



Narrative methods for assessing “quality of life” in hand transplantation: five case studies with bioethical commentary

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Abstract

Despite having paved the way for face, womb and penis transplants, hand transplantation today remains a small hybrid of reconstructive microsurgery and transplant immunology. An exceptionally limited patient population internationally ($N < 200$) complicates medical researchers' efforts to parse outcomes “objectively.” Presumed functional and psychosocial benefits of gaining a transplant hand must be weighed in both patient decisions and bioethical discussions against the difficulty of adhering to post-transplant medications, the physical demands of hand transplant recovery on the patient, and the serious long-term health risks of immunosuppressant drugs. This paper relates five narratives of hand transplantation drawn from an oral history project to show how narrative methods can and should inform ethical evaluations and the clinical process of hand transplantation. The interviews with patients and their partners analyzed here lead us to suggest that qualitative accounts of patient experiences should be used to complement clinical case studies reported in medical journals and to help develop instruments to assess outcomes more systematically.

Keywords Reconstructive surgery · Hand transplantation · Vascularized composite allotransplantation · Person-centered medicine · Disability · Research ethics · Caregiver burden · Qualitative methods · Informed consent

I wondered how it would actually feel—how odd is that going to be?—to have *another man's* hands touching me? I can tell you that is not a factor at all. From the moment they're on, they're his hands, moving those hands and using those hands with his own mind and his own heart. The hand is just the physical instrument. Him touching me and him holding me and all that, it's coming from Rich—his heart, his emotions. To me, from day one, they were his hands.

~ Cindy Edwards, widow of a double hand transplant patient

Don't turn a scientific problem into a common love story.

~ Andrei Tarkovsky, *Solaris*

Hand transplant ethics and quality of life: an empirical problem

Twenty years since the first modern attempts at human hand transplantation (HTX) in 1998 and 1999, these operations exist as a fringe hybrid of the clinical specialties of reconstructive microsurgery and transplant immunology, offered only under experimental protocols in most cases. Based on perceived success with early hand transplants, “vascularized composite allotransplants” (VCA) of the face, abdomen, penis, and womb were developed and are now being performed around the world. However, there is limited agreement on how to assess outcomes, evaluate candidates, and discern between successful and unsuccessful VCA since the specific nature of cost/benefit tradeoffs for these surgeries and their aftercare remain unclear (Caplan et al. 2018). In this paper we argue that qualitative data—especially first-hand narrative insights from participants—may illuminate the lived benefits and challenges of hand transplantation in ways that could be helpful to HTX and VCA stakeholders (including providers, policy makers, patients, and organ donors), and scholars studying research ethics, informed consent, or the management of chronic conditions or disability. The empirical contribution of our paper includes five narrative case studies of hand transplantation based on oral

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history interviews with patients and their caregivers, followed by discussion of three themes related to quality of life (QoL) occurring in the narratives.

As has been argued in the bioethics literature about these operations, the singular goal of a hand transplant is improving the life of the patient (Siegler 1998; Simmons 2000; Dickenson and Widdershoven 2001; Hettiaratchy and Butler 2003; Tobin et al. 2005; Benedict 2017; Caplan and Purves 2017). Like recipients of life-saving solid organs, hand transplant patients must take health-compromising immunosuppressant drugs for the rest of their lives or for the duration of their graft's viability. Unlike a solid organ, a hand transplant is not immediately functional, and HTX patients must also participate in grueling post-operative therapy as well as frequent evaluations of hand health and function (Bueno et al. 2013). Because living with organs from another person—especially intimate social organs like hands—is a complex unfolding phenomenon necessitating preparation and adaptation on the part of many parties, the subjective reflections of those who experienced QoL-related tradeoffs from HTX firsthand can inform discussions of risks and benefits, indications and contraindications, and other important aspects of the process (Svenaesus 2012; Neukom et al. 2012; Williams et al. 2016; Shildrick et al. 2017).

Despite the fact that presumed success with early hand transplants has already paved the way for other forms of reconstructive transplantation (Petruzzo et al. 2010; Baylis 2004; Ren and Laugel 2013), the idiosyncratic nature of these procedures and their small numbers frustrates professional agreement on the indications for successful outcomes (Caplan et al. 2018). The existing QoL outcomes data on HTX present insufficient grounds on which to base claims that hand transplants enhance life sufficiently to be justifiable, much less a “standard of care” for patients despite recent arguments for their potential in this regard (Breidenbach et al. 2016). In fact, it is unclear whether some of the hand transplants that have been described as “successful” in early case studies and review articles would be characterized as such from the patients' point of view.¹

Because hand transplant recipients and their partners or caregivers possess intimate knowledge of the processes involved in maintaining a hand graft—and because limited case data (fewer than 100 people have received hand grafts since 1998) makes information on and from patients a valuable resource—one might expect to see in the literature on HTX a concerted effort to capture and publish data

on all factors related to the hand transplant experience. However, with the exception of news media interviews and press releases, which have consistently followed successful hand transplant surgeries, first-person empirical insights from patients remains limited. While there have been some attempts to describe transformations in the quality of life of HTX patients using self-reported, survey-based methods or thematic analysis of semi-structured psychiatric interviews (Bachmann 2007; Jensen et al. 2012; Kumnig et al. 2014; Jowsey-Gregoire and Kumnig 2016), neither of these approaches does the work of describing “what happened” or “what it was like” for recipients and their families before and after hand transplant surgery.

In a 2012 paper titled, “Quality of Life Considerations in Upper Limb Transplantation,” Jensen et al. conduct a review of all hand transplant-related papers offering analysis of recipients' QoL. The authors identified approximately 250 academic papers on hand transplantation, of which 27 were included for consideration having “quality of life” as their main topic of inquiry. Only 3 of the 27 papers included interviews with patients as part of their methodology. Unfortunately, none of these three studies were conducted using open-ended questioning techniques by non-program-affiliated researchers, and none of them quoted patients describing their experiences. In some cases, no attempt was made to approach patients directly for their point of view even when the stated goals of the research were compatible with doing so. In one such study, Slatman and Widdershoven (2010) present what they describe as a “phenomenological narrative” account of the first two hand transplants in Europe. Because the authors “were not in a position to collect information from face-to-face interviews,” they accomplish their analysis using data collected from news media reports. Slatman and Widdershoven acknowledge that in their phenomenology of hand transplantation, “empirical analysis of embodied self-experience is limited” (p. 72).

Hand transplant textbooks seem to make more space than peer-reviewed journal articles for patient perspectives. In *The Science of Reconstructive Transplantation*, (ed Gerald Brandacher 2015), an early chapter featuring exposition on, “The Daily Life of a Hand Transplant Recipient” (p. 45) offers a firsthand account of HTX challenges and opportunities as told by a patient recipient. The article is written in the first person and details the process of evaluation and recovery, including day-to-day challenges and opportunities and general reflections. It is an interesting and helpful account in many respects, but limited in its empirical utility as the textbook editors do not describe the process of inclusion and development of this narrative (i.e., editorial and authorial decisions about preparation and representation including why this narrative was chosen from among other HTX cases). In a chapter for another medical textbook, *Hand Transplantation*, (ed. Marco Lanzetta and Jean-Michel

¹ See the July 25, 2016 article in *TIME* magazine: “‘I Can Do Absolutely Nothing’: The first American with a double hand transplant wants them removed” by Alexandra Sifferlin as well as “The case of Clint Hallam's wayward hand: print media representations of the ‘uncooperative’ disabled patient” by Fiona Kumari Campbell (citation below).

