

## Flowing and Flown: Transition and the Crafting of Possible Futures

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### Abstract

In this multimodal essay, we share a short film about the experience of growing up as a pediatric heart transplant recipient and reflect on our collaborative project. Our work reveals the tensions associated with coming of age in the interstices of transplantation, disability, and difference, while living with existential uncertainty and the rituals of care that structure daily life. Through filmmaking we seek to build knowledge ecologies: communities for learning and living within the transitory spaces of modern medicine.

### Keywords

pediatric heart transplantation, transition, collaborative methods, reflexive epistemics

### Introduction

This multimodal essay is a mosaic, the result of collaboration and compromise. Drawing upon reflexive epistemologies developed over the past half century within feminist and decolonial STS research on epistemic authority, subject formation, and knowledge production (Fortun 2009; Harding 2009; Sandoval 2003; Sørensen and Traweek 2021), we engage in reflexive storytelling. Our focus is a story about the experience of heart transplantation in childhood and the challenges of negotiating the transition into adulthood and adult medical care.

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Woven throughout are reflexive practices—alternating turns as storyteller and audience, teacher, and student—that build intersubjective spaces for the telling and retelling, interpretation, and reinterpretation of narratives. Storytelling is our collaborative practice of sense-making, which we enact and share through text, film, and dialogue.

## Tinkering with Epistemic Tensions

Sarah and I met in 2017 at a heart transplant “transition clinic” held at a large teaching hospital in Southern California. It was an opportunity for adolescent and young adult heart transplant recipients and their families to meet the hospital’s cardiology team, visit and tour the adult clinic, and celebrate the passage from pediatric to adult health care. Sarah was invited by the clinic’s organizers to speak and answer questions as a former pediatric patient who had transitioned to adult care.

Transition, or the move from pediatric to the adult healthcare system, is an emergent topic in transplant medicine as more pediatric heart transplant patients are living to adulthood (Blum et al. 1993; American Academy of Pediatrics et al. 2002). Though the first pediatric heart transplant surgery occurred over fifty years ago, only recently have pediatric heart transplant recipients begun surviving into adulthood. Transitions, of all kinds, are challenging times for many. For heart transplant recipients this transition is particularly perilous, marked by a change in legal status with important consequences to the process of decision-making and management of one’s own care that can lead to difficult changes in the roles and responsibilities of family caregivers. It also represents a “high-risk age window” when adolescents and young adults face worse transplant organ survival than younger children (Foster et al. 2015).

At the time we met, Sarah was twenty-five years old. She had received her first heart transplant at three and had double transplant surgery for heart and kidney organs when she was seventeen. Eight years out from her last transplant, she was in graduate school earning her master's degree in clinical psychology with the hope of building a career assisting other young transplant recipients. Sarah is among the first generation of pediatric heart transplant patients to survive and build a future in the interstices of precarity, disability, and medical innovation. In contrast, after working in science educational programming and documentary television, I returned to graduate school in education, conducting doctoral research within a team participatory research study in advanced heart failure (Raia and Deng 2014) and interested in how young people made sense of the complexities of organ transplantation and their transition to adulthood. Unlike the medical model of transition, which understands it as a discrete event, I employed an anthropological point of view. Following Victor Turner, I regard transition as a process, a becoming (1970, 94), and leveraged my experience as a producer to engage visual storytelling as a research method.

As an educational researcher, I drew upon multiple traditions including critical disability studies (Erevelles 2000; Shildrick 2019) and critical media literacy (Kellner and Share, 2007) to position visual storytelling as an educational intervention. Through storytelling, I wanted young people to have a chance to reflect upon their own labor, to see their survival as an accomplishment. My hope was to create a series of short, educational films to support knowledge ecologies for living and learning within the transitory spaces of high-tech modern medicine. In this project, teaching and learning were posited as an ongoing activity for every participant, thereby revising the conventional interpretive power relations of researcher and subject to examine interactions from many perspectives, including epistemically. When I shared the project with Sarah and invited her to participate, she jumped at the opportunity, telling me that she was willing to work on any research project that focused on heart transplant recipients. Sarah's eagerness reflected her own experience and engagement with scholarly research. It also reflected her willingness to be a representative—to tell a story—in the hope of helping others through the process of transitioning. Through our research, Sarah learned techniques of visual storytelling. In turn, I learned about the experiences of coming of age and imagining a future hitherto unrealized.

