

they put me on what's-it-called, Rapamune. And of course the Rapamune does the exact same thing that the Prograf does. So they had me taking both of them at the same time, and in the meantime the Prograf is screwing my kidneys up, and uh—so now they've taken me off the Prograf, and now I'm on a drug they call Myfortik. And I take that four times a day. And then I take Rapamune. Ya know uh it's two milligrams a day. And I'm still on the steroids. And I was supposed to be well *off* the steroids.”

Despite a long period of satisfaction in which doing small hobbies and having a human hand again conferred high satisfaction, over time the deteriorating quality of his clinical relationships, personal health, and the graft itself have soured Dave's experience. He described several times throughout our interview the frustration that came with not knowing why his drug regimen was being changed or why doctors wanted to do a particular procedure:

“I mean they've been doing this off and on throughout the whole, whole thing! Ya know they'd call up and they'd change [my drugs], and uh, say you were gonna go I for surgery or something. They'd have you stop taking a certain drug and go back on the other drug, ya know 'cause one drug slows down the healing process. Ya know and this is what I've been trying to tell 'em about [my damaged, bleeding] fingertips! Ya know you've got me on a drug that slows down the healing process! Can you just take me off that and put me on something else for a while? And ya know it's just like—I get no response. That's my biggest frustration: I get no *response*. ... It got so bad, that I went down there in June, and when we sat down to talk, the first words out of my mouth I told them, 'I am ready for it to come *off*.'”

And I think it just shocked them. 'Cause all the sudden they wanted to do this, and they wanted to do that.”

Because Dave’s hand transplant came as part of a research grant and his continued care is covered under Louisville’s funding, if Dave wants a second opinion at another institution, he has to pay for it out of pocket (which he can’t do). The experientially *proprietary* nature of Dave’s relationship with the Louisville program has thus been a major source of dissatisfaction with the hand graft that has little to do with the phenomenology of the hand, itself (about which Dave still has positive feelings). Dave says, “I really am I am very frustrated. ‘Cause I feel I’m getting no—I, I feel like I’m going backwards. You know what I’m saying?”

While a few of the doctors who brought Dave into the Louisville study remain there, most have gone on to start new reconstructive transplant programs at other institutions. As we talked, it seemed to me that deteriorating clinical relationships were as much a source of stress for Dave and Karen as the complications of the hand transplant aftercare (which include, for them, yearly trips to Kentucky for checkups, and winters spent in an RV in Arizona to protect the hand graft from the cold). Dave frequently compared his (more positive) experience working with the doctors on the original Louisville team to that of his experiences working with newer, in his opinion more aggressively experimental, doctors. Karen has a similar outlook:

“The treatment that Dave got at that beginning, right after his surgery with that particular team of doctors and nurses was most excellent. You couldn't ask for a better group of people. As time has gone by, a couple of the doctors have left the program, and each time one of the doctors leave ... Each time one of the doctors leaves, the new doctors coming on board, it seems like they don't have the ownership of the program that the previous doctor did.”

Ultimately, Karen says, she would not want Dave to choose the hand transplant if given the choice to make over again. At this time, Dave still has his hand graft although the function and appearance of the hand have gone down dramatically. He says, “if I could work my hand, the way I *should* be working it, I could probably get 50-55 percent function out of it. Ya know, but the way it sits right now, basically all I can do is hold something between my thumb and finger. My index finger. That’s it! Somebody hands me a receipt I can grab it—well heck, I could do that with a hook!”

It is unclear what kind of exit strategy has been prepared for Dave and Karen by the Louisville hand transplant team. Although Dave’s hand graft has been described as in a state of non-salvageable, slowly progressing “chronic rejection,” and although he has been recently diagnosed with metastatic squamous cell carcinoma,¹ diabetes and kidney problems that are complicated by his immunosuppression, Dave is deeply conflicted about the idea of losing the hand graft. In scientific presentations to the VCA community, Dave’s doctors say that they want to respect his wishes in terms of keeping the graft as long as possible because “he is attached to it.”

Narrative 5: Vasyly Rohovvy

Vasyly Rohovvy is a bilateral hand transplant recipient currently living in Austria, although he is originally from Ukraine and was living in Ukraine when an accidental blast injury resulted in the loss of his eyesight and both hands. When I interviewed Vasyly, he was visiting the University of Pittsburgh for a conference on eye transplantation; his sister and personal caregiver,

¹ As reported by Louisville team member Tuna Ozyurekoglu on Thursday, November 15th 2018 at the 6th biennial American Society for Reconstructive Transplantation (ASRT) meeting: <http://www.a-s-r-t.com/2final2018MeetingProgramScheduleweb.pdf>; confirmed via email 27 November 2018.

Elena, was traveling with him. Vasyly wore dark glasses as we sat on a patio near the Cathedral of Learning in Oakland. He was cheerful, having been a keynote speaker at the conference the night before, and spoke excellent English with a strong Slavic accent.

Vasyly considers himself a lucky person despite the many considerable challenges he has faced. He says he had a “very happy childhood” which he attributes to a lack of access to drugs and alcohol on the streets in the USSR when he was growing up. Nevertheless, Vasyly understands that, “there was disadvantages and advantages, so to say, in USSR. For children it was a good childhood,” he says. “For my parents it was not so good, because, I don't know how to say... In that time, they say that there was no freedom. I don't know what does it mean, ‘freedom.’ There was no slavery, but I don't know. My father was happy, so to say, when USSR fall. My mother was not happy.”

The accident occurred when Vasyly was eighteen years old and studying IT. He describes the event:

“I was going home with my dog and about 600 meters from my home I saw a car and inside the car I saw a bag. I saw that someone had forgotten it. I wanted to find out what it is in that bag, if it's money. I stopped and picked it up and I tried to open it. That didn't work and then I yanked harder. I lost my eyesight on the spot. I couldn't realize, of course, what happened to me. I tried to rub my eyes and only then I understood that I have no hands. I was scared and I ran to my home, looking for help, but I took a wrong direction. I ran to another side, so to say. I ran and hit cars, walls, trees, I don't know what else, and fell down and stand up, but because so big blood lost, after the next fall I couldn't stand up anymore. I was lying on my

back and thought that I was dying, but suddenly something in my head began to scream, 'Call for help, do something, don't sleep!'"

Vasyly says that the snow on the ground that day helped the ambulance to find him quickly after a bystander dialed for emergency help. A week later, Vasyly's parents rented a car and took him from his hometown to Kiev (about 300 kilometers away). At that time, doctors were able to save his right eye, but nevertheless, Vasyly says, "I didn't want to live. I didn't know how to live without hands, with burned face, with very poor eyesight. I stayed at home by myself and didn't want to see anybody." Vasyly's sister, Elena, was instrumental to his recovery via hand transplantation, "My sister started looking for clinic that could help me. She went to the internet café and she looked for a clinic that can get my hands back, so to say. In a few months she found in an article about the hand transplantation in France. We found a teacher and she helped us to translate a letter from Russian to French and we sent that letter to France, Lyon."

After Vasyly and his family identified hand transplantation as a potential route to restoration, they negotiated with programs in several different countries to achieve candidacy. He describes the process of evaluation and waiting for a hand:

"Of course, it wasn't possible for us to get an appointment [in Lyon, not being] a resident. We tried to do it, to find money ourselves, but the French doctor didn't want money, they want involvement of Ukraine government. We couldn't do that and after that my sister found a clinic in Germany, in Munich. We went to that clinic, I passed all medical checkups. It was 3 years after the explosion. I didn't have German citizenship and therefore they couldn't find money for surgery. I was waiting for the answer about 2 years from Germany. They didn't answer to us and my sister went once again to Germany and took all my all medical results and

brought them to home. She found another clinic in Austria in Innsbruck. We sent a letter to the director of the clinic in Innsbruck. He answered us and said we can come to Austria, to Innsbruck. In 4 months in 2005, my sister and I came to Innsbruck. I passed all medical checkups once again and then was waiting for the results... About 11 months I waited for a donor and in May 2006 I received a call from the clinic that they have hands for me and after that I was 17 hours in surgery.”

Vasyly knew that the hand transplant would mean that his life “will be forever connected with my doctors and with the clinic.” He describes himself as being a tireless worker for the health and functionality of his hand grafts and an eager participant in the process, despite the downsides of taking transplant drugs: “After the hand transplant I did the therapy, every day from Monday to Friday from 8am till 5pm. I take immunosuppressants and there are a few side effects.”