Dubernard), Daniele Bachmann covers the topic, “Quality of Life in Hand Transplant Patients” (2007, p. 363). While Bachmann conducted psychiatric interviews with hand transplant recipients sufficient to yield insights about their motivations and experiences, her chapter spans only three pages of the 400+ page textbook and sentiments from participants are summarized heavily without context. Bachmann writes:

[T]ransplantation of hands changes the patient’s body in a radical way; he does not get his own hands back (we say “he” because all transplanted patients thus far have been men), nor does he return to a previous state. The recipient has to make the donor hands his own, and, even with the recovery of motor functions and sensitivity, these hands are forever present before the patient’s eyes ... The hands are also highly charged with meaning in the human being’s imagination: ... What, for example, did the donor’s hands do before his death, during moments of intimacy? The patient’s ability to integrate the transplants is also dependent on the reaction of the close family circle, which could display feelings of rejection, of disgust or worry, or, on the other hand, could be quite happy for the patient and give him vital support in accepting the transplant (p. 365).

Here Bachmann alludes to several potential avenues of interest and concern regarding the post-transplant lives of people with hand grafts. Unfortunately, the chapter’s conclusion follows soon after revelations that transplant hands change the recipient’s own body in “a radical way”; that hand grafts are “highly charged with meaning”; and that the patient’s pleasure in owning the hands depends heavily on the acceptance of others. Readers can only wonder at the sentiments Bachmann’s patients may have expressed that would lead to such compelling statements because data from interviews are not published alongside professional analysis.

It must be asked whether—and if so, how—the benefits of hand transplantation amount to a significant gain in quality of life for patients. According to Kay and Wilks 2013, “Of the large number of [hand and face] transplants completed now, *outcome data of value is to be found in few*,” (p. 1457, italics added). More recently, Health Quality Ontario (HQP), a multidisciplinary health care research group based in Canada, analyzed the HTX literature for cost-effectiveness, concluding that, “the quality of the studies we could find was very low” (2016, online). Although it is difficult to prove the absence of something, we concur with Kay and Wilks’ and with HQP’s observation that satisfactory information about patient outcomes is lacking in the peer-reviewed literature on HTX. We add that this privation incapacitates bioethicists and policy makers when evaluating hand transplantation, as well as making informed consent difficult for patients and providers who must determine

whether a particular hand transplant will be worth the risks and burdens.

In a 2018 review of VCA ethics, Caplan et al. explain the importance of accurate, in-depth outcomes reporting to the development of clinically successful VCA programs:

VCA requires providers to judge the extent of a potential candidate’s distress and consequent need. This is perhaps the greatest ethical challenge in the clinical selection process. A graft or prosthesis might provide a satisfactory outcome for one patient but not for another with similar injury and functional outcome. Because VCA recovery is psychologically taxing and requires consistent adherence to monitoring and treatment protocols, some patients might be better psychosocially suited to VCA than others, based on variables including anxiety, stress-related, somatic, psychotic, and substance misuse disorders, maladaptive coping strategies, good treatment adherence and connection with social supports ... Maintaining comprehensive data in standardized, transparent formats will be key to long-term viability of the field (accessed online).

As Caplan et al. point out, because each prospective patient has unique needs, goals, and expectations for their hand graft, employing narrative data to engage in narrative evaluations with individual patients may remain more helpful or straightforward than a whole suite of scientific measurements for determining relevant features of a person’s candidacy or for understanding their outcomes as hand transplant patients. Ascertaining the human factors contributing to patient adherence is certainly a shared preoccupation of practitioners in the field (Cendales et al. 2011; Errico et al. 2012; Breidenbach et al. 2016). Below, we relate five hand transplant narratives based on oral history interviews with patients and their closest caregivers, followed by brief interpretation. These five narratives were chosen for the light they shed on the human dimensions of “success” in HTX, such as how the 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 play a role in mediating outcomes for these high-risk, high-commitment procedures.

Narratives of health and medicine: methods and scope

In recent decades, narrative methods for research and clinical assessment have gained consideration in a range of academic and health sciences disciplines (Charon 2001; Coulahan 2003; Geisler 2006; Webster and Mertova 2008; Woods 2011; Alnaes 2012; Neukom et al. 2012; Brockman 2013; Cudney 2014; Peek 2016; Constant and Roberts 2017). In

primary and chronic care medicine, in particular, calls for attention to narratives and narrative processes have increased in frequency and prominence (Editors 2007; Kalitzkus and Matthiessen 2009; Sgro et al. 2016; Charon 2016; Murphy and Franz 2016; Shildrick et al. 2017; Hurwitz and Bates 2018). According to some healthcare providers, the advantages of patient storytelling and its counterpart, critical listening, are practical and immediate: the patient's experience of illness/disorder becomes a valuable source of knowledge both framing and emerging within the clinical setting (Charon 2006; Shakespeare 1996; Wiltshire 1999). Physician and literary scholar Rita Charon has argued that patient narratives are not merely ornament to the scientific record but an irreducible feature of medical diagnosis and decision-making, writing, "Clinicians have always at least implicitly understood that the most fertile and clinically salient information we derive about patients comes from listening to them talking about their illnesses" (2006, p. 192). In other words, the commitment to treating whole persons in medicine may entail a basically "narrative" orientation to patients' complaints, one which sees their life course and its meaning as relevant to disease management and diagnosis.

Despite far-reaching and longstanding recognition of the central place of patient narratives in the process of medical care, Charon reminds readers that, "'At the risk of sounding anecdotal' is the preface to much of the story-telling that goes on in medicine, and students or clinicians who take the time to hear patients out are thought of as either poorly trained or daft" (2006, p. 192). In *The Illness Narratives*, Arthur Kleinman censures the overly "scientific" restrictions some lay on the scope of medical knowledge as dehumanizing to those seeking care, writing, "the everyday priority structure of medical training and of healthcare delivery, with its radically materialist pursuit of the biological mechanism of disease... disables the healer and disempowers the chronically ill" (1988, p. 9). The answer to widespread reductionism in medicine, according to physicians like Kleinman and Charon, is a balancing respect for what patients choose to talk about and for their intimate position in the geography of knowledge on a particular condition or disease process.

The extent to which narratives of illness can inform clinical practices beyond the dynamics of the provider-patient relationship depends on the goals of the discourse and the methods of narrative researchers. Although "narrative" is a tool humans use to generate immediate recognition of meaning in many situations, narrative reconstructions of illness events are not self-evident with regard to their value as empirical data or as moral illustrations. For example, subjective firsthand impressions from patients would not be as effective as straightforward numerical measurements for tracking and describing certain aspects of postoperative management in HTX, such as kidney function over time while on immunosuppressants. Likewise, a single narrative

case study published in a medical journal or textbook that relates in emotional detail the experiences of a patient could be informative, if the narrative is authentic to that person's interests and feelings, but could also be a source of unbalanced representation distracting from other types of stories and concerns (see Jones 2014 "Narrative Ethics, Narrative Structure" for more on this effect). As bioethicist Christine Mitchell has written, "stories... import ethical principles and norms that exist apart from the stories themselves and warrant consideration beyond the tools of narrative analysis" (2014, s. 13). Thus the "situatedness" of narratives in the context of other informative data—including additional firsthand or historical accounts, academic or scientific studies, news articles, expert observations—is important to consider in every case.

