

**Enhancement of “Quality of Life” As a Justification for Hand Transplantation:  
A Review and Critique of the Bioethics Literature After 20 Years of Experience**

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# **Enhancement of “Quality of Life” As a Justification for Hand Transplantation: A Review and Critique of the Bioethics Literature After 20 Years of Experience**

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The initial and most widely referenced arguments for the ethical permissibility of hand transplantation (HTX) cite the bioethical principles of autonomy and beneficence to claim that, despite significant drawbacks of immunosuppression and surgery, HTX has the potential to enhance the lives of patients who fit appropriate criteria and are well-supported. However, the question of whether current cases of HTX can be described as having “enhanced life” has not been answered with attempts to assess patients’ experiences comprehensively (integrating quantitative, qualitative, and narrative research tools). This master’s thesis provides an overview of “quality-of-life” oriented arguments in the literature on hand transplant ethics, focusing on how authors structure the permissibility of HTX in the absence of robust outcomes data, and criticizes this literature for its lack of empirical data reflecting HTX patients’ perspectives.

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## **1.0 An Overview of “Quality of Life” Arguments in the Bioethical Discourse on Hand Transplantation**

In the twenty years since the first published journal articles argued for the ethical and scientific viability of hand transplantation in the modern era of immunosuppression (Siegler, 1998; Simmons, 2000; Breidenbach, Tobin, Gorantla, Gonzales, and Grainger 2002), hand transplantation (HTX) and other forms of vascularized composite allotransplantation (VCA) have been seen to be possible (Kann, Furnas and Hewitt, 2000; Lanzetta et al., 2004; Gander et al., 2006) and beneficial for properly selected and supported recipients (Schuind, Abramowicz and Schneeberger, 2007; Foroohar et al., 2011; Breidenbach et al., 2015; Cooney et al., 2018). Nevertheless, serious side effects of immunosuppressant medications have been experienced by patients (Hatrick and Tonkin, 2001; Hettiaratchy, Butler, and Lee, 2001; Baumeister et al., 2004; Boratynska et al., 2014; Kaminska et al., 2014), and new scientific techniques to minimize immunosuppression are not yet well understood with regard to their ability to improve the balance of risks and potential benefits of hand transplantation, the procedure’s risk:benefit ratio.

Because HTX does not afford lifesaving or life-extending benefits, its permissibility resides in its potential to enhance patients’ subjective quality of life (QoL) for as long as they have their hand graft. Realizing these potential gains in QoL are complicated, however, by the vicissitudes of lifelong immunosuppression and the limitations to both QoL and, potentially, to longevity that immunosuppression presents. This master’s thesis argues that data describing and assessing patients’ own understanding of their experiences of HTX, as well as data regarding their pre- and post-operative QoL, should be systematically collected and then employed to inform arguments regarding hand transplantation in the HTX bioethics literature. By “bioethics literature”

I mean both commentary by bioethicists as well as papers co-authored by bioethicists and HTX clinician-researchers which have as their main topic traditionally “bioethical” issues including arguments about the permissibility of the practice, as well as arguments focused on processes of candidate evaluation, informed consent, and post-transplantation support for recipients and their informal caregivers.

In this first section 1, I present a brief overview of the bioethical discourse on hand transplantation, paying special attention to the way patients’ quality of life before and after HTX has been imagined, characterized, and evaluated in these papers. This review reveals that first-person data from patients’ own perspectives figure only minimally in these bioethical analyses, despite the fact that HTX was actually being performed experimentally around the world. Thus research illuminating ground-level insights from the HTX patient population was possible to carry out, if it had been prioritized by research teams. In this thesis I argue that, in particular, the lived QoL tradeoffs in hand transplantation have not been adequately addressed in the HTX bioethics literature that instead relies on imagined QoL. I analyze several papers to support this observation.

In section 2, I argue that HTX researchers and clinicians should make a priority of collecting and assessing first-person accounts from HTX patients. I suggest how analysis of such grounded accounts might address the challenge of representing QoL tradeoffs to HTX candidates more accurately during the candidate evaluation and informed consent processes. Systematic attempts to describe and assess patients’ experiences are needed to begin to answer the question of whether hand transplants adequately enhance life to justify continuation of the practice. It is not, I will show, an original idea that bioethical arguments need to take such qualitative data into account in their examination of the risk/benefit tradeoffs for evaluations of outcomes and ethicality of either research involving human subjects or clinical interventions. In the case of hand

transplantation, patient-participant perspectives are needed both to elucidate whether HTX is justified as a QoL-enhancing intervention and to better support decision-making by patient candidates and professionals in the field. I conclude section 2 with support from other areas of bioethics and person-centered healthcare/philosophy of medicine on the need for “commonsense” experiential understanding of the lived effects of HTX interventions, via robust integration of the advanced conceptual-analytical skillset of clinical bioethics with grounded qualitative research illuminating the lived/embodied knowledge of affected populations on their target area of concern (patient-participant quality of life).

*Making “quality of life” a goal of organ transplantation*

Emergence of the notion that “quality of life” could be the goal of organ transplantation has been called “a quiet revolution in organ transplant ethics” by bioethics scholars (Caplan and Purves, 2017). The original and most widely referenced arguments for the ethical permissibility of hand transplantation cite the unique rehabilitative potential of these surgeries to claim that, despite significant drawbacks of immunosuppression and grueling aftercare, the risk/benefit balance of HTX can be positive for properly evaluated and supported patients (Siegler 1998; Dickenson and Hakim, 1999; Simmons, 2000; Breidenbach, Tobin, Gorantla, Gonzales, and Grainger 2002; Tobin et al., 2005). Mark Siegler, an ethicist who worked with one of the pioneering HTX research groups, describes how pre-experimental discussions of the ethics of hand transplantation circled the question of whether the improvement to quality of life from the patient’s perspective could balance the risks and burdens of chronic immunosuppression:

After listening to papers discussing the laboratory and clinical background studies, the likely potential risks of the procedure, and also the potential benefits of the procedure, I concluded ... that it was ethically acceptable to proceed with the trial.

In reaching this conclusion, I balanced the potential benefit of a successful cadaveric hand transplant ... against the major likely risks of the procedure, risks which include the need for chronic immunosuppression and its consequences (1998, 2781).

Two decades later, in 2019, science journalist David Dobbs considered the fundamentally subjective nature of risk/benefit tradeoffs in HTX for a WIRED article on U.S. hand transplant results. Dobbs describes the difficulty of balancing known risks with unknown benefits in hand transplantation where the goal is not to save, but to enhance, life: “Most people readily accept [the risks of immunosuppression] to get a new heart, lung, or liver ... But a hand transplant sharply changes this calculus. Is taking dangerous drugs for the rest of one’s life worth the satisfaction of tying a shoelace or moving a strand of hair from a child’s face? Such deeply personal questions test the boundaries of medical ethics” (Dobbs, 2019, 44).

Although skepticism as to the permissibility of HTX and VCA remained strong among some medical and ethical professionals throughout the field’s early years of human experiments, (Foucher, 1999; Hatrick and