Vasyly had severe phantom pain after the explosion, which fortunately resolved after the hand transplant. Although his eyesight is now totally gone following complications in a repair attempt, Vasyly says that the aesthetic, human appearance of his new hands is highly valuable to him. “I was very afraid that I will get big hands. I asked my doctors to find for me good hands. I had very long fingers ... I asked my sister, as I said, to tell me how do they look like and she said ‘No worries, they fit you perfectly.’” His function is also good following extended efforts in the hand therapy clinic in Innsbruck: “I did the therapy for 3 years. I know there is very few patients who did therapy for so long as me. I learned a lot of things that I took for granted before the explosion. To eat. I had to relearn everything, to dress myself, to eat with fork, spoon, to open a bottle.”

Although early on the management of transplant medications was difficult, insofar as, “It was very difficult to take a lot of pills—about 20, 25 pills. Of course, I felt sick.” However, Vasyly

says that, “nowadays I take 3 pills in the morning and 3 pills in the evening” which is very manageable. The special advantages of hands over prosthetics are clear to Vasyly. “Feeling sensation is very important for me, because if you cannot see, you only have one connection with the world. Fortunately, my hands can feel rain, sun, wind and I can feel almost human being if I touch your hand, I can tell—I feel.” At this point Vasyly invited me to test his sense of touch and sensation. I reached out to shake his hand. “Your hands are a little bit cold... Cold finger as I imagine.” He was right, my hands are often cold.

Nevertheless, Vasyly reminded even at the end of our interview that, “Hand transplant, it is not a miracle. [I knew] I will not get my old hands. I will get new hands and these hands will cause pain, there is a lot of work to do and a lot of things depends on me, not on my parents or on my doctors, only on me.” One aspect Vasyly discussed at length is the idea of reasonable expectations as a factor to success. “I didn't have very big expectations. Therefore, I wasn't disappointed. Before the hand transplantation I met other hand transplantation patients. I saw what they can do with their hands and I talked to them. I think it's very important for everyone who wants to get new hands to talk to people who already have them.” Vasyly has gone on to marry a woman he knew before his injury, has a daughter, and continues to receive some day-to-day care from his sister Elena.

Vasyly recognizes that aspects of his life have been extraordinary, where his hand transplant experiences represent a necessity for his welfare and hard work. “We were just an ordinary family from Ukraine. [My doctors] told me I had only one solution, they told me that don't give up, one day you will get your hands.” But no amount of relevant preparation, he emphasizes, can ensure success with a hand transplant. Vasyly says, “I'm very lucky.”

Narrative 6: Sheila Advento

“We all have meningococcal agents at the back of our throats, as I understand it,” says Sheila Advento, trying to describe the source of a viral infection that, several years ago, almost killed her. Although meningococemia is non-threatening among people with a healthy immune system, for some reason, Sheila was susceptible at that time, and from what she thought was an average cold or flu, her health deteriorated rapidly. By the time Sheila was rushed to the hospital for acute nausea and fatigue, she was gasping for air and had to be induced into a medical coma to save her major organs from failure. Unfortunately, the illness resulted in severe necrosis of all four of Sheila’s limbs, and she left the hospital a quadruple amputee.

Sheila Advento was born in the Philippines but came to the United States as a young child. The potentially disruptive or disorienting immigration experience was mitigated by early introduction to American culture via school. Sheila says, “Maybe a month after arrival, I went to school right away, so I got adjusted almost immediately.” Plus, “It’s mandatory that we learn English in my country, as well as any other country really. We watched a lot American movies and stuff.”

Sheila was an independent person supporting herself and going to school before she got sick. It was difficult to transition to a life where all of her personal needs had to be met by another human:

“I cried a few times, but I was also under antidepressants, so that helped me. I was in the hospital and then also I was in rehab. Especially when I was in rehab, I felt like I was confined in secure place, in a secure bubble. Where they do the exercises, occupational therapy, physical therapy, and doing things that I eventually got accustomed to and knew what to do because I was in this bubble. It wasn’t until I

was discharged that things started clicking, how difficult life is as an amputee. I was getting really depressed, and I didn't know how to handle things emotionally. I was frustrated a lot, I took it out on people. I didn't know how to calculate the frustration into my life. I didn't know how to handle anything. I just wanted to be independent, and it was hard to ask for help, it was *so hard* to accept help. I didn't want to pity myself, I didn't want anyone to pity me. It was all these heightened emotions that I'm not familiar with that just came into the picture. ... [Before], I did everything on my own. I got dressed on my own, I did my makeup and my hair on my own, did the laundry on my own. Then all of a sudden all that's gone.”

Eventually, Sheila and her family hired a personal assistant, but things started looking up especially after Sheila came across an article about hand transplantation. Sheila says, “I reached out to the facility. I reached Dr. Lee, who was there at that time. He almost immediately responded back. I sent him pictures, and we just exchanged communication to the point where I was invited to do the screening.”

Compared to other narrators on this project, Sheila’s evaluation and waiting period for hand transplantation were rather fast (completed within a year):

“For about a week I did all the necessary screening process that they required. That includes psychological testing, a lot of blood work, seeing multiple doctors, and meeting with a transplant team. Then eventually, it wasn't that long after, I got approved for a transplantation. I thought that I may have to wait years. That was a reality I was thinking about, that I would have to wait years for a donor. had a safety bag on the side, just in case [and] I only waited nine months. I remember I actually had a day off of work and I was just watching TV. I got a call and I was told that I

needed to travel right away, because I had a donor waiting, so my mother and I traveled to Pittsburgh. We took a plane to Pittsburgh.”

At the time of our interview, Sheila was completely satisfied with her experiences as a hand transplant recipient. Despite what she describes as a “grueling” the post-operative therapy and medication regimen as well as some debilitatingly severe headaches in the early phase, Sheila described her experiences in positive terms, emphasizing the gradual return of function and sensation in her hands as a thrilling and pleasurable, unfolding experience. “I’m able to do so much more. It’s exciting for me. For instance, I’m able to grab somebody’s arm, I’m able to hold somebody’s hand, I’m able to hold my boyfriend’s hand. It’s a nice feeling. Not having hands, eventually you lose the intimate feeling... I feel like my sensations are back. It’s just very exciting. Everything is so exciting for me.”

As part of my evolving oral history protocol, I asked as one of my final questions for narrators how their relationship with their clinical providers has evolved over time. At the time of our interview Sheila Advento was happy with her outcomes and with the quality of her care from the team at UPMC (although by the time of our interview the program had migrated to Johns Hopkins University). However, as recently as November 2018, one of the lead surgeons on Sheila’s team has reported that Sheila is in renal failure and in need of a kidney transplant. He also admitted that Sheila is now seeking care outside of their program (Shores et al, American Society for Reconstructive Transplantation, Chicago 2018). Sheila attended the meeting where these results were presented; however, she was not invited to speak publicly about her experiences. She did personally confirm this distressing, ongoing outcome to others and her lost faith in the transplant team at UPMC/Johns Hopkins (see chapter 3 for more on the rhetoric offered by field professionals at this meeting).

At one time, Sheila's uncomplicated answer to my then-standard question about clinical relationships did not merit much further consideration. With the above information, this is no longer true, and for many reasons which I will discuss at length in the next two (concluding) chapters, I find Sheila's narrative of hand transplantation to be one of the most disturbing accounts of biomedicalization of physical disability in the hand transplant literature.

EH: Do you feel like you have a good relationship with your doctors?

SA: Yes, very good. ...They're easy to talk to. They check up on me. They call or send text messages, just to check up, to follow up. I think that's wonderful, because not a lot of doctors are like that.

EH: Yeah. Why do you feel like the relationship with your doctors is so strong?

SA: I think, because they want the best for me, regardless of the hand. With the hand transplant they want to make sure that I'm doing okay, they want to make sure that I'm healthy... What my progresses are and what the changes are, so forth. I update them also, a lot.

EH: Yeah.

SA: Just the fact that everybody wants the best for it, with their hand transplant.

EH: Do you feel like their interest is really about you?

SA: Yes, definitely.

Narrative 7: Josh Maloney

“I remember them cutting my clothes off to check, make sure the rest of my body wasn't wounded and me trying to stay calm. As far as I know, I never went into shock. I never screamed,

I never cried, I never passed out,” says former Marine and hand transplant patient Josh Maloney recalling the day he lost his dominant right hand. It was the second day of a two-day convoy training exercise and Josh was one of the leaders.

On that day they were using shot boxes, which Josh describes as “basically a big four-foot-long by six-inch thick steel tube filled with compressed air and baby powder, to simulate an IUD going off.” Unfortunately, the box they were using was faulty, and instead of sending current on command, it was sending current all the time—so when one of the Marines skipped protocol and plugged the wires into the box without first checking that the charge box wasn’t active, it detonated. Josh says that when the explosion went off, everything happened, “fast.” “Diaz had his knees around my neck keeping my head straight. I had Marines with my arm out and I kept asking him, ‘I know I’m messed up, but do I still have fingers? Is my arm gone? Somebody tell me something.’ Nobody would tell me anything. I remember—it was January 31st, 2007, it was cold.”