In the rest of this section we describe activities informing our own research, including techniques for analysis and interpretation of the five narratives. The oral histories of hand transplantation related below are based on 14 interviews with hand transplant recipients and their closest caregivers collected by first author Emily R. Herrington from 2015 to 2017. As a qualitative research methodology, oral history is uniquely concerned with illuminating a topic or event of interest (in this case, the outcomes of human hand transplants) by considering its impact on the life course of individual participant-observers. Patient narratives as told to doctors can be useful tools in the clinical setting, without the cases under discussion being widely shared. The audiences for medical oral history research, however, are external to the immediate clinical setting; the creation of an historic document (including published transcripts and researcher interpretations/summaries) for edification of publics is the primary objective (Yow 2015). In the introduction to the edited volume, *Oral History, Health and Welfare*, Paul Thompson argues that oral history techniques can bring practical advantages to researchers in almost any field: "[Oral histories] allow us to explore those crucial areas of life which the written record scarcely touches: the private world of family relationships, for example, and all the influences from childhood onwards which go into the shaping of a professional life, and the often crucial support of partner and family through adulthood" (in Bornat and Perks 2014, p. 3 "Introduction"). The more intimate view of events or phenomena furnished by oral histories can be especially useful to medical humanities researchers. Thompson explains: "Oral history can delve into the hidden world of the institution, the clinic or the hospital, revealing the daily experience of routines and treatments as told by the subjects, clients or patients at the receiving end of services" (in Bornat, p. 4).

Oral historian Valerie Yow has emphasized the unique capacity of oral histories to allow outsiders to imaginatively enter a firsthand view of a culture, event, or situation (Yow 2015). Compared with other qualitative research

methodologies such as grounded theory, phenomenology, cross-sectional survey research, and ethnography, oral histories may be less invested in answering questions about specific problems, infrastructures, or hypotheses than in providing the complete picture of an event or topic, inductively, from the “ground level” of participants’ reflections on their experiences. While other qualitative research methods may elicit story-telling from interviewees, use narrative summaries within analysis, or combine methods without using the term “oral history”—insofar as oral histories are included for consideration or complication of existing knowledge, they serve to illuminate “what happened” and “what it was like” from the viewpoint of actual participants.

Narrators for our oral history of hand transplantation include single and double hand transplant recipients at various temporal distances from their surgery (including an interview with Matt Scott, recipient of the longest-surviving hand graft at ~20 years). The oral history process adheres to the twin principles of (1) questioning rather than measuring and (2) generating hypotheses using theoretical coding. One-on-one interviews followed a script of open-ended questions and yielded extensive conversations ranging from 50 to 140 min per interview. Approximately 10–30 min at the beginning of each interview was spent talking about the narrator’s childhood and family or vocational background. Framing the topic of concern—in this case the outcomes of hand transplants—with discussion of the narrator’s early life and interests is typical of the oral history approach and helps anchor recorded testimony more strongly in the narrator’s own speech and values (Yow 2015). An important aspect of our oral history methodology turned out to be the decision to interview caregivers and partners in addition to (and separate from) interviews with hand graft recipients. Capturing the feelings and experiences of partners in the post-surgical phase of treatment, which lasts several years or the rest of the recipient’s life, was enlightening: substantial burdens of longitudinal care fall on them. Caregivers are also affected by the emotional condition of hand transplant recipients, and in some oral histories, they provided frank descriptions of difficult events while patients—possibly feeling the burden of gratitude (Ross et al. 2010)—emphasized positives.

Data gathering for this project began in April 2015; interviews were conducted by phone or in a neutral location by first author Emily Herrington. Descriptive coding of interview transcripts commenced as data were collected, consistent with the grounded theory approach to iterative thematic analysis (Corbin and Strauss 2015). Early codes informed the development of different and more sophisticated questions as the interviews progressed. As links between common ideas or story types began to emerge organically through the codes, direct comparisons of primary data could be made, and the salient aspects of these comparisons were developed into more comprehensive

themes (such as: “emotional affiliation with graft” or “effects of open-ended expectations”). Themes were progressively reinforced or complicated and subdivided by ongoing analysis and data collection; on some topics “saturation” was achieved. While “saturation” describes a state of analysis in which no new ideas, descriptions, or sentiments are emerging on a specific topic within collected data, themes that reach saturation are not necessarily exhaustive accounts of underlying phenomena as they can be complicated by new insights or revised analyses. For instance, on the question of whether hand recipients and their families had a difficult time accepting the donated nature of their own or their partner’s hand graft, almost every narrator described feelings of identification and affiliation with the hand graft that were unexpectedly robust (but this does not mean strong emotional attachment to a hand graft can be expected in every case). Other activities informing our interpretation of the oral history interviews include close reading of key papers in the literature on hand transplantation, attendance by one or both authors at three international meetings on VCA science or ethics (in spring 2015, spring 2017, and fall 2018) and ongoing HTX ethics related collaborations with clinical providers of hand transplantation conferring broad practical knowledge of hand transplant protocols and health policy developments.

The five oral histories related below are presented to demonstrate the value of first-person illness narratives to knowledge-making and development of best practices in the hand transplant field. They are chosen for their value as illustrations of the change in quality of life experienced by HTX patients and their families when trying to navigate the long and many-faceted process of hand transplantation. Although hand graft recipients and their partners or family members gave individual interviews for the oral history project, we reunite their voices in our representation of each case of hand transplantation to more efficiently understand the effect of that particular hand graft on participants’ quality of life. The third-person prose format allows us to track back and forth between narrators’ individual and shared perspectives as needed, as well as to add transitions and interpretive summaries (based on the longer and more comprehensive oral history recordings on file). To write the narratives in this way, first author Emily Herrington used the horizontal “split screen” feature in Microsoft Word to view the transcripts of recipient and partner/family member simultaneously while moving chronologically through the writing of their story. Quotes were chosen for their qualities as robust descriptions, efficient summaries, or unique expressions of experience. To avoid reducing the individual value of narratives via over-summarization, we aimed for a “middle level” of abstraction and length of exposition. Our goal was to help readers imagine key features of each narrative while more generally

gaining perspective on the lived effects of hand transplantation on recipients' quality of life.

Five oral histories of hand transplantation

Narrative 1: Matt Scott

Before becoming the world's first indisputably successful hand transplant patient, Matt Scott owned and used an Otto Bock myoelectric prosthetic hand, one of the best brain-controlled devices available for non-biological restoration of hand function. During a phone interview with first author Emily Herrington in October 2010, Matt said,

Having a prosthetic just wasn't the same. Don't get me wrong—the prosthetic served me well. It served me *very* well. I was able to become a top paramedic in my field, (with some adjustments), and I got married and fathered two kids. I was successful in the ways we define 'success.' But mine was a traumatic amputation, you know, and after thirteen years of having a prosthetic, I had grown so dissociated with it that I'd come to detest it.

Matt lost his left hand on December 23rd of 1985 in an accidental fireworks explosion while he and friends were celebrating the holidays. Although the accident was deeply traumatic, Matt went back to work as a paramedic the next fall. Matt reported his healing process as difficult emotionally and laborious, saying shortly after the accident “[I was] absolutely convinced that my life as I knew it was over. I was never going to be a medic again. I was probably going to end up on a street corner, selling pencils or something like that, that typical thing. I absolutely believed that in the beginning.” Friends and family were crucial to his eventual transition back into a regular schedule of work and life. Matt says, “As time moved ahead and the people around me were encouraging and working with me and helping me to rationalize and figure out things—and as things became more evident that I *could*—I think the idea that I *couldn't* just became further and further from my psyche. It was more of, ‘Now, how can I get back?’ as opposed to, ‘What am I going to do to get back?’ I knew what I had to do, and I just went out and did it.”

