy diagnosis was that Shauna had an allergy to *yellow flowers* and recommended setting a dish of her pee in the sun to confirm. Somehow our parents found this assessment trustworthy and reasonable. They didn't take her to a different doctor (a

regret). Real information only came to light after Shauna suffered a cold and went to a clinic for a chest x-ray. It revealed an enlarged spleen, a potential sign of liver damage. The doctor at the clinic was alarmed by Shauna's symptoms and referred her to a pediatrician at the hospital who took her on as a patient and ordered blood tests and a liver biopsy.

Having a pediatrician was exceptional. They are scarce in Saskatchewan and tend to deal with serious and complicated cases, not the primary care of healthy children. Shauna's pediatrician was caring and also diligent. He diagnosed Shauna after a consultation over the phone with a doctor at the Sick Kid's Hospital in Toronto: autoimmune chronic active hepatitis.

Autoimmune hepatitis is a rare disease that is idiopathic, characterized as an attack on the liver by one's own immune system causing inflammation and scarring. This was explained as Shauna's immune system being "overactive," targeting her own liver for no known reason, mistaking the liver as foreign, as though confused about its own identity. It hardly seemed plausible. The diagnosis wasn't cataclysmic but it was still alarming, like a brush with the unfathomable.

Our mother saw the Bay of Fundy as a kind of trigger for Shauna's illness but the rest of the family never really took her seriously. It seemed random, circumstantial and too dramatic. At the same time, it was also the closest thing to an explanation we had. Autoimmune diseases are mysterious, even incoherent. Unknown causality made

Shauna's illness seem like an inner violation, at least the Bay of Fundy could externalize it and map it onto preconceived notions I had that illness and disease were something foreign, not something that originated from within.

It started as a joke to quip that Shauna had the Bay of Fundy Disease. She and I thought it was a clever way to amalgamate her autoimmune disorders (with her subsequent diagnoses of inflammatory bowel diseases - Crohn's and Colitis - and Primary Sclerosing Cholangitis). The Bay of Fundy entered into our shared sisterly lexicon as a place that was dubious, a source of contamination and impending doom. We taunted each other with dulse - the thick, reddish and chewy seaweed snack that the Bay is known for, and the mineral rich salt that's harvested there and sold to tourists. Shauna once sent me by mail a Burt's Bees bath product called a "Detox Dulse Bath" from the "unpolluted waters of the Bay of Fundy." She adorned it with poison signs and wrote on the package "Dear Anita, I dare you to have this bath!" Now it seems to me that we were mocking the prospect of Shauna's mortality, but it didn't seem that way at the time.

Freeman writes, "we do not know, and cannot know, where the story in which we are engaged will lead. The result is that there is a perpetual slippage, an existential gap, between immediate experience and its retrospective transformation through narrative. The present, despite its presence, is characterized by a kind of absence . . . There is something missing now, in my immediate experience."¹⁹ The open-endedness and

¹⁹ Freeman, *Hindsight*, 85.

uncertainty of experience is resolved only after the fact. Hindsight produces insight into human existence because as Freeman rightly contends, “We are frequently late in our understanding of things.”²⁰

The Hepatic Happening

The narrative temporality of transplantation ties the purpose and meaning of experience to a happy ending. Ciara Kierans observes that dialysis is often represented as “time arrested” or “a life on hold” always “projecting on towards transplantation, a vague undefined point in the future where normal, independent activities are expected to resume.”²¹ Kierans argues this is reinforced by “mythologies of progress, the idiomatic expressions employed by society, donor awareness groups, and physicians of transplantation that describe transplantation as a new lease of life.”²² The waiting period is merely the “before” part of an idealized imagined future free from illness.

When our lives are defined by “projected scenarios,” we commit what literary scholar Stephen Crites calls a “formal error” of “treating [the future] as if it were past.” He explains, “the future is vague and sketchy, incomplete and thin,” properly more like a loose scenario” without a certain outcome. When we allow the future to determine the

²⁰ Ibid., 26.

²¹ Kierans, “Narrating Kidney Disease,” 351.