Josh kept his head throughout the life flight: “I laid there telling jokes trying to keep everybody else calm. One, I knew if I lost my cool, as cold as it was and as injured as I was, I would probably die if I allowed my heart to race, to go into shock or anything. Marines are a special breed. I knew my guys would take care of me, but anything they could use to make fun of me later, they would.”

The oldest of four children, Josh says that throughout his life, he has had a strong sense of himself and his goals for life. Of his early and lifelong desire to be a Marine, he explains, “I always thought, watching war movies ...I bought into—and I still do to some degree—that patriotic rhetoric. [As a career, it seemed] you get to play with cool stuff. I wanted to be a pilot, and then I realized how much math was involved and I was like, ‘No, I’m good.’”

Once his family realized Josh was serious about joining the military after high school, since several family members had been sailors many of them assumed Josh would also join the Navy. Josh narrates, “I was already the black sheep for going in the Marine Corps. Then, [my family] wanted me to get a trade when all I wanted to do was blow things up. I was an 18-year-old kid. Think about the future or you're going to give me high explosives? I'll take the high explosives.”

I met Josh for coffee at a Starbucks near Moon, Pennsylvania, about 30 minutes from Pittsburgh, to conduct our interview on his experiences as the first recipient of a hand transplant at the University of Pittsburgh Medical Center (UPMC). By that time, Josh had undergone a self-requested amputation of the unilateral hand graft, having found the therapy and Rx protocols too burdensome to justify for his lifestyle long-term. Josh continued: “I take things as they come and don't really think about it beyond that. [I'm that] type of person. I don't care. In a lot of ways, I can take some subjects and think deeper on it, but things that happen in my everyday life, I don't.”

Patti Maloney, Josh's mother and also a narrator for the oral history project, says that, “along with Josh not having strong opinions on anything, (as I say facetiously)—as he came into his own through being in the Marines and everything he became very strong-headed.”

Josh sincerely enjoyed and never regretted his career path into the Marines, despite being deployed twice to Iraq. Of that time, Josh recalls a comfortable relationship with duty and routine—“You didn't have to think. You didn't have to worry. You just did what was in front of you”—and amusing stories, “I remember being stopped on a security halt and an Iraqi vehicle went by that must have had dinner in the back, in the trunk, chicken. The chicken fell out because it was tied to a milk crate and it came undone. You have seven Marines fully armed chasing the chicken...”

I asked Josh whether he might be performing some optimism for the sake of the interview, at least in terms of his war memories. He answered, “No—I remember the bad things more often than the good. It was just—it was one of the scariest moments of my life. I turned nineteen in Tikrit on the air field that's outside Saddam's palace. It was scary as hell, but it was also some of the most fun I've ever had in my life.”

Patti says that despite reservations from the rest of the family, “Josh loved being in the Marines. After a couple years when he came back to visit, on one of those—I just looked at him and he wasn't that skinny little kid that went off, he was this big guy... I can literally remember the moment when I was standing there looking at him thinking, ‘Wow has he grown up and changed.’ Just that whole wow, he's no longer my little boy kind of thing.”

In the hospital after the accident, Josh says, he didn't seem to fully appreciate the disabling nature of his injury, inquiring about his professional capacities rather than his health, “I came out of surgery, the first time after they made sure I was okay, and my platoon was still around me, they had all driven up to the hospital. I remember acting like, ‘When can I get back to work?’ Was the first words I said to anybody. I just wanted to go back to work. Then, I don't remember much after that.” Josh was transferred from the first hospital to Walter Reed, “where they did more surgeries and helped me heal up.” After mixed experiences at Walter Reed, Josh and his family negotiated his care back to Pittsburgh, where he was treated at UPMC and eventually, heard about hand transplantation. He says, “I started dating a girl whose aunt worked for UPMC at Mercy and that's how I heard about the transplant program. ... She actually handed me a flyer than had been circulating through UPMC. We were at a family dinner and I actually called that number that night and left my information. I got a call back the next day.”

The evaluation process Josh describes as relatively straightforward, despite having little idea what to expect when the graft hands finally arrived. “They walked me through it all,” he remembers, “I had to get all the blood work and the psychological testing. To me it was all pretty easy because—being a Marine, to me, it was like, ‘Okay that's the next mission. This is what I want, this is what I want to do’ [even though] there was nobody that had done it before me that could walk me through the process and tell me what to expect. I knew going into it that I was the guinea pig.”

According to most hand transplant experts and Josh’s own clinicians, he had an excellent functional outcome in the early post-operative period of about two years. “Therapy was painful,” Josh says: “It was worth it but it was painful.” He quickly started seeing returns on his investment and recalls using the graft hand as an exciting experience. “I was getting really good with it. Really, really good. Way more than Vijay or anybody else thought I would ever get because I pushed myself. Then I started trying to... I got arrogant and stupid and thought that after a year of therapy, it was just going to stay that way that I didn't have to maintain it. I took advantage of it and I stopped paying attention and functionality went down.”

The more disappointing aspect of the hand transplant long term, says Josh, was the aggregate effect of all the work and worry that had to be managed on a day to day basis. The contingencies of life grew, yet his hope of returning to a combat role was not coming any closer to fruition. Josh says he grew weary of the constant surveillance and the experience of hand transplant patienthood. He also experienced episodes of acute rejection that were unpleasant and in some ways, off-putting to others. Patti Maloney remembers the long arc of Josh’s relationship with his graft as being affected negatively by complications of immunosuppression and the

transplant lifestyle: “[He was experiencing a lot of rejections and] I think it was in that time that Josh had just reached that point in his mind like he wanted to not have to be a slave to the routine.”

In retrospect, Josh thinks, “I did it for the wrong reasons. I did want to get back into the military, thinking that that would be my shot to get back in [to the military]. I kept thinking about that the whole time the process was going on for it.” Patti thinks that ultimately the hand transplant amounted to a role Josh played that he also grew out of in a timely fashion: “Josh was ... the first one [at UPMC]. That's an awesome responsibility and I think he tried to live up to that for as long as he could and then he just didn't want to be that person anymore.”

Narrative 8: Joe Kinan and Carrie Pratt

Joe Kinan and Carrie Pratt are an impressively committed, seemingly truly cohesive, couple who met many years ago at an international conference for burn survivors. Carrie, a native of Ferndale Washington with an easygoing demeanor and sharp powers of observation, suffered a serious burn injury when she was just a baby and has been attending support groups for burn survivors most of her life. Joe, a victim of the infamous 2003 New Jersey Club Fire, is now the first hand transplant recipient at Massachusetts General Hospital’s emerging VCA program, and a soft-spoken person of amazing willpower.

Carrie’s description of her early life highlights her strong sense of independence and self-knowledge following a childhood in which bullying was an occasional feature. “I always wanted to be a nurse. But, uh, the four years in college was more than I could stomach. After not enjoying high school too much. I just had a different learning style and I was told in college it would be different but I just...wasn’t willing to give it a try—I wanted to start working right away, so, I passed on that and went to beauty school instead.” Joe who made his career in men’s clothing before the fire, like Carrie found work gratifying and a source of independence.

The couple met approximately ten years ago. Carrie describes that time period and the importance of the community that brought them together:

“I was, um, in a bad marriage at the time, and my husband was also a burn survivor, and so the first year I came to World Burn was an extremely emotional experience for me. Just because of where my life was at home and just meeting all of these amazing people, strong amazing people, and Joe was, in the group with so many other new faces and he was just, um, happy go lucky and joking... When you look at him you would expect him to be um, like a little bit more... on guard or worried that he’s gonna be judged. But that’s one thing that I learned on that first day was that everybody there, if they’re being there they’re comfortable with themselves not necessarily outside of the conference but at the conference everybody comes out of their shell and they talk and joke and it kind of brings them back to who they used to be before their accident. I was introduced to him by the director of my foundation that I was there with, she had just run into him and she...brought us over and said, ‘You have to meet this guy he’s absolutely incredible,’ and he just started cracking jokes about his appearance right off the bat and I just thought, ‘This guy must have been through hell, and he’s been through so much, and he—he still has this light about him and he’s still so positive.’ Uh, and we became friends after that conference. We didn’t talk a whole lot but we would email a couple times during the year, and then we would see each other at the conferences during the year, and over the years of our friendship we would talk more often. Once I got divorced he kind of became my sounding board for everything I had been through and, you know because he wasn’t a big talker he listened, which was really nice to have

somebody listen, and not judge you. So. And it wasn't until, we were in Galveston Texas, five it'll be five years ago this October uh, at a conference, that, something was just different between us. And I'd been divorced for, a year and, um, we decided that we would have a long distance relationship which was a little scary but, we made it work. Yeah, so we've been friends for nine, going on nine years I think."