Navigating personal relationships was described by Matt to be, in some ways, more daunting: “I was a young guy. I was 24 years old. The idea of dating and things like that with a hook... I thought, ‘that's a horrible thing to think,’ but it's what I was thinking when I was that age. I did have that period of depression, but once the prosthesis came, and I saw it was cosmetic, by and large, in its appearance, and it opened and closed, and once I learned how to use it and once I got fairly adapted and adept with it, things started to

look a little bit better.” Matt says his Otto Bock prosthetic hand “worked well,” but nevertheless did *not* feel to Matt that it was ever an adequate substitute for the real thing. Matt reports the prosthetic was uncomfortable and annoying (he had to have a spare battery with him at all times and to check the device's charge consistently throughout the day). He also remarks that it was unbalanced and heavy, causing occasional pressure sores “and things like that.”

Eventually, Matt says, he was “successful in all the ways we define success.” But the feeling of otherness and loss did not disperse over time. Instead, he says, it was the opposite: “When I would meet people, I would position myself where my prosthesis was out of their view. I would turn my body so that they couldn't see that. Until some point in time when ... they would finally realize that, then I have to explain my life to them and what happened and how I did this. It just became a very tedious and angering-type way of living.” The cumulative effect of these negative social interactions made life difficult to enjoy on a daily basis. “Inside, no, I wasn't happy,” Matt says. “I was probably more angry than anything. As the years went on, I became more and more angry. Of course, the anger was inward, but sometimes I directed it outward, and was sometimes harsh at times with people, not because of their shortcomings but because I was angry with myself.”

It was many years after Matt's accident that hand transplants began to be seriously considered by doctors as a possible solution to chronic disability of the upper extremity. Matt remembers clearly the day he heard about hand transplantation:

I was in London, England, of all places. I was over there on a little bit of vacation. On the day that we were leaving, my dad's wife came upstairs. She went down to the coffee shop and came upstairs with the newspaper and said, “You're not going to believe this.” I said, “What's that?” She showed me this article in the Sunday London Times, I'm pretty sure that's what it was, about this hand transplant team in Louisville, Kentucky. Now, I'm in London, England. I've been in the United States, I didn't hear a word about it. I had to go to London to hear about it. It was a big, two-page article. I read it, read it again on the plane ride home, and the next morning, after waking up, I called Jewish Hospital in Louisville, Kentucky and said, “I want to be part of this.”

Hand transplants were an entirely new option at the time and there was no guarantee a biological hand graft would be as functional as Matt's Otto Bock prosthetic. Matt says he was well aware of the risks of participation, “My wife at the time was a registered nurse. I was a paramedic. It's not like we had to learn a whole lot in the way of things, I mean, other than the specifics

of transplantation, but I understood the pharmacology. I understood the problems that are going to happen. I understood [much of the science of] rejection.” Still, Matt had to seriously consider the many potential complications and sources of pain associated with hand transplantation (including physical and cognitive side effects of immunosuppression, disruption of life during a long healing period, intense post-care treatment, pain, and the constant possibility of graft loss).

In our interview for the oral history project, Matt describes the hand transplant as a needed intervention conferring not functional restoration but what might be termed narrative transformation. From the moment he woke up with the graft hand, this element of healing from a long-time psychological wound was present:

When I woke up from the surgery the first time and I looked to my left, my hand was gone. It was wrapped up in all these bandages. There was a little bit of Betadine, maybe a little bit of bloody drainage there, but the hand was gone. This time I woke up and looked to the left and there’s fingers pointing at me. It was like it was almost a replay of that waking up in the recovery room 13 years prior. It was very weird. Yeah, it was very weird... [The hand] was very heavily bandaged and everything, and I see this index finger and middle finger and ring finger pointing out at me and I’m like, “Oh, my God!” It was just the strangest, strangest feeling of like, “I’ve been here before,”—but the outcome was different. Instead of it being gone, it was now back.

After the hand transplant (and a great deal of media coverage of it), the putatively negative—and, for Matt, experientially negative—labels “amputee” and “disabled” could no longer be associated with his identity. The positive valuations people seemed to make of Matt after learning of his participation in a “miraculous” groundbreaking surgical experiment made a conspicuous difference in the way that Matt perceived his own value, particularly as reflected in the eyes of others. The hand transplant also conferred some advantages in terms of function and aesthetic restoration—however these have never been the focus of Matt’s reflections on his experiences.

Years after his transplant, Matt met his donor family to thank them for their gift and says he feels nothing but gratitude for the opportunity to participate, stating that, “If it fell off tomorrow, I’d do it again. I feel like I’ve been healed in a way that would make another amputation far easier than the first one.”

Narrative 2: Rich and Cindy Edwards

One night in February 2006, a chiropractor from Oklahoma was driving to a hunting trip with friends when a brush fire completely overwhelmed his truck. In the attempt to escape the flaming vehicle, Rich Edwards’s hands were severely burned, and healed into claw-like stumps that Rich called “deranged looking.” Before the accident, Rich had been a well-respected chiropractor with a busy practice in his hometown. He had to quit working at his practice and suffered extreme depression as a result of his injury. Rich recalls:

I lost most of my fingers, 7 of my fingers [in the fire]. My hands were distorted, and contorted, but I was still somehow determined that I was going back in to practice. That set in depression, for the first time in my life. I was extremely depressed for years... I still had hope that I could find somebody who could fix my hands, get them limber, and movable again, instead of clenched up into kind of a fist. We found what, we thought, was the most outstanding [hand surgeon] who was at Duke University. He did 5 or 6 surgeries, and my hand was actually worse off than it was before he even started. I was very unhappy about that.

After frustrating experiences with traditional reconstructive methods, Rich and his wife, Cindy, turned to doctors in Louisville, Kentucky to discuss hand transplantation. Rich had never tried prosthetics. Although prosthetic rejection had been a stipulation of candidacy in the early years of the Louisville hand transplant program, the lead surgeon at the time of their consultation, Warren Breidenbach, thought Rich might attain better-than-average results due to the fact that his hands had never been amputated, and thus some length of the existing nerves could potentially be preserved and transplanted into the graft hand, reducing the amount of time for recovery following transplant. Although Rich was initially rejected as a candidate by the the first psychiatrist in Louisville, he was eventually reevaluated and approved for transplantation.

Unfortunately, Rich’s desire was not to regain *some* function from his new hands, (which was likely), but to regain enough function to be able return to his chiropractic practice (which was not). Transplanted hands do not work as well as a “normal” hand; even an excellent functional outcome with a hand graft will never attain the same level of dexterity, sensation, and strength as the original. It may have been a collectively conditioned response, or an indication of the importance of understanding the limitations of these surgeries, that when Emily Herrington first began researching hand transplants in 2010, almost every member of the team Herrington interviewed in Louisville observed, “Our patients aren’t going to be concert pianists, you know.”