We worked within a collaborative experimental design. Though we acknowledged our different personal histories, status, and interests, we shared common identities as women of color, each from different diasporic communities. We also shared a common purpose in crafting stories as a practice of sense-making. Our work contributes to feminist science studies' attention to exclusionary practices by attending to young people as knowledge producers, taking seriously their part in the "knowledge ecologies" (Sofoulis et al. 2012) of transplant medicine—especially within relations of power vis-à-vis adults and the institutions, such as schools, families, clinics, and hospitals, that structure their lives. In the next two sections, Sarah and I share the short film we crafted together as well as an edited dialogue we recorded after watching our film. In the intervening years, we collectively experienced the COVID-19 pandemic and its lingering effect texture our discussion.

## Film



Figure 1. Film Still *Sarah* (2018). The overlapping medical crisis Sarah faced as a teenager.

Full film: [https://drive.google.com/file/d/1nVgmsfVOXzsaB\\_U2xz9JohM7WXlebj-k/view?usp=sharing](https://drive.google.com/file/d/1nVgmsfVOXzsaB_U2xz9JohM7WXlebj-k/view?usp=sharing)

## Dialogue

Nadine      What are your thoughts looking at it [our film] now? Have you seen it recently?

Sarah        I haven't seen it since the last time I watched it with you. It's different. Life's so different. COVID ruined everything really.

Nadine      How did it affect you?

Sarah        The whole experience gave me such severe anxiety. It's changed everything. I'm not the person I was in that video.

I think this video made me reflect on my life more than I've ever done. The process of making it or just, I've been processing. It's been hard. And I see myself as that carefree person....

I don't think I was emotionally mature enough at that time to grasp everything that I physically went through. Understanding that this is not normal, I just didn't see it as such a huge difference.

- Nadine I don't know your experiences, but I think when you made that film, you were already visiting clinics and tried different, informal ways to support students and patients. And you were still in school, and you were thinking about your next jobs and whatnot...It was a year-long process of making the film. I don't know if you remember that, but you were a teacher in that and you took on the persona of a teacher. So, you I don't find that you were carefree in that way, but I felt like you were trying to help others manage it, by managing yourself in a way. That's how I understood it.
- Sarah That's an interesting perspective. I see what you mean that I took on that, like, everyone must know everything and must be educated because that's just what just everyone must know. It's just COVID's changed a lot of me. It's taken pieces that I want back.
- Nadine In the film, you said that you wanted to change the world. Has that changed?
- Sarah No, I want to change the world. I want to do something and make my mark in this world. Not huge impact, you know, like with my name in lights and stuff, but just like something where I know that, if I didn't participate in that, then it wouldn't have happened.
- Nadine Do you have nostalgia looking back on the girl that you were in that film?
- Sarah I feel sad for her because COVID is coming around the corner and because there was that moment in my life when everything was peachy and great, and everything was going to work out.
- Everything didn't work itself out.
- I was recounting everything that I was seeing in the video and remembering the...like, dude, I felt like *that* was bad. I'm not even bad then, now I am. And so...
- Nadine What do you mean you're bad now?
- Sarah My blood pressure, it's been out of control for the past three months and I'm just like...no one knows why. So, it's not fun.
- Nadine So, I wanted to ask you something about what you imagine your future will be like. Do you think that it's possible for you, for other young people who have transplants, to thrive, to imagine thriving into adulthood?
- Sarah I think it's a possibility. But I also know that it's hard. It's not easy. I used to think it was easy, but coming into adulthood and realizing, no, I can't

do everything like everyone else because everyone else doesn't have fucking doctors. I have to go to the pharmacy and pick up meds and have to sit there and work literally at least two to three hours making my meds.

I have a friend, well, someone I know through a lot of transplant groups, and he was thirty-two years out. He had his heart transplant for thirty-two years. He was good. He's on the waitlist, day six inside the hospital right now. I'm like, "Bro, you were at thirty-two. What the hell happened?"—and it just tanked. His world just stopped. Like, that could be me. That takes one second, one bad blood result and you're done.