At some point during the development of his friendship with Carrie, Joe's plastic surgeon in Boston introduced to him the idea of hand transplantation and invited him to consider being evaluated for their program. Because the extent of Joe's burn injuries caused the loss of all of his fingers, at that time Joe was able to do very little for himself: "I figured out how to get myself a glass of water. Just little things. I did eventually get a device, I made it myself actually with a friend of mine, that did work good in order to hold a fork so that I could feed myself. But getting dressed was an obstacle, shoes, pretty much everything. I did figure out how to hold my toothbrush..." After being offered the possibility of a hand transplant, Joe says, "I went home and thought about it and I called Carrie, who was just my friend at the time, and asked her what she thought about it. Then after her conversation I thought about it some more, 'Do I want to be on medicine for the rest of my life?', things of that nature." Carrie says that the idea of constant medications was especially hard to get used to, especially for Joe: "Joe's never been drunk in his life, he's never taken illegal drugs, he's never been high never smoked a cigarette, like he was—straight as an arrow, clean—when it came to bodybuilding the only supplements he ever took was protein powder..."

After the hand transplant, Joe and Carrie say they purposely remained in state of watchful awareness rather than emotional investment. Carrie describes that time:

“We really didn’t have any expectations which, I think, is a good thing. Um, I kind of compare it to, you know when you have a new baby you—are hoping that it’s healthy, and that you don’t have any health issues, and that your child’s gonna be different than any other child. Whatever that is, um, but you can’t expect your kid to be born, and to be a certain way that you have imagined in your head, and I guess that’s kind of...what we did with his hand. He got this hand, and it was—a hope—that he would be able to do things that he couldn’t do with the stump that he was left with. And none of it was immediate, at first the biggest milestone was being able to pick up a marble, um, and that was like two months in. And that was a huge deal.”

According to both narrators, there was a long and surprisingly arduous period of adjustment before Joe got any real function and benefit out of the graft hand. Carrie says, “I would say the first three months were pure hell. It was...horrible. Um, and if that was something—that somebody could have told us before the transplant I think it would have made the transition a little easier? But nobody knew.” Along with grueling therapy and nerve pain, Joe endured near-constant vomiting and nausea for over a year before his body adjusted to the medications.

One interesting and especially rare outcome of the hand transplant for Joe and Carrie is the rich familial relationship they have developed with the family who donated Joe’s graft hand. Because Joe and Carrie’s donor was a high school senior who died in a freak accident, it was easy for them to triangulate between demographic information they were given about the hand donor and the local news covering the tragic death. When Joe and Carrie first met the family, Joe says their connection was, “strange in a good way.” He explains that it, “Seemed like friends that you hadn’t seen for a bunch of years. We sat down and started talking. ...I didn’t know what to expect

and I wasn't trying to expect too much. Since then they have asked and we've accepted that [our newborn daughter] Hadley—if she could be considered their granddaughter—because her son's hand is on me so his DNA is inside of me now. They asked if she could be part of the family.”

Although it may seem surprising to outsiders, phenomenologically *and* biologically Joe and Carrie say it makes sense for the donor family to participate in their life in this intimate way.

Carrie describes their connection in strongly affective language:

“We know in our minds that having this hand on his body had nothing to do with [our getting pregnant] because all the transplant medication Joe was taking should have, for all intents and purposes, made him sterile—even if he *hadn't* had a vasectomy. But it didn't. Um, so like, I've said, and Mary [the mother] says it too—it's like this little person is supposed to be here. We don't know for what reason, but um, it makes Mary feel better to think that Troy had something to do with it. It's not like, Joe took on Troy's DNA profile because he didn't. But, there's some part of Troy in Joe that's now Joe. The hand belongs to Joe, it's his hand, um—but I think it makes Mary feel better, thinking that there's some part of Troy... in Hadley. And when we told [our doctor] this he kind of laughed and he said hey, 'Anything's possible.' You know? Not that it's her biological grandchild by any means. But, um, that we don't know if we would have had her before. So, anything's possible, but she feels like this—this is her grandchild and we're perfectly fine with that. We love them to pieces, we absolutely love spending time with them, we were at their house last weekend, um—there was a big memorial softball tournament in Troy's memory and so Joe along with the family got to throw out the first pitch. Troy used to be the pitcher, at his high school, so... that was really

special for all of his friends to see, and all of his family, and, for his parents most of all, to see, um, Troy's hand doing what it used to do, which is, pitching, which ... was pretty cool.”

Joe and Carrie are still navigating together the many challenges and opportunities of human hand transplantation. When asked what they would change or do differently if given the opportunity, Carrie says her only regret so far is the lack of adequate preparation and inability to accurately imagine the intensity of the early post-operative period, concluding, “I’m glad it took a whole year for us to get through the process. Um, being able to ask questions that we thought were pertinent to the surgery, the one thing that we did hold back on was—and Joe expressed this to me later—was, ‘I’m afraid to ask too many questions because I’m afraid they’re gonna say, we changed our minds, you’re not a good candidate for this.’” Carrie emphasizes the extent of this mistake anecdotally: “[Our doctor] Curt said, ‘That’s the stupidest thing ever, you could ask us anything and there was nothing that was gonna change our mind about you being the first patient at MGH to do this.’ Um, so it’s—I think that would be one of the things I would tell patients is, ‘Don’t’ be afraid to ask every question that’s on your mind.’”

3.3 ORAL HISTORY OF HAND TRANSPLANTATION: THEMES AND CONCEPTS

Based on the interviews with hand transplant patients and their caregivers, I present several thematically organized “gestalt” insights pertinent to understanding what counts for success in this field, and how success has been achieved through the mental and physical work of patients and those who support them. Taken together, the narratives illustrate that in hand transplantation, compliance is a collective achievement of medical providers, caregivers, and patients rather than

the sole burden of the hand graft recipient. Second, physical sensation, manual and psychosocial function, and the health of a hand transplant are deeply related categories of the HTX experience and should be treated as such in scientific measurements of efficacy in hand transplantation. Finally, insofar as “success” is achieved in HTX, it can only be defined by the conceived desirable outcomes of the hand transplant as envisioned by the patient and their family.

“Compliance” is a collective achievement

Researchers in the field of hand transplantation make much of the process of patient selection and the need for strict adherence to immunological protocols and hand therapy guidelines. When guidelines are not followed, patients can be charged with “noncompliance,” which effectively brands clinical interventions as *personal* failings if the treatment ends badly (see chapter 1 for discussion on noncompliance issues in the first modern case of human hand transplantation). There has, however, been little work to understand longitudinal compliance and its challenges from the viewpoint of patients and their caregivers who carry out the work from day to day (Kumnig and Jowsey-Gregoire, 2016).

In addition to engaging in hand therapy and medication management for the rest of their lives or the lifespan of the graft, patients and their caregivers must perform the real work of forging and maintaining the relationships that make hand transplants possible. From the start, hand transplants involve a host of actors and actants—a huge network of laborers are needed not only to organize and perform the transplant medically, but also to help the patient care for the hand graft, to guard against outside threats, to interpret signs (e.g., of infection or progress), and to help shape new meanings in response to contingencies. As Angel Gonzales describes in his oral history interview:

“[My partner’s arms]...were basically dead weights, in these casts, and swollen and just, needed constant maintenance—you know, we had to unwrap the arms, wrap the arms, uh, multiple times a day, massage them, work them out it was just a regime of things that, basically by the end of the day you were glad that the day was over!”

Because in the short term of hand transplantation, functionality will go down before it goes up, for bilateral HTX patients especially family caregivers or attendants have to be willing to put in as much work as the patient. These care activities may or may not be aspects of the recovery process that they relish or even expect.

In hand transplantation, for almost all aspects of the preparation, surgery, and aftercare, as the saying goes, “it takes a village.” In their seminal 1977 book on architectural evolution and livability, *A Pattern Language: Towns, Buildings, Construction*, authors Christopher Alexander, Sara Ishikawa and Murray Silverstein write, “when you build a thing you cannot merely build that thing in isolation, but must also repair the world around it, and within it, so that the larger world at that one place becomes more coherent, and more whole; and the thing which you make takes its place in the web of nature, as you make it” (p. xiii). Recalling the surprisingly wide and robust circle of effect the hand transplant had on his social relations, Matt Scott said, “I started to realize that this is not just me. This is everybody around me. Everybody around me who knows me, even my friends will go, ‘Hey, you’re friends with that guy who got the hand, right?’ ... It spread that far out that it affected more than just me and my small nucleus. It went far around me.” Matt Scott’s experience was unique due to the way his experience of celebrity patienthood contributed to the social effects he describes—nevertheless, hand graft recipients across my oral history interviews have remarked on the local, rather than individual, effects of these types of transplants.