²² Ibid, 352.

plot structure of our lives we give a “specious pastness” to the future. Crites explains, “In a well-strung narrative, reinforced by its closure, by apparent completeness of its action. The specious future . . . will appear as necessary as the past.” But the future is, as Crites describes it, more like a “free unchoreographed dance” or “improvisatory harlequinade.” Narrative creates a future “rendered more finished than the one that the Harlequin can in fact go careening into.”²³ Indeed, Kierans found that when transplantation is a treatment option there is always the sense of a “cure” on the horizon, which lends itself to a plot structure that creates a false sense of resolution. Kieran’s argument is that the actual experience of kidney patients lacks a resolved ending. Instead, they encounter “the unpredictability of the future and the fears of returning to the past.” In closely examining her interview data, Kierans finds stories that reveal “the painful lack of an ending” and a future “held hostage to the unpredictability of kidney disease.”²⁴

The Bay of Fundy spoke to this unpredictability. It was never used as a “straight” explanation for Shauna illness. We really didn’t think her health problems were so simple and monocausal, and that she was certainly going to die. We were making fun of it as a “sufficient” explanation and used it like a metaphor imbued with irony and the awareness that meaning cannot be simply taken at face-value. Irony is distinguished by knowingness and recognizing the “poorness of the comparison.” According to White, this is what makes irony the most complex of the figures of speech - it includes “reflection of the

²³ Stephen Crites, “Storytime: Recollecting the Past and Projecting the Future” in *Narrative Psychology: The Storied Nature of Human Conduct*, ed. Theodore R. Sarbin (New York: Praeger, 1986), 163-169.

²⁴ Kierans, “Narrating Kidney Disease,” 341.

inadequacy of the characterization”²⁵ and adds layers of meaning that are self-critical and self-reflexive. Meaning is not wholly fixed but more emergent as irony, according to White, “tries to understand itself.”²⁶

I attribute a lot of self-critical and self-reflexive knowingness to Shauna. In fact, I think she knew that what she was going through had more in common with an “improvisatory harlequinade” than a fairy tale with a happy ending though it wasn’t overtly acknowledged. She said as much by occasionally referring to her future transplant ironically as the “hepatic happening.” A “happening” can simply be defined as an “event or an occurrence.” It is also an art term that came into usage in the late 1950s meaning “a partially improvised or spontaneous piece of theatrical or other artistic performance, typically involving audience participation.” Examples of famous happenings include Allan’s 1961 work “Yard,” which “involved the random scattering and piling of tires over the floor and an invitation to visitors to climb over them,” Marta Minujin’s “Reading the News” (1965) where the artist wrapped herself in newspaper and lied down in the river until all the newspaper slowly dissolved away, Jean Tiguelly’s self-destructing sculpture “Homage to New York”(1960) “composed of bicycle wheels, motors, a piano, an addressograph, a go-cart, a bathtub, and other cast-off objects” that smoldered and burned to ruins in a 30-minute performance piece.²⁷

²⁵ White, *The Tropics of Discourse*, 5-6.

²⁶ *Ibid.*, 19.

²⁷ “Happenings” <https://www.theartstory.org/movement/happenings/>

The hepatic happening was a wry use of words. It is a quirky way to refer to a liver transplant but at the same time entirely apt as a critical counterpoint to the shored-up transplant narrative. On the one hand, it signals levity that on the surface seems inappropriate to the gravity of the situation. However, in poking fun it raises ironic critical meaning and reframes liver transplantation in a way that we can begin to see that there might be something wrong with the picture. Before I started this project writing about Shauna's death, I wrote a poem about it and called it the Hepatic Happening. It made the point that Shauna's transplant was *unscripted from the start*. I described waiting as *the unspooling of unplottable materiality toward a vagrant ending*. I characterized the deterioration of her health as *the capricious improvisations of demise and a free-f(or-)all*.

It's a struggle to give expression to the incompleteness and uncertainty of waiting, as it was to find meaning as the grand design and overall plot structure of the transplant story was becoming more elusive. Ann Jurecic makes the point that narratives simplify indeterminacy and in doing so they can misrepresent "the fundamental indeterminacy of life."²⁸ The hepatic happening rejects narrative closure and draws attention to the uncertainty that spirals around without the guardrails of a tidy ending, or the promise of an ending where everything is resolved. It points to the *semblance* of what liver transplantation is supposed to be (a transformative narrative structured by a beginning-middle-end) and renders it illusory.

²⁸ Jurecic, *Illness as Narrative*, 31-38.