As years passed post-transplant, it became more and more clear to Rich and Cindy that the much-desired result of returning to his work after hand transplantation would remain out of reach, and Rich's depression again became debilitating. While experiencing some return of function and sensation *was* deeply meaningful to Rich and Cindy (for example, being able to hold hands together and to pray, more bathroom autonomy), his spirits continued to plunge. Cindy, who had worked in Rich's chiropractic practice, commented:

Rich couldn't live like this, like the way it was [after the fire]. 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... I don't recall really hoping that he'd go back to practice or believing that he would. He did. He was hoping and believing. I didn't necessarily bank on that, but I was hoping he be able to go back emotionally into the practice. We had an associate doctor that was carrying the practice for us while he ... After our accident, we had to hire a doctor to carry on the practice. I thought, "Well, if he could go back in and just oversee and work with the patients and all this, even if he couldn't put his hands on them and adjust..." That was my hope for him, but, because he *physically* couldn't do it, emotionally and mentally, he just actually was defeated. He was just defeated by it and didn't want anything to do with the practice, didn't want to go back in if he couldn't do it. He pretty much didn't want anything to do with it. That was hard. That was an expectation that we never achieved. I was also hoping that he would be able to do more with his hands, and he just can't. He just can't do more. I mean, he can't. They told us he wouldn't be able to button buttons. Okay, I accept that, but he just won't... I wish, just sometimes, just very, very little, that Rich would have prosthetics instead because, then, he wouldn't have to take all those medications.

At the end of the summer 2015, Rich visited a shooting range near his home and killed himself. Cindy mourns the loss of her life partner and is conflicted when describing whether she thought hand transplantation had been the best option for their family. Rich's death was not widely reported in the media, and there has not been, to our knowledge, a clinical case report published on Rich's outcomes. While suicide approximately 5 years after a self-styled "life-enhancing" operation may not look like success to some, Cindy has stressed repeatedly in interviews that the hand transplant was better than no change at all, because he had been so dissatisfied with the appearance and functionality of his injured hands.

We believe Rich and Cindy's story displays prominently the contextual nature of what counts for success in different

patient narratives of hand transplantation. Rich's hand transplant could be considered technically successful and ethically justifiable on some dimensions: the hand was not lost to rejection and the quality of his life did temporarily improve as a result of the intervention. However, it could also be argued Rich's first psychiatrist in Louisville was correct about the negative aspects of Rich's candidacy for hand transplantation given its limited prospects as a long-term solution to the depression he experienced as a result of his burn injury and perceived disability. *Was* Rich a poor candidate for hand transplantation due to his ongoing depression and exaggerated hopes for a discreet and unfeasible outcome? Or was hope itself a *telos* of the hand transplant treatment as experienced within the constraints Rich and Cindy's life—an end in itself conferring a reinvigorated "purpose" to their shared existence, from which new meanings could have, but unfortunately did not, arise?

Intriguingly, in our conversations with Rich and Cindy, both partners mentioned a shift in their values regarding healthcare, which was both necessitated and facilitated by the hand transplant process. Before the accident, Rich and Cindy said, they were: "Chiropractic, not medical." In their words, both partners believed in the power of the mind to heal the body and soul. Rich had even been dismissive of people claiming to suffer depression in the past, and both partners were suspicious of medicalized tendencies toward unnecessary high-tech intervention, and they were not organ donors. Rich and Cindy's philosophy of health and medicine greatly changed after the hand transplant experience. First, the high level of compliance and cooperation necessitated by hand transplant recovery made it necessary to "buy in" to traditional western medical values of transformation and scientific progress—this was not, they reported, difficult as the hand transplant was such a unique, exciting, and emotionally moving prospect. Secondly, the extraordinary "gift" of the hands elicited feelings of wanting to reciprocate and persuaded them of the value of other types of transplants—both Rich and Cindy quickly became strong advocates of organ transplantation and donation, and Cindy donated Rich's hand grafts to medical research after his death.

Narrative 3: Will Lautzenheiser and Angel Gonzales

Double hand transplant patient and former quadruple amputee Will Lautzenheiser was an early-career professor of filmmaking in Boston before a virulent streptococcus infection in fall 2011 necessitated amputations of all four of his limbs. Will's recovery process included noting and critiquing the ways in which socialized expectations and aesthetic ideologies seemed to mediate his experience of disability in public spaces. Will also found solace in humor: as a former English major, Will enjoys observing the inescapable presence of hand metaphors in the English language:

There’s so many figures of speech and whatnot that relate to our hands and our feet and walking or crossing our fingers, or whatever.... If you don’t have [hands and feet], you have to find a way that when people use them, they don’t feel uncomfortable. They just put their foot in their mouth, so to speak. See what I mean?... You have to be able to diffuse it, otherwise people are always going to feel awkward around you or whatever. One way, as I said, I was an English major, so I just thought, ‘I can use this. I love language.’

Will has even performed standup comedy in which his jokes often moved toward the tension of his appearance by acknowledging and commenting on his experiences as an amputee.

Will’s partner, Angel Gonzales, is a thoughtful and reflective Brooklyn native of intimidating self-knowledge, with an apparent talent for nurturing peace and health in challenging circumstances. Will and Angel had been dating for a < 2 years before Will’s sudden illness and the amputations that followed from it. Angel stayed to help Will through the healing process, and describes the decision as second nature: “I’m not ... *interested* in running away; I’m interested in the difficult aspects, if that makes sense. The difficult to me is more interesting. That’s ... more of my character.”

Will and Angel worked through months and years of readjustment involving prosthetics, care assistance, and modifications to their apartment allowing Will to perform a range of daily tasks for himself. Life had attained a degree of normalcy when doctors in their hometown of Boston offered Will the opportunity to participate in an experimental double hand transplant. Angel describes his reaction to the offer as mixed, and in some ways he was bluntly skeptical. Growing up in Brooklyn, Angel says, he was immediately looking for the “catch” and describes his reservations:

For all purposes [Will was] was *healthy*, he just didn’t have arms and legs. So these medications introduced a whole new set of things that might happen which will not necessarily facilitate *life*. You know, the skin cancers, diabetes, you know all kinds of maybe kidney problems—so in that sense I’m like, “You really need to consider this.” And, I kind of, wasn’t just, jumping on *board* with it, but, I was also not gonna say, “Well you can’t have *arms*” you know; I wanted it to be his decision.

Will received a double hand transplant in October 2014.

In the recovery period, Will and Angel worked diligently to keep the hand grafts healthy. Their daily schedule, and many aspects of their life together, had to change following surgery. Of special concern to the couple was the temporary loss of all their work finding some equilibrium at home between Will’s needs and Angel’s ability to offer care, since

Will’s hands would be in hard casts for months, and then useless “dead weights” while the nerves slowly regenerated (function for hand grafts and hand replants returns slowly as nerves regrow, about a millimeter per day). Fortunately, the double hand transplant has not been a problematic development as Angel once worried; rather, the couple reports being truly delighted by the new hands, even before they were functional.

Both Angel and Will use the analogy of caring for an infant to describe the early period of living with the hand transplant. Angel said of this time that they were constantly on guard for signs of infection and rejection, but that the excitement of their new situation and its potential made the uncertainty more bearable:

To me it was, I guess, the closest I’ll ever be to ...*having* a child? So it was kind of like, these sort of instinctual things come with it... you know [with a hand transplant] some people suffer from pain and, you know, stay up all night so, [Will’s transplant hands] were very *quiet* babies. [Laughs.] So um, it kind of, it came natural, in that sense? It didn’t seem foreign, you know what I mean, that I could *help them along* and try to kind of, discover or, figure out, *together* what would be best and how we could help the arms grow. It wasn’t so much like, “this is where you know you can sense your feelings and what can we expect,” just we’re constantly watching them ... I think when Will has fully regained sensation, or *if* he fully regains sensation, uh, and proprioception—so that he doesn’t have to think about where his arms are—that will be the sort of, the day that the baby’s grown up!