Whether clinical, familial, or collegial, the relationships supporting the substantial work of hand transplantation are crucial to patients' thriving. Instances during which the shared nature of "compliance" in hand transplantation can be especially visible are those in which HTX recipients were considering exit strategies. Josh Maloney recalls, "I was afraid to disappoint [my doctors] when I told them that I wanted to have the hand removed. When the functionality started dropping, I felt like I was disappointing them. I felt bad because of it. ... I finally just said, 'I think now is the time. I've given it everything I can, it's not getting any better.'" Even in the less intensive rehabilitation processes of solid organ transplantation, care providers typically consider it part of their job to check in on their patients, to motivate them in completing care protocols, and to communicate consistently about health events. As organ transplant clinicians Williams, Low, Manias, and Crawford argue, "A quality partnership with frequent interaction between the health professional and patient is necessary to support medication adherence... Post-transplantation, patients require repetition, reassurance and re-enforcement long-term by staff trained in adherence counselling within a supportive healthcare system as taking multiple doses of different medication every day is taxing" (2016, p2252 and p2260).

Jan Plock, a plastic surgeon and burn care physician in Zurich who is starting a VCA program in Switzerland, was a resident at UPMC, Pittsburgh, when hand transplants were being performed and treated there. In a Skype interview Plock says he observed loose obligations to patients among some HTX doctors (compared to the personal commitments held by counterparts in solid organ transplantation) and the high cost for patients when their care team was unreliable or constantly changing:

"What I see in other transplant centers is that the centers really have a very strong connection to their patients, and I think there are huge differences in the different

U.S. centers. For example, the [Brigham and Women’s Hospital] team seems to have a very strong communication with their patients; other teams who did a very low number or a few patients have this quality. Then there are other teams where there is only *one* surgeon who has this quality of relationship with the patient so the *team* can’t handle that relationship, it is more of a personal commitment ... Observing the situation at UPMC the only thing I can really say is the patients were not happy with the situation, and the situation is that their doctors, the surgeons who had transplanted them, were not there any more. The hospital was the providing institution so they were bound to this hospital and the doctors that were there were not the ones that had initiated the process. And this is a really neutral statement because nobody could do anything about it [at UPMC]. They didn’t know or had not known before [that the program was moving to Johns Hopkins]—the situation just changed.”

Because many hand transplant recipients live a long distance from their center of care (especially in the U.S.) maintaining therapeutic relationships can be particularly challenging. Many narrators expressed dismay recalling how many trips they had to take for yearly checkups and to manage complications—trips which were made at their own expense, a fact which caused bitter feelings in some cases. Other recipients have found the necessary migrations of hand transplantation to be enjoyable on some level, “I have since come to think of Louisville as a home away from home,” said Matt Scott describing his regular visits there. For HTX patients who experienced the phenomenon of their original clinicians leaving for new opportunities or to start VCA programs in other places, advocating for their own interests with newer doctors who did not

Despite these reported complications in the short term, in the conclusion of their paper, Cendales et al write that, “We have shown that hand transplantation can be performed using a de novo belatacept- based treatment in a CNI- free regimen, providing sufficient prophylaxis from rejection, reversible rejection when occurred, and reduced side effects, the latter particularly important” (2018, p. 1806). Revealingly, the authors do not mention the fact that their patient resides extremely far away from the transplant center but was personally responsible for getting to and from his monthly appointments. Cendales et al write: “Per protocol *the patient resided locally for 3 months* and returned to his local residence in month 4. Thereafter, *the patient returned to our center monthly for his belatacept infusion until the end of the study period at postoperative month (POM) 18*” (p. 1805, italics added). These are significant details because in traveling to these mandatory monthly appointments, the patient—who lives in Laredo, TX, on the border with Mexico—had to travel a distance of over 1,400 miles to Durham, North Carolina for these experimental treatments. One might commonsensically wonder what other tradeoffs have been experienced by this patient in terms of the hand transplant when we have no firsthand feedback from him on the gains and burdens he has experienced in any publication or presentation by Cendales’s group so far.

Regrettably, the example related above is not an isolated case of abstract representation of patient experience at the service of “progress” in the hand transplant field. At every conference I have attended on VCA (three so far), the need for consistent outcomes reporting has been emphasized by field leaders but no strategies have been agreed upon for filling empirical gaps. There is an International Registry of patient data but it is not complete or up to date lacking insights from many programs and patients. Furthermore, patients who have lost their hand grafts are not followed at all, and complications, including patient deaths, are not discussed in the media with as

much regularity as successful surgeries or milestones. Even when outcomes are published in a timely fashion and a patient followed over time, manual function (grip strength, etc.) and the clinical management of immunosuppression or rejection/infection are discussed, but not the factors contributing to patients' quality of life post-transplant. Thus, the impact of managed complications and the post-transplant lifestyle (including travel to and time spent in the hospital and at appointments, or the temporary loss of manual and social function during recovery from surgery and from infections/complications) are not considered—after 20 years of hand transplantation we can find out almost nothing about patients' lives from the literature and even conferences are thin on this aspect.

As Judy Segal writes in *Health and the Rhetoric of Medicine*, “The most salient narrative of medical history is the narrative of progress, the narrative that says, ‘We used to have things wrong, and now we have them right, or are on the road to having them right’” (2008, p. 21). When clinical researchers push success narratives, publishing and discussing primarily quantitative “scientific” variables from their experiments without considering complicating on-the-ground participant perspectives, a dangerous loss of focus on research subjects' *personal* interests in the outcome of experimental interventions can occur. This is emblematic not just of one-off case study representations of success in hand transplantation but also of the “top-down” rhetoric from contemporary field leaders. In a recent feature-length article on hand transplant outcomes by science journalist David Dobbs, the tendency of hand transplant thought leaders to present outcomes in terms of their own needs and not their patients' is strongly highlighted. Dobbs interviewed me for his article on modern hand transplant outcomes and I encouraged him to attend a scientific meeting on the topic. Dobbs acquired a media pass for the 2018 conference of the

American Society for Reconstructive Transplantation (ASRT), giving the following reflection on representations of patients' experiences by surgeon-scientists at the meeting:

[S]uccess was the theme of the conference that day, and [Gerald] Brandacher [head of the ASRT] underscored that idea in his opening speech. Just as solid-organ transplants had moved 30 years earlier from doubt to acceptance, he said, so reconstructive transplants were poised to do the same. Challenges remained. Now that many patients had been on immunosuppression for years, Brandacher noted, they were suffering more renal complications and chronic rejection of the grafts. In his opening talk at the conference, Brandacher acknowledged that the VCA field had not resolved all its issues. But his main message was one of success and the need to move forward. Most of the day's talks followed this lead. The last speaker of that afternoon's long opening session, a bioethicist, in fact, ended by crying, "Let us plow forward with this incredible field!"
(<https://www.wired.com/story/devastating-allure-of-medical-miracles/>)

As demonstrated above and in previous chapters, when doctor-scientists create opportunities for their patients and also *frame how those opportunities will be managed and assessed*, professional considerations in the literature may travel farther and farther from the site of the patients' and their families' ever-evolving needs in relation to their own health and even the health of the hand graft(s). As Stefan Timmermans and Marc Berg warn in their 2003 book on evidence-based medicine, *The Gold Standard*, "the emphasis on following standard procedures, based on scientific evidence, could leave precious little room for patients to influence the course of their own care trajectories. Moreover, an emphasis on objective evidence might direct the physician's attention even more to laboratory tests and other objective measures of the patient's

condition, and belittle even more the importance of the patient’s own story and experiences” (p. 118). If, as Timmermans and Berg argue, representing patients’ experiences in such unrealistically calculated ways is contrary to medical knowledge and possibly ethics, *why* have reductive quantitative methods for assessing medical outcomes become the seemingly “natural” vocabulary for doctors relating case studies to their peers (especially in a field like hand transplantation where the stated goal of the treatment is subjective improvement to patients’ quality of life)?

To illustrate how such ungrounded, seemingly out-of-touch vocabularies have come to dominate clinical discussions of outcomes in this and other fields of medical science, the next sections explore the concepts of medicalization and biomedicalization as they relate to the evolution of treatments for hand loss in the 20th and 21st centuries, turning first to disability scholars for a critical framing of key developments and processes.