For me to see life in the future of whatever I want to do and, like, to plan for it. It is rough because I wasn't given a guideline of how to do it. I don't think anyone is. Let's be honest, no one's given a guideline of how to do life. But, like, there wasn't a question: "Oh, so what colleges are you going to apply to? What is your major going to be? What do you want to do when you grow up? Why do you want to do that?" Those conversations weren't happening at the appropriate times. It should have been happening, but it didn't because I was sick.

Nadine Another perspective is that one of the doctors in your program noted that you and your peers are among the first cohort surviving into adulthood. In a sense, I think you're finding that path because it didn't exist.

I remember these parents—I don't know if you noticed at the time—but we went to a transition clinic group and there were parents there and they were so fascinated by you because they didn't think that their daughter had an independent future. And here you were, you were in college, you were doing research, you were telling your story, you were there to help them out. And I remember the parents were just in awe. I also remember noticing all their stress, all their concerns for their daughter, like they were watching you so carefully. And I just remember you showed them that there was a future of possibilities, and I just thought that was so extraordinary.

Sarah I think that's really amazing to hear. Like I said, I do want to make an impact and if that's the way I can do it, I'm going to do it.

## The Work of Storytelling

In his 1936 essay "The Storyteller," Walter Benjamin mourned the end of storytelling. He positioned storytelling as the sharing of experience that "goes from mouth to mouth," and pointed to a decline in storytelling in an age marked by technological and information transformation (1968, 84). The world in which

young people with heart transplants are coming of age is a world vastly different from Benjamin's. Yet his acute attunement to the fragility of the human body still resonates and the challenges of transforming experience into stories that can be transmitted mouth to mouth persists within experiences of medical innovation.

During preliminary fieldwork in pediatric post-transplant cardiology clinics, I noticed the centrality of storytelling in medical encounters. As a series of specialists rotated into the clinic's examination rooms, I kept hearing them ask their patients whether they were "telling their story." I understood this as a diagnostic tool, a way to see if young people were reconnecting to school, classmates, family, and friends due to the extended periods of disconnection and recovery required by their medical care (Yates et al. 2010). In the context of a small, windowless examination room, where the differences between young and old, patient and caregiver, expert and novice were stark, and where the adults far outnumbered the patient or their allies, the demands for a young person to answer in the affirmative were high. Many deferred responding or murmured "yeses." As an educational researcher, I could not help but recognize the challenges the question posed: Can you organize and narrate a story of one of the most momentous events in your life? Can you objectify your experience to share with others, thereby opening yourself to the possibility of further curiosity and questioning? Can you reject the idea that your heart transplant is a singular story, that it is "your story," or that it is the only story you should tell? As I witnessed this, at times, painful exchange, I recognized that filmmaking was one means to help young people answer the question—not that there is only ever *one* story to tell; rather, through collaborative visual storytelling, young people could have a ready response helpful to them, and to others, within multiple contexts, including a clinic examination room. I could leverage my experience in media production to teach and support young people through collaborative visual storytelling. In turn, young people could teach me how they navigated transition and their experience of living and growing up as a heart transplant recipient. Together, we could enact respectful design by teaching, learning, and researching side by side (Erickson 2006). Therefore, the research took multiple methods and analytic practices into account in designing a collaborative practice that attended to power disparities across participants and co-created new possibilities for understanding and thinking about ecologies of care afforded through the collaborative crafting and sharing of young people's stories. On one hand, the narratives opened reflexive spaces for Sarah and others to see their everyday practices, their rituals of care, and to learn to see that work as an achievement. On another, the resultant films allowed adult caregivers to hear the stories heart recipients wanted to tell, while contributing to emerging studies in transplant medicine.

That is the work of storytelling: to make sense of experiences and to share them with others. In the process of re-viewing the film, another dimension of storytelling emerged. The film is an artifact, produced at a particular moment in

time. Seeing it again revealed the impermanence of knowing. It positioned Sarah as a subject within her narrative in a way she had not seen before. It called on us to respond and re-engage with the work of interpreting and reinterpreting her story. Collaborative, reflexive, storytelling demands this attention: that we listen, engage, and, in that process, contribute to knowledge ecologies—communities for learning and living within the transitory spaces of modern medicine. In collaboratively crafting narratives of heart transplantation, Sarah and I share emergent expertise of transitioning to adulthood and learning to navigate and realize unstable and unpredictable futures. In recognizing young people's epistemic status as knowledge makers, we listen and learn as they share their stories and efforts to craft a future in these precarious times.

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