In a similar vein to the undetermined sense of value and development that Will and Angel placed on the hand grafts, Will describes the process of coming to know or fully own his new hands as one of watchful awareness of emerging significance. Morphologically, Will’s transplanted hands have undergone subtle aesthetic transformations, and these alterations of form and function have been the focus of much semiotic speculation. He describes a pattern of continuous discernment early on in which he was attempting to differentiate between the physical qualities of his hands that might be consequences of his own actions and care, versus those that may be from the lifestyle of his donor, versus those that might indicate underlying biological processes (including signs of rejection and infection). Will describes his experiences of coming to “own” his new hands as an emotional and rewarding learning process:

I have a couple of scars that weren’t things I had earned. I saw them on the hands, and I thought, “Well, that’s fascinating. I wonder how my donor acquired them.” Everyone has scars on their hands, but gener-

ally, you know where you got them. You've got stories related to them, and this is one of these weird cases where I literally don't know where my hands have been, which is funny.

When I was in Phoenix [giving a talk for a transplant conference], I unwittingly learned a lot about my donor, because I was talking as part of a panel that presented this donor case, and I was a patient sort of representing one of the beneficiaries. This donor actually benefited 10 different people with 11 different organs ... One thing I learned is that my donor practiced karate, and I only imagine that maybe some of the scars that came, I think some of the scars that came around his hands must be from that. I don't know, of course, but it's possible.

There's an interesting transition. Several weeks after, I noticed, of course, that the hands were rough, were calloused, and I noticed several weeks after my transplant, I was home for a while, that the skin began to slough off my hands. The callouses began to wear away, basically. The skin underneath was sort of fresh and pink and soft and all this ... There are ways that you can build strong hands, and build callouses up on your hands, and whether [my donor] did that or not, I don't know. But that work was going away, and it was represented in a more—not necessarily the hands of an academic, because my hands weren't all that soft, I don't think—I don't know. I took that as a, "It's okay. It's all right for me to think of these as mine."

At the same time, of course, I can't feel everything in them yet, and the nerves are only slowly going down, and I don't have total appropriation in them. There's a lot about them that still feels not quite mine. I don't think I'll ever lose—as much as they feel increasingly like mine—I don't think I'll ever lose the sense that, in a way, I owe something to someone with them. I don't think that's a bad thing. That's not negative. It just makes me realize, it's a reminder that I need to be grateful, and not just for this. I'm happy with that.

Narrative 4: Dave and Karen Savage

Dave and Karen Savage live in Bay City, Michigan, near where Dave grew up, and where they both enjoy residing in close proximity to their extended family and adult children. Dave describes his childhood in Michigan as peaceful and enjoyable, drawing (for emphasis) an implicit comparison between the values characterizing those simpler times and our contemporary landscape: "Back then it was easy growing up. You went around, did whatever you wanted to do—if you wanted to go out, there was nobody lurking around in the shadows, ya know? It was a *good* time."

Dave and Karen met in their 30's after they had both been married with kids of their own, and long after Dave suffered a traumatic injury to his dominant right hand in a machine press accident. Dave, a quiet person whose economical style of speaking leaves some work to the listener's imagination, describes the accident as a "plain and simple" event resulting from the confluence of two factors. The first factor Dave characterizes as material or environmental insofar as, "some of the devices that were there for safety just weren't on the machine,"—a fact both Dave and the corporate insurers who covered the accident attributed to oversights by the company Dave continued to work for the rest of his professional career. The second factor Dave narrates as his own failings of attention and knowledge at the time, "You're young and you've got a job and ...ya know, there are safety rules that are involved in it and you don't know 'em all."

At the time of the accident, Dave knew immediately that his hand would have to be amputated. Dave says, "[the machine press] just smashed it ... You could tell [my hand was unsalvageable] just by looking at it." Although Dave (like many narrators) uses second person when recalling many events, including the loss of his hand, he recounts the time period directly after the injury in first-person terms, emphasizing, perhaps surprisingly, the lack of disruption to his life that the loss represented and his own agency in managing his post-traumatic experiences. Dave says:

When I woke up after the surgery, first thing is my wife was standing there with my draft notice. Uh, so if that would've came a day earlier, the accident would've never happened because I wouldn't've went to work. But then, I looked around and I seen where I was at and I said, "I ain't staying here." So, ya know, I worked a deal to get out of there and all I needed was a pair of shoes. So my father-in-law lent me his shoes, and I got up and walked out and went to the other hospital... Um, like I said it's hard to explain. I lost [my hand] in an industrial accident and uh, life went on from there!

Dave also revealed his humor in this bit of narration. Asked what inspired his decision to switch hospitals following such a major, seemingly traumatic surgery, and he said:

DS: They couldn't put me in a private or semi-private room. They put me in a twenty bed *ward*. And everybody was in that ward from crazy people on up. So, I didn't wanna be there.

EH: Ok, and how long were you in the second hospital?

DS: The second hospital? Oh, gosh I dunno probably about two weeks, maybe.

EH: Wow, and that was just caring for the wound itself or did you receive other types of treatment?

DS: Yeah, it was just caring for the wound, waiting for all the swelling to go down, stuff like that, ya know—the other reason I wanted to go to that hospital is ‘cause my mother worked in the kitchen.

EH: Nice.

DS: So I knew I’d eat good. (Laughing)

Dave describes life post-amputation as being much the same as life before, with a few modifications. At the time of his injury, Dave’s first wife was pregnant. Although he does not indicate this special family status as a reason for wanting to return to work, he says that the loss of his hand did not diminish his ability to do so, “I might’ve been off work 7, 8 months at the most? I was going crazy—I *wanted* to go back to work. When they called me and asked me if I’d come back to work, I didn’t even hesitate. I didn’t even have my prosthetic yet, when I went back to work.”

When Dave and Karen met in the mid-80’s, Dave was still using a simple cable hook prosthetic to help manage daily tasks. He says of the device that, “sometimes it helped [and] sometimes it got in the way.” Dave and Karen both observed that the serious limitations of using the hook when interacting with other people was the most frustrating aspect of its manifestation as a “replacement” for his lost hand. Sometimes these interactions were upsetting and isolating. Karen describes the feeling in sharp recollection: “Dave helped me get off the ground a youth football program, and he was one of the coaches. Our son [Gus] did a lot of the demonstrations ... because Dave couldn’t throw a football, or catch the ball in a way the kids would be instructed to catch it. ... That bothered him because he was there to be a coach and be there to help them, and I think it bothered him a lot that the kids would shy away.”

Although Dave was an amputee for over 30 years before having the opportunity to participate in hand transplantation, the long period of post-traumatic recovery and adjustment did little to diminish his interest in being made whole again through some kind of intervention. “[Dave] never wanted to think of himself as being handicapped,” says Karen. However, the loss never felt justified, and it was hard to fully accept. Karen says, “If certain safety factors would have been enforced—if the company would’ve done what it should’ve done to guarantee all their workers’ safety—this probably never would’ve happened to him. I think anybody would resent having been pushed into working in a situation that wasn’t safe and now he’s got to deal with it the rest of his life.”

Dave never stopped thinking that someday—not supernaturally, but possibly within his lifetime—he would have two hands again. He believed in the power of science to provide a path to restoration. Dave says, “like one guy was trying to figure out why certain animals could grow their limbs back. Ya know? And thinking they could apply that to humans,

and I dunno whatever became of that.” Karen remembers exactly when that distant possibility became a close reality:

Dave was pretty functional, but ever since day one with me, he always said, “If there’s another way to get another hand, I’m going to try it.” We joked about the idea that, yeah when we get to heaven, we’re going to have perfect bodies, God is going to give us perfect bodies, and you’ll have your hand back, and I’ll be skinny, and we would make a joke about it. That’s kind of how it was with us from the beginning. Then, one night on TV they had an article about Matthew Scott and his hand transplant, and I saw that and I looked at Dave and his eyes were like, “Wow—I have to check on this,” and he said to me, “How will we ever find out about this guy? How do we do that?”