4.2 HAND LOSS, PHYSICAL DIFFERENCE, AND THE “SOCIAL MODEL” OF DISABILITY

In the above epigraph, a French psychoanalyst and participant in several of the world’s first hand transplants, Gabriel Burloux, invokes images of Frankenstein’s monster to emphasize fears of psychological rejection in early hand transplantation (in Lanzetta and Dubernard, 2007, p. 375). Notable in Burloux’s chapter, the ontological state of being “pieced and sewn together” is the speculative source of horror—a somatic fact eliciting revulsion from others or from oneself. Since I started writing this dissertation project, images of Frankenstein’s monster have entered my mental and visual field of view with increasing regularity as 2018 marked 200 years since Mary Shelley first liberated her “hideous progeny.”

For me, Shelley's haunting depiction of scientific tragedy is made more unsettling because the story's horrific ends emerge not from defects in the monster-protagonist's nature or character but as an outcome of the unearned abuse and "othering" the creature endures from *every* person to whom he appeals for the most basic of human needs: care. Here is the creature approximately mid-way through the novel, begging his creator for a chance at life, which he characterizes as life with seemingly any amount of affection in it:

"I learned from your papers that you were my father, my creator; and to whom could I apply with more fitness than to him who had given me life?" ... he continued, "If *any being* felt emotions of benevolence towards me, I should return them a hundred and a hundredfold; for that one creature's sake, I would make peace with the whole kind! But I now indulge in dreams of bliss that cannot be realised. What I ask of you is reasonable and moderate; I demand a creature of another sex, but *as hideous as myself*. The gratification is small, but it is all that I can receive, and it shall content me. It is true we shall be monsters, cut off from all the world; but on that account we shall be more attached to one another. Our lives will not be happy, but they will be harmless, and free from the misery I now feel. Oh! my creator, make me happy; let me feel gratitude towards you for one benefit! Let me see that I excite the sympathy of some existing thing; do not deny me my request!" (Shelley, 1994, p. 99-100 & 105, quoted from Dover Thrift Editions, republication of the third edition of *Frankenstein* (chapters 16 & 17); italics added).

This pitiful appeal follows several chapters of acute emotional suffering by the creature in which his gestures of friendship and bids for inclusion in human society are met with fear, revulsion, and physical violence by individuals and whole communities. The creature has learned to care for

himself but longs to be cared for, in turn—the same way he has observed (from afar) human families caring for each other throughout his solitary travels.

Much has been made by literary scholars of the negligence of Doctor Frankenstein in his abandonment of his living creation. As an archetype, or foil for, differing concepts of scientific progress, an overlooked feature of Mary Shelley's groundbreaking novel are the less dramatic, yet richly narrated character-building events in which the unnamed creature's tremendous capacity for human connection are demonstrated through his eloquent words and compassionate behaviors. What clearly prevents this individual's personhood from evolving fully, in Shelley's depiction, is his lack of an acceptable degree of human appearance or an advocate of "normate" status (Garland-Thomson, 1997, p. 8) who could translate his physicality as not-monstrous, but different. As science and technology scholars Megan Halpern and colleagues write in an article that reinterprets *Frankenstein* for interdisciplinary readers, the Victorian horror story that pervades so much of contemporary bioethics and technoscience discourse is about, "what it means to care for, or fail to care for, one's creation," as much as it is "a cautionary tale about the evils of scientific hubris." Halpern et al conclude of their study that, "[Shelley's novel is] a parable about the dire consequences of care's absence ... [and it] ... cautions us against abandoning our creations to the world; in order to protect both the creation and the world, we have to take part in the discourse and deliberation about how it is taken up and integrated into its social contexts" (Halpern, Sadowski, Esrich, Finn, and Guston, 2016, p. 49-50 & 55).

Burn survivors, people with congenital deformities, and others whose physical appearance has been a source of exclusion or abuse by society often gain critical resources for life through the advocacy of a friend or family member or through laws that have been advocated which protect their rights to equal treatment (Davis, 1995; Schweik, 2009; Johnson, 2010, p. 474; Kafer, 2013,

process of learning to rely on others for many of her daily needs, “It was so hard to accept help. I was getting really depressed, and I didn't know how to handle things emotionally. I was frustrated a lot, I took it out on people. I didn't know how to calculate the frustration into my life. I didn't know how to handle anything. I just wanted to be independent, and it was hard to ask for help, it was so hard to accept help ... I did everything on my own—then all of a sudden all that's gone.”

With the above voices of dis/ability in mind, one can perhaps appreciate why people doing the work of living with disability in our society describe feeling fatigued by conversations about their differences, while at the same time having to constantly engage in political and personal arguments for their right to be included, educated, valued, and of course, allowed to live (<http://disability-memorial.org/>).

The “social model” of disability

The “social model of disability” is an envisioning of disability and disfigurement which is in many ways the direct opposite of that assumed by modern medical professionals. Disability scholars and activists have robustly challenged the view that, “unusual embodiment is inherently inferior” (Garland-Thomson, 2002, p. 7). Scholars and activists whose views of disability are informed by a social/relational model rather than a “medical model” argue that, “the ‘problem’ is not the person with disabilities; the problem is the way that normalcy is constructed to create the ‘problem’ of the disabled person” (Davis, 2017, p. 3). Writing on what she terms a “political/relational” model of disability, Alison Kafer locates disability not in individual deformities but “in built environments and social patterns that exclude or stigmatize particular kinds of bodies, minds, and ways of being...[as well as] in inaccessible buildings, discriminatory attitudes, and ideological systems that attribute normalcy and deviance to particular minds and bodies” (Kafer, 2013, p. 6 Kindle edition). James Wilson and Cynthia Liewicki-Wilson give a

similar perspective in *Embodied Rhetorics: Disability in Language and Culture*, insisting that, “Transforming disability ... entails more than just including the disabled. True transformation would permeate the entire social order and generate changes in economic organization, ethical thought, educational practices, the organization and design of social space, and the interactions and habits of people in all aspects of daily living” (2001, p. xii).

Despite the above liberatory views of dis/ability in society, there is a somewhat contradictory thread in some of the disability studies literature that seems to demand an unmodified embrace of the “dis/abled” identity category in ways that may feel forced or inauthentic to some people. For instance, even the raucously affirming disability advocate Alison Kafer concedes that despite finding joy in communities of disabled people and valuing her own experiences as a dis/abled person, she does not want to become more disabled than she presently is (Kafer, 2013, p. 4 Kindle edition). Kafer acknowledges that a paradox exists in “...the possibility of simultaneously desiring to be cured of chronic pain and to be identified and allied with disabled people” (ibid, p. 6). We may also recall that burn survivors Joe Kinan and Carrie Pratt—also strong advocates and activists on the part of people with disabilities or physical differences—signed up for a risky and potentially burdensome experimental treatment for a chance to gain more independence and functionality in their lives (see chapter 2). Social models of disability that invite positive participation in dis/ability as an identity category also suffer in the sense that disabilities can be more dynamic than other cultural markers—conditions of disability or chronic illness wax and wane throughout the life course, taking on different meanings and statuses. As Rosemarie Garland-Thomson writes in *Extraordinary Bodies*, “The physical impairments that render someone ‘disabled’ are almost never absolute or static... Some conditions, like multiple sclerosis or arthritis, are progressive and chronic; others, such as epilepsy, can be acute. Even seemingly

static disabilities like amputation affect activities differently, depending on the condition of the rest of the body” (1997, p. 13, italics added).

In their 1988 book on the lifetime management of chronic illness, *Unending Work and Care*, sociologists of science Juliet Corbin and Anselm Strauss summarize these learned social reactions to and associations about disabilities that, “Having a chronic illness or disability may well be acquainted with having a failed body. Illness aside, whatever one chooses to do, physically or mentally, usually assumes that one has a functioning body capable of carrying out the desired activity” (p. 7). Indeed, the first doctor I interviewed for my master’s project on hand transplant history called the phenomenon of losing a limb “upper extremity castration” to indicate his understanding of a unique category of relational impotence stemming from hand loss. In my oral history narratives (see chapter 3) the physical difference of upper extremity loss is experienced by many narrators as embodied inferiority. Several hand transplant recipients or one-time candidates for hand transplantation have made comments such as, “I’m ‘on disability’ but I’m not ‘disabled’.” Most of my narrators with unique arms or hands saw themselves as, and *wanted to be seen as*, autonomous, strong, capable, unique, even *fun*, people—and most naturally wished to signal their self-sufficiency and sense of social value to others. Unfortunately many experienced difficulty signaling their own normalcy, self-sufficiency, and vitality to others when they lost their hands because for strangers, this lack signals a person as impotent or (apparently to some) incompetent.