Not only was there not a “happy ending” it was hard to identify anything as an ending at all (in my poem I wrote there was *No way to describe the rest of the performance; Maybe some saw the coherent shape of a downward spiral; a definite crash*). The relationship between a “happening” and “happy ending” is not entirely discordant or contradictory. Feminist scholar Sara Ahmed’s theoretical unpacking of “happiness” makes the point that the word happy itself is etymologically linked to the word “happen.” They both are derived from the Middle English word “hap,” which means chance, luck or fortune. Ahmed writes, “the etymology of ‘happiness’ relates precisely to the question of contingency.” “Hap” has the potential to be good or bad. “Happiness,” Ahmed explains, “remains about the contingency of what happens, but this ‘what’ becomes something good.”²⁹

A departure between a “happening” and “happiness” occurs if happiness is conceptualized as an end, or an imagined future. An “end-orientation,” or a teleological model of happiness, moves away from contingency or “chanciness” and fixates on what is *supposed* to make us happy according to socially agreed upon ideas of what is “good.” Ahmed uses the example of a “happy family.” She writes, “The family would be happy not because it causes happiness, and not even because it affects us in a good way but because we share an orientation to the family as being ‘good.’”³⁰ Similarly, the

²⁹ Sarah Ahmed, “Happy Objects” in *The Affect Theory Reader*, eds. Melisa Gregg and Gregory J. Seigworth (Durham: Duke University Press, 2009), 30.

³⁰ *Ibid.*, 41.

conventional transplant story circulates with a firmly entrenched and cliched idea of what constitutes a “happy ending.” The “hepatic happening” is a trenchant critique of this story because it re-focuses attention back to “chanciness” and unpredictability, and the fact that we can’t just direct our lives toward the “happy endings” we desire. Organ transplantation is trapped by its narrow orientation towards success and preoccupation with life that turns away from death, loss and failure. The metaphor of the “hepatic happening” at least opens up the possibility that liver transplantation can be otherwise. It is a disruptive trope that rejects narrative conventions and predetermined meanings, even if, at the end, it offers nothing in its place.

I ended my hepatic happening poem cryptically: *Or find nothing; Hollow out a cave; Find nothing but darkness in the hollowed out cave; Or find the words ydnuf fo yab eth; Circling back upon itself.* The crypticism stems from thinking that what happened to Shauna could only have secret meaning or hidden meaning. I’ve always imagined that Shauna could have come up with a more lucid explanation of it all. She had (mostly unspoken) plans to write about illness. In the end, I’ve been left to appropriate her story, or at least *meld it* with mine to the point that what she would have thought and what I think has become indistinguishable. I’ve imagined the following conversation:

Me: Do you remember when Ollie [our cat] won a year supply of cat food?

Shauna: Yes, wasn’t that a Purina Pet Food Sweepstake? Wasn’t it the grand prize?

Me: No, I don't think it was the grand prize. I think the grand prize was money, like 10 thousand dollars or something that would have seemed enormous to me at the time. I remember filing out the entry form, cutting it off the box of Tender Vittles, and sending it in. The year supply of cat food was like 3rd prize or something.

Shauna: Still I think we were quite shocked that you won.

Me: I know!

Shauna: Didn't you just get sent a bunch of vouchers.

Me: Yes. It was like more cat food coupons than you could possibly imagine.

Shauna: I don't think you have won anything ever since.

Me: I haven't. Do you think luck is finite?

Shauna: No

Me: Do you think I used up too much luck when I won that cat food sweepstake?

Shauna: No

Me: Maybe I did.

Shauna: No

Me: It would have been lucky for you to have gotten a liver transplant though. Much luckier than cat food.

Shauna: Especially that cheap cat food we fed Ollie.

Me: You never really cared about Ollie. Not the way I did.

Shauna: You whined and cried to get that cat. Like it was the end of the world.

Me: I had no perspective.

Shauna: You needed that cat as your ally though. You felt all alone. Isn't that what we learned in family therapy?

Me: Ha. Do you think you are unlucky?

Shauna: That's a dumb question.

Me: But you died!

Shauna: Is that what you think? That it was bad luck?

Me: What then, God?

Shauna: It has more to do with God than with cat food.

Me: Hmmmmmm

Shauna: It's too painful to think about. If it's either God or cat food, I am going to go with God

(Shauna, you did! I mean that's where so many people said - you went into the loving arms of God)

Me: Am I supposed to say cat food now?

Shauna: Winning that cat food was lucky.

Me: If we could do it all over I wouldn't enter that contest.

Shauna: If we could do it all over we wouldn't go to the Bay of Fundy.

*"We didn't just think it funny; we both felt deep down some tug, some old wish to believe again in something that was close to our hearts."*³¹

(Shauna exit. Gone)

³¹ Kazuo Ishiguro, *Never Let Me Go* (New York: Vintage Books, 2005), 67.

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