The next day, Karen says, she “got busy with the TV, with local newspapers, and got a contact information for the person who did the interviews, and then that person that did the interviews gave us contact information for the hand transplant program in Louisville.” After a long period of evaluation and negotiation with the insurance company that covered his initial accident, Dave was listed as an experimental patient for the Louisville hand transplant program. Jewish Hospital, which hosts the program, agreed to cover all costs except the follow-up immunosuppression, which Dave would have to take for the rest of his life.

Karen describes the exciting decision to try for the hand transplant as being heavily mediated by reminders of what could happen if the transplant went badly:

[The doctors] wanted us to be totally aware of what it would do, what it possibly could do. It was a big concern to the point of, ‘Maybe we shouldn’t do this’—because maybe all these drugs are going to hurt you in the long run, and there won’t be the benefit we’re expecting out of the transplant. The other part of it, when you think about it, is hand transplantations—if a person’s going in, and they’re having liver, or heart, or lung transplants, you’ve got to have that to live. A hand transplant is something you’re going to have to improve your quality of life, but you can get along without it.

Dave and Karen waited what seemed to them a long time for a hand graft to become available. Dave says he waited through, “like four false alarms there,” which were stressful and discouraging. However, after the match was made and the transplant surgery accomplished, Dave and Karen both describe being amazed by their instant affiliation with the new hand. Dave again emphasizes a feeling of continuity or normalcy rather surprise or transformation on waking up after surgery: “I didn’t feel any different. I looked down and I saw it there, and right away ... everything was mine! Ya

know and as far as my wife she felt the same way!” Karen agrees, “It was immediately his hand.”

For many years, the transplant conferred both functional and psychosocial benefits, sufficient to be worth the work and effort needed to maintain it. Dave says, “when you first get [a hand graft] you know it’s all great and you know, you put all this hard work in with the physical therapy and all that ... at first everything was great!” However, minor complications and difficulty managing transplant drugs caused more and more stress and discomfort as the years went by. From Karen’s point of view, the changes to their quality of life were not always good ones:

EH: How did life change after the transplant?

KS: He’s grumpy.

EH: Really?

KS: Yep. A lot of times he’s not feeling really good. I tend to blame it on the medicine.

EH: Was it like that from the very beginning?

KS: Let’s see. It’s kind of hard for me to say because at first, when he first had the surgery, you got your surgery recovery time. You know, where you’re not feeling good because you just had surgery, and all this stuff is healing up, plus he’s on all the new medicine where he doesn’t feel good because his stomach’s upset from taking all this medicine. That lasts a long time. Once the hand starts looking better, and he starts feeling better, it kind of eases up, but it never goes away.

Dave acknowledges that there were numerous challenges. In managed complication after managed complication, he discovered firsthand that high levels of immunosuppression would protect the graft hand but harm his own health, and vice versa. By the time of our oral history interview approximately 10 years after his transplant surgery, Dave was easily animated when talking about the long-term challenges of hand transplantation, especially in terms of post-transplant medications:

[At one point] they changed [all of my drugs]. Uh, I started out with Prograf and Cellcept? Something like that, and since then, they’ve taken me off Cellcept and 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-looking hand 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 that deteriorating clinical relationships were as much a source of stress for Dave and Karen as the complications of the hand transplant after-care (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 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% 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,² 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: Joe Kinan and Carrie Pratt

Joe Kinan and Carrie Pratt are a strongly 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 Station Nightclub fire in New Jersey, and a soft-spoken person of remarkable willpower, is now the first hand transplant recipient at Massachusetts General Hospital's emerging VCA program.

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 4 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 10 years before their interview. 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... 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.” Um, 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

² As reported by Louisville team member Tuna Ozyurekoglul 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.

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 and threat of illness was hard to get used to, especially for Joe:

[With a hand transplant] you’re making a perfectly healthy person, deathly ill—you’re turning them into a cancer patient essentially. With zero immune system and 75 pills a day. ... 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 supplement he ever took was protein powder. ... As far as taking all that medicine after the transplant, I would say, there was never concern of addiction, you know I was forcing him into taking more [pain medication] towards the end, because I could see him wincing, I could see him, almost *overdoing* it in his OT. So I was pushing him to continue and he would say, “No I’ve had enough I’m done with this [opioid] I want to get off of it” so I kept him on it as long as I could. Then once he got off it he truly felt everything. 100 percent. And, I guess he wanted that—he wanted to know what was working and what wasn’t.

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. 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 3 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 explains 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 donor’s 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, if anything, they would change or do differently given the opportunity, Carrie says her only regret so far is the lack of accurate expectations she and Joe had regarding the intense difficulty of the early post-operative period. In some ways the incongruity between their imagination of life after hand transplantation and its exhausting reality was unavoidable given the lack of peer mediated education regarding what to expect. Carrie says, “I wish there would have been resources for us. I wish there would’ve been—like a book, or a piece of paper that was given to us that said, ‘Here’s a list of transplant patients and their significant other, that would be happy to talk to you.’” Carrie concludes that having a lot of time to ponder the consequences was an important aspect of the process for this reason: “I’m glad it took a whole year for us to get through the process ... 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.”

Understanding quality of life through patient narratives of HTX: ethically relevant themes

Imagining what a hand transplant will be like, and what it will represent in terms of a change to the life course of a person and their family—including aspects of lifestyle, value, and identity—is a process requiring several intertwining avenues of deep concern. Patients and caregivers must work to discern whether a hand transplant will be affordable for their family and whether the biological risks (including lifelong reliance on and weakness from toxic immunosuppressive drugs, surgical complications, and possible graft-related illness) will be worth the psychosocial benefits that (may or may not) follow as a result of the hand transplant. For bilateral amputees, the calculus is especially precarious: if the transplant fails, they could lose valuable time learning how to use a prosthetic, or they could be set back in their ability to wear a prosthetic for months or years (due to an additional healing period before getting fitted for a second one).

In this final section we offer three thematic observations from the above stories—with commentary on their relevance to the bioethical challenges of determining quality of life effects in HTX. Our first annotation to the above narrative summaries is the idea 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. Our second is that the goals of a hand transplant are emergent, not predetermined; patients do not reach a discreet destination or point of full recovery, but will

rather see gains and losses in psychosocial and manual function over time due to complications from drugs, rejection episodes, or the limitations of the post-transplant lifestyle. Finally, from patient descriptions of their expectations and their feelings about what happened, we observe that success in hand transplantation begins at a patient family’s conception of possible outcomes and the relevance of returnable functions to their evolving goals in life.

“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 (Cendales 2011; Errico et al. 2012; Breidenbach et al. 2016). However, there has 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 (Jowsey-Gregoire and Kumnig 2016). 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!

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.

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, “[W]hen 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” [24, p. xiii]. We believe hand transplant programs could and should do more to prepare whole families for a hand transplant. For communicative efficiency if not longitudinal “success,” the people involved

should feel that they are in a safe and supportive environment for discussing their hopes, concerns, and evolving needs with regard to the hand transplant. Because highly involved caregivers have provided critical support to medication and therapy adherence efforts in many cases, they may also benefit from individual attention from behavioral health staff at follow up appointments.