Angel Gonzales relates the frustrating arc of his and his partner’s relationship with the outside world following the latter’s quadrilateral amputations:

I think people respond to the [transplanted] arms in a way that is ... different ... from the way that they respond to someone who has all four limbs gone, you know what I mean? Like they can almost accept that he’s in a wheelchair because he has

no legs, but you know they kind of freak out when he has no legs and no arms they're like "whaaouuo" you know? But now that he has arms it's a little bit easier to be out in public, not that we cared either way it's just—for the sake of other people, it's easier to be outside, with the arms. Um, you know what I mean, like, they seem to respond less to him um, in this pitying way or in this kind of freaked out way where they would come and address *me* about his condition. You know [in those cases] it's like, "He's right in front of me," or you know what I mean um, that would happen if we would go shopping at Trader Joe's and I would be like, uh, "He's right there!" (laughter) ..."I would just kind of shrug and give them a quick answer and keep moving, um, which is actually something a [physical therapist] taught us.

For Rich and Cindy Edwards, the responses of strangers to the sight of Rich's injuries and the loss of face, so to speak, that he felt in public based on other people's staring was one of the hardest aspects of trying to navigate life following burn trauma. Cindy narrates, "Rich couldn't live like this like the way it was. People were always staring at his hands. Children were always staring and pointing. Even though he can't do hardly anything with his hands right now, at least they look mostly normal." As I was completing the descriptive codes for my oral history interviews, the code "Other People"—referring to instances in which narrators recalled

Rosemarie Garland-Thomson has pointed out that acts of staring can be an inward journey as well as an outward gesture, when starers are made self-aware and an engaged rather than individual experience unfolds via this recognition:

Triggered by the sight of someone who seems unlike us, staring can begin an exploratory expedition into ourselves and outward into new worlds. Because we

come to expect one another to have certain kinds of bodies and behaviors, stares flare up when we glimpse people who look or act in ways that contradict our expectations. Seeing startlingly stareable people challenges our assumptions by interrupting complacent visual business-as-usual. Staring offers an occasion to rethink the status quo (2009, p. 6).

Responses of society to disability and embodied difference are also plastic and dependent on circumstances, having historically been determined by prevailing social attitudes on the moral status of a marking differences (including questions of heritability and the circumstances leading to acquired conditions) in making decisions on how to care for or otherwise manage the presence of non-normate individuals. As a group of medical ethicists and psychiatrists write concerning the public “acceptability” of novel forms of reconstructive transplantation following hand transplants, Sarwer et al write that, “Perception of personal sacrifice and accountability for facial trauma plays a role in public endorsement of face transplant. Transplant to ameliorate injury sustained secondary to military service garners nearly universal support. Victims of disfiguring accidents receive substantial support as well, though transplantation is valued more highly for ‘blameless’ accidents than for accidents partly resulting from the victim’s own actions” (p. 28-29).

In a related example, a surprisingly charitable attitude towards individuals with inadvertently acquired physical disabilities in Nazi Germany inspired a proliferation of assistive technologies for that population even as the same administration sought to end the existence of people whose difference was considered both unwanted and “innate.” Historian Robert Jay Lifton writes, explaining how superficially progressive resources for the treatment of people with certain disabilities aided Nazi narratives that their doctors were ethically and scientifically administering medicine:

[A]t the same time that they developed a policy of sterilizing or killing people considered unfit for a society of the strong, the Nazis boasted of spectacular results and humane employment arrangements for people who had lost hands or limbs, especially in combat. In these ways, most doctors could continue to view themselves as authentic physicians, whatever the degree of Nazification of their profession (1986, p. 40).

In western cultures where restoring the so-called “usefulness” to society of disabled persons is considered a good, strategies for mitigating disability directly by healing/restoring the bodies of affected persons are praised for their power to remove a source of unwanted difference—even as more discernibly eugenics-informed erasure of disabled *persons* has lost public and professional approval. Today the trope of astonishing restoration of disfigured bodies to healthy norms can be encountered in nonfictional settings as diverse as TV journalism, scientific papers, direct-to-consumer prescription advertising, and the rhetoric of holistic and religious healers. As Kafer has restated from a selection of science news articles: “Thanks to new developments in medical technology, we are ‘soon’ going to be living in an era when ‘brainpower will let the paralyzed walk, [and] allow the mute to speak.’” She adds matter-of-factly that, “Enabling ‘the paralyzed’ to walk is one of the most common expectations for [medical] technologies” (2013, p. 107 Kindle edition).

4.3 HOW DID WE GET HERE? MEDICALIZATION, BIOMEDICALIZATION, AND HAND TRANSPLANTATION

As western medicine advanced in the 20th century, the processes referred to by science scholars as “medicalization” entailed the scientific measuring, sorting, mending, disciplining, and instructing of patients and communities under the authority of emerging scientific standards and field-specific best practices. As STS scholars Clarke, Mamo, Fosket, Fishman, and Shim describe these transformations:

Historically, the rise in the United States of Western (allopathic) medicine as we know it was accomplished clinically, scientifically, technologically, and institutionally from 1890 to 1945. This first ‘transformation of American medicine’ was centered not only on the professionalization and specialization of medicine and nursing but also on the creation of allied health professions, new medico-scientific, technological, and pharmaceutical interventions, and the elaboration of new social forms (e.g., hospitals, clinics and private medical practices) (2009, p. 50).

The “medicalization of society” has been theorized and documented by sociologist Peter Conrad, who explains, “The main point in considering medicalization is that an entity that is regarded as an illness or disease is not ipso facto a medical problem; rather, it needs to become defined as one” (2000, p. 182-184 Kindle edition). Disability scholar and literary theorist Arthur W. Frank has called this phenomenon, “the modernist expectation that for every suffering there is a remedy” (2013, p.80 Kindle edition). Early hand transplant ethicist Mark Siegler, arguing on behalf of a clinical attempt at hand transplantation, exemplifies this point of view when he writes in 1998 that, “The public expects that previously untreatable medical and surgical conditions will

yield in time to scientific research and that novel treatment developed by clinical scientists will be introduced into practice with a minimum delay” (1998, p. 2782).

“The consequences of this master narrative,” Frank goes on to say, “are complex.” Of course, physical and cognitive disabilities of all kinds have become the objects of much medicalized attention, little of which has been objectively or even superficially oriented toward the benefit or well-being of the communities targeted for interventions. Media and disability studies scholar Fiona Kumari Campbell has lamented that among the insults and injuries of medical science toward people with disabilities is the apparent lack of interest shown in generating healthcare products and services that respond authentically to dis/abled individuals’ *actual* needs. Campbell argues that, “Medical practices, organized around the medical model, presume that the doctor’s task is to diagnose diseases, to discover their causes and symptoms, and design treatments. Any knowledge standpoint of the patient [on this model] is sloughed off” (2003, p. 443). In a similar vein of critique, Alison Kafer scornfully reviews medically driven efforts to normalize physical and cognitive difference in her 2013 polemic, *Feminist, Queer, Crip*, writing that the medical model of disability, “frames atypical bodies and minds as deviant, pathological, and defective, best understood and addressed in medical terms. In this framework, the proper approach to disability is to ‘treat’ the condition and the person with the condition” (p. 5, Kindle edition). Kafer reminds readers that normalizing “treatments” for disability and physical disfigurement have been justified “on the grounds that such acts will lead to better futures for the disabled person and/or for their communities” and she reminds readers that such efforts have included: “everything from sterilization to institutionalization, from bone-lengthening surgeries to growth attenuation” (ibid, p. 29-30).

The healthcare processes of “biomedicalization” have arisen alongside those of medicalization in recent decades as a more networked, information-driven orientation to biomedical research and delivery, facilitated by 21st century advancements in data science and biotechnology. As STS scholars Adele Clarke, Janet Shim, Laura Mamo, Jennifer Fosket and Jennifer Fishman write in their 2003 article theorizing biomedicalization, “Biomedicalization describes the increasingly complex, multisited, multidirectional processes of medicalization, both extended and reconstituted through the new social forms of highly technoscientific biomedicine” (p. 162). Unlike traditional western medical approaches which produced their effects through the discovery and disciplining of molecular and behavioral activity, according to Clarke and colleagues, “The historical shift from medicalization to biomedicalization is one from control over biomedical phenomena to transformations of them. ... [Biomedical] innovations and interventions are not administered only by medical professionals but are also ‘technologies of the self,’ forms of self-governance that people apply to themselves (p. 167).

I believe it is via the criteria of ‘biomedicalization’ not ‘medicalization’ that hand transplantation is mostly accurately characterized and critically viewed. Whereas traditional “medicalized” treatments for upper extremity loss or injury have aimed to return discreet aesthetic or psychosocial function(s) at the site of injury, the radical transformation of a patient’s care trajectory necessitated by hand transplantation—where a candidate essentially moves from “healthy” amputee to post-transplant “patient” indefinitely—requires individual and community “buy-in” on a level that is unprecedented by even the most invasive brain-controlled prosthetics.

Because prosthetics necessarily come on and off (an annoyance remarked on by almost all narrators for this project) their use or disuse does not command a change ontologically or even nominally to the user’s Self or how they think of themselves. By contrast, hand transplantation

involves protracted somatic and behavioral changes which are experienced by recipients and their families as genuine transfigurations of their identity and/or lifestyle. During a 2008 panel on transplantation innovation at the Cleveland Clinic, Dr. Thomas Starzl (considered by many to be the “father” of modern organ transplantation), described related phenomena succinctly when he said, “Putting a new hand or face on someone is astounding. It changes the morphology of the brain, which can be observed with functional magnetic resonance imaging. It changes the soul, if that is what you want to think of when talking about the brain” (Cooley et al, 2008, accessed online). This approach of wholesale transformation rather than localized restoration is consistent with the processes of biomedicalization as through hand transplantation, recipients’ lives are profoundly enmeshed with the evolving biotechnologies and “self” technologies of immunological monitoring, graft rehabilitation, and maintenance for as long as they have their hand graft. Such robust alterations of routine and self-understanding have been recognized as challenges in selecting “ideal” patient candidates (Taylor-Alexander, 2014) for hand transplantation as prospective patients are judged based on their ability to withstand and participate fully in the transformation, hybridization, and collaboration needed to make a hand transplant work.

Viewing HTX procedures and outcomes through the concept of biomedicalization gives us tools for understanding which support activities and rhetorical strategies might produce or undermine a person’s quality of life through hand transplantation. In a biomedicalized society, novel constructions of wellbeing coalesce around emerging and pre-existing concepts of illness and the “multiple” or entangled body (Mol, 2003; Shildrick et al, 2017) as, for instance, online communities of people identifying “with” or “as” a particular medical condition form to equip themselves with rapid-cycling knowledge about their condition, and to develop tools for collective bargaining on available treatments. Adversely, biomedicalized approaches can entail a greater

requirement for surveillance or more invasive access to personal data by medical experts, and can create uncertainty/precarity which is experienced as a risk state by participants.

As can be witnessed in the oral history chapter of my dissertation (chapter 2), the new layer of stress, labor, and “precarity” added to the lives of hand transplant caregivers by these procedures is a repeating feature, even when narrators ultimately expressed satisfaction with the hand transplant. “Uncertainty, referring here to doubt about how to act, is a well-known challenge in healthcare. ... Medical uncertainty has a deep moral and existential dimension: *it provokes fundamental questions about whether lives are worth living*, about balancing potential with risk, and about weighing danger against benefit,” Write Stefan Timmermans and Mara Buchbinder citing Renee Fox’s ideas on this topic. The authors continue, “Fox emphasized that uncertainty could not be dispelled with scientific or technological advances. She drew attention to the recursive nature of uncertainty: while technologies may address some forms of uncertainty, they seem bound, inevitably, to uncover previously unrecognized forms of uncertainty or to produce new ones” (2012, p. 13, italics added). Because “uncertainty is inevitable whenever new technologies produce previously unavailable knowledge about patients” (p. 14), the passage by Timmermans and Buchbinder could be easily be applied to describe the situation encountered by hand transplant patients: these surgeries may create more uncertainty than they dispel about whether life will be “worth living” after the intervention. The threat of rejection—which must be constantly monitored and protected against—and the specter of life-threatening complications from immunosuppressant drugs attend all gains to lifestyle and self-description following hand transplantation. (Despite these factors, efforts at dispelling uncertainty in the VCA field so far have not included efforts to ask patients why and how the surgery worked to transform their lives; as above the “gaze” of most papers in the literature has been on measuring duration and function of grafts, identifying

molecular processes of immunomodulation, and classifying variables of acute and chronic rejection.)

Conclusion

This chapter offered a rhetorical reading of representations of hand transplant outcomes in medical literature, demonstrating the emphasis on preselected criteria for effectiveness and declarations on how protocols for managing rejections and infections were sufficient to allow the hand graft to continue. This narrow view of success is in sharp contrast with the patients' accounts offered in the previous chapter, as well as insights from STS and disability studies. The chapter ends by calling for more authentic methods of representing patients' experiences and for connecting the "success" of medical experimentation to actual factors impinging on patients' quality of life.

Recognizing the range of meanings and values *attributed to* a hand transplant, and the new sources of meaning and value *afforded by* a hand transplant in the lives of recipients and their families, enables diverse stakeholders to understand how very personal, subjective factors must be accommodated in quality of life assessments both prospectively and post-transplant. Physicians and ethicists working to improve the process of hand transplantation operate blindly when they cannot accurately envision the factors contributing to past successes and failures; qualitative and quantitative approaches are needed to understand outcomes in this and other fields of transplantation (Shildrick et al, 2017). Of course, if narrative or other phenomenologically oriented methods are to be deployed more systematically across the hand transplant field, patients should have a say in determining how their feelings and experiences are emphasized in medical representations and how their personal reflections are "sliced and diced" so to speak, as data. Thus, in closing and in the next and final chapter of my dissertation, I argue that more research on the

ethics of representing others in academic medical journals (either as persons or as abstractions) is needed.

5.0 CONCLUSION

“Never turn your attention off, and always show respect for what people choose to tell you. This was the first reason I listened; the second reason was that the stories were beautiful and well-told, and I knew that there’s no beauty without meaning (aesthetics is not merely ornament and appreciation; it is a form of knowledge).”

~ Alessandro Portelli, *The Death of Luigi Trastulli*

Ten years since I began studying the history, outcomes, and ethics of human hand transplantation (HTX), my understanding of the value of these surgeries has been informed by conversations with amputees, hand transplant recipients and their caregivers, doctors and researchers in hand transplantation/reconstructive transplantation, and crucially, by my readings in academic disability studies. My final conclusion based on the arguments and observations presented above is that hand transplants are ethically complicated, lifelong interventions that require, above all else, a team of care providers who are committed as their first priority to the health and well-being of their patient recipients, not to advancing the science of the field or their own professional interests.

In this dissertation, I have shown that where outcomes of experimental operations are reported in the detached parlance of objective science, discerning the lived experiences of patient participants can be nearly impossible. I discussed how hand transplants received major coverage in news media even though they represent minimal achievement surgically and scientifically—the main development making HTX possible at the turn of the 21st century was interdisciplinary coordination and reexamination of transplant ethics and this work was accomplished *discursively*.

This is important, I argued, because almost all of the rhetorical heavy lifting giving rise to HTX relied on the promise of “beneficence,” or the idea that HTX present an opportunity to improve the quality of life (QoL) of a vulnerable population of care seekers despite the known burdens of immunosuppression and steroids.

The very notion that “quality of life” could be a site of intervention for organ transplantation has been called “a quiet revolution in organ transplant ethics” by prominent bioethics scholars. Nevertheless, twenty years after the first speculative discussions on the risks and benefits of hand transplantation, the specific nature of these tradeoffs in human experience are still unclear. As I revealed through my interpretation of HTX oral histories in chapter 2, the nature of quality of life effects after hand transplantation are far more challenging, person-specific, complicated, and drawn-out than medical case studies and reviews represent. Because for bioethicists and surgeons it has always been a narrow question of balance whether hand transplants are permissible, the specific nature of quality of life tradeoffs for HTX patients should not be going unexplored in this field, since patient-centered policies and procedures in hand transplantation cannot be developed without access to qualitative data which take into account the large-scale impact of these surgeries on patients’ lives.

Finally, in chapter 3 I undertook a close rhetorical reading of representations of HTX outcomes in medical discourse showing how clinical stakeholders depict hand transplant outcomes as “successful” through a series of gestures that include recitations of preselected criteria for effectiveness and declarations on how protocols were deployed to efficiently manage complications like rejections and infections. However—as I show through my discussion of theory in disability studies and STS following the rhetorical analysis in section 1, the lived reality for patients “beyond the lines” of these texts could be very different from the sanitized progress-

oriented depictions of HTX professionals. More work must be done, I argued, to determine more authentic, accurate methods for representing subjects of medical experimentation, especially in treatments that seek to improve patients' quality of life.

The ethical dimensions of my dissertation are significant and urgent. The hand transplant field has evolved and expanded rapidly without robust knowledge of what has happened to, or is going on with, existing patients. The exceptionally limited number of recipients ($N = <100$) means the hand transplant field suffers from shortage of data as a fundamental problem. Indeed, the value of direct, peer-to-peer consultation with knowledgeable "people like me" is a recurring theme across my oral history interviews, yet because competitive research programs are geographically and intellectually siloed, a central meeting place for information exchange (intellectual perspective) and affective connection has not been organically facilitated. Efforts to rehabilitate hand transplantation will, in my opinion, begin with serious international conversations on the ethics of representing patients and other vulnerable stakeholders (either as persons or as abstractions) in this field, guided by a patient advocacy and support network.

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