The definition of success in hand transplantation is emergent, not predetermined

Regardless of how candidates might envision an intervention like hand transplantation in terms of restoring their quality of life or a specific function, outcomes in this field will always be a complicated palimpsest of pre-existing associations and novel, as-yet-uncategorized sensations. For this reason, anticipating that a hand transplant will allow for the return of a *particular* lifestyle or vocation is not only impractical, it may be a dangerous recipe for disappointment. In our opinion, when assessing quality of life outcomes, “patient-centered” means “patient-defined”—even if the imperfect, intuitive definitions given by patients means working with a vocabulary that is possibly resistant to standardization. When physicians create opportunities 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 patient’s and their family’s ever-evolving needs in relation to their own health, the health of the hand graft, and the health of their relationship with care providers.

Software engineers are familiar with the problem of over-determination of methods and endpoints in designing and implementing new technologies. The following passage from a paper describing parallels between engineering and evolutionary biology sketches concepts that are relevant, we think, to the unfolding contingent, iterative, and enmeshed technologies of hand transplantation:

[W]hile human engineers are certainly goal oriented in the short run and nature is not, their guesses as to what a new device might eventually be used for often fall flat ... adherence to a strict linear approach to design has often been identified as the key reason for the frequent failure of large-scale software projects, which some estimates put at over 50% of projects. It is common, for example, for precise requirements to be unclear at the beginning of a project, and many complex design problems often don’t come into view prior to implementation (Calcott et al. 2015).

This description of an “iterative” design process in highly interactive technological disciplines is similar to challenges associated with demanding, constantly unfolding, medical

interventions like hand transplantation. Extensive follow up is needed to understand this point in terms of its implications for hand transplant guidelines; our conclusion, below, offers preliminary extension and application.

Success begins at conception

In the above narratives, patients described hand transplant successes and their level of satisfaction in relation to what they had conceived, prior to transplantation, as likely desirable outcomes. For example, a powerful yet erroneous conjecture about what kind of life would be possible with a new hand seems to have led to eventual dissatisfaction and disaffiliation in the case of Rich Edwards. Similarly, another recipient interviewed for the oral history project describes having hoped to regain a combat role in the military after hand transplant; failing this outcome, he stopped going to hand therapy every day and eventually requested re-amputation of the graft. His transplanted hands, like Rich’s, were unable to take on new meanings after years of grueling therapy did not afford the hoped-for outcome. The semiotic calcification of the transplant as “unsuccessful” in a specific endeavor led to severe negative sequelae (depression and suicide) for Rich Edwards and to graft loss for this other recipient.

As Carrie Pratt notes above, having time to imagine all the possible outcomes of hand transplantation, and the challenges associated with them, was a helpful part of the preparation process. An expanded version of her comment sheds light on why a presumable barrier to hand transplantation (the long evaluation process) might actually be a facet of successful HTX procedures:

I’m glad it took a whole year for us to get through the [evaluation] 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 along with many other narrators in the oral history project expressed a sense of frustration regarding the gap between how difficult they imagined the transplant recovery process being and how difficult it actually was (hard to the point of unmanageable). Patients who had significant nerve pain, who were sick for months on end, or who struggled to keep up with the drugs and daily hand therapy relied greatly on the support of partners, friends, and other support networks. An additional point meriting consideration in this quote is the extent to which the idea of an “ideal patient candidate” could impact the consent process for these surgeries (Taylor-Alexander 2014). In cases where patients are

evaluated and must prove themselves worthy of an intervention, they may be afraid to ask all the questions that they feel are important prior to signing consent forms (see Parker 1995, pp. 196–197). This effect may be heightened in experimental scenarios where “gatekeeping” mechanisms are particularly visible and accepted.

Based on our analysis of themes of expectation and reality in hand transplant oral histories, more research is needed to identify methods to help patients and their caregivers develop and maintain a more flexible or responsive set of goals for life-long productive participation. Because a hand transplant is constantly evolving and there are no guarantees at the outset of the process, we believe patients and caregivers who adopt an “open-ended” concept of what the new hand will or can mean in their lives may fare better after hand transplantation than those who desire a specific functional or occupational outcome in return for their efforts. Thus, providers who take extra steps in the selection and preparation process to “paint a picture” of day-to-day contingencies (in addition to discussing risks statistically), could not only better inform the informed consent process, but also help to lay valuable groundwork for patients and their caregivers as they navigate good and bad days after surgery. Further research might investigate whether other fields of medicine (such as obstetrics, genetic counseling, or marriage and family therapy) possess conversational or conceptual preparation tools that are inclusive of partners and that facilitate open-ended goal-setting; perhaps such tools could be adapted as guides for pre-operative discussions with hand transplant candidates.

Narrating the future of hand transplants and VCA

In conclusion, 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. The ethical dimensions of our argument 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 ($N \leq 100$) means the hand transplant field suffers from shortage of data as a fundamental problem. This limited quantity of data, as well as the heterogeneity of the patient population and disparate protocols among HTX programs internationally, intensify the necessity for experimental groups to be as thorough, prompt, and accurate as possible when publishing results. While scientific data, abstracted from events of interest in the form of preselected fields, summarizing figures, and other systems of statistical representation can be powerfully descriptive for experts and

informed third-party audiences, only patient stories travel between different registers of expertise and experience to give insight beyond the scientifically defined variables of interest.

Despite the variation in the above narratives, indeed perhaps because of that variation, examination of the experience of living with transplanted hands can inform clinicians’, patients’, and policy makers’ evaluation of the risks and potential benefits of these procedures. As bioethicist Paul D. Simmons wrote in the early years of hand transplantation, “The benefits of [VCA] do not lend themselves to quantification... [Patients] speak from experience on weighty matters of importance to them that relate to relations with loved ones, intensely personal losses and a sense of what is worth it when an opportunity for restoration presents itself...” (Simmons 2000). The hand transplant narratives interpreted in this paper demonstrate the relevance and usefulness of narrative accounts to the clinical process. As medical humanities researchers Valerie Kalitzkus and Peter F. Matthiessen argue, “Because the language and lifeworld of patients and physicians can be so far apart, it might be helpful to have an intermediary... [or a] ... facilitator between the physician’s and the patient’s world” (2009, p. 85). As intermediaries or interpreter of patient experiences in hand transplantation, we think analysis of oral histories is an apt method for interpreting first-person experience, especially given its framing of the object of concern within the life narrative of the recipient or caregiver (rather than as an event occurring as part of the larger story of transplantation or medical science). Ideally for these highly cooperative, dynamic interventions, a more observationally rich ethnographic methodology incorporating firsthand observations on patient and family routines for care would be most revealing. However, Kalitzkus and Matthiessen also note the time-consuming nature of even the most basic narrative inquiry in medicine (2009, p. 86), so more robustly experiential research may be difficult to support.

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. In addition to calling for greater utilization of narrative methods in the hand transplant field, we recommend sustained discussion of the ethics of representation itself, not only in hand transplantation, but also in other fields of medicine where calls to innovate must be weighed against patients’ interests in pursuing other options. 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 we suggest that more research on the ethics of representing others in academic medical journals (either as persons or as abstractions) is needed.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. For this type of study formal [IRB] consent is not required.

Informed consent Informed consent was obtained from all individual participants included in the study. Additional informed consent was obtained from all individual participants for whom identifying information is included in this article. “Deed of Gift” forms for all narrators are on file with the first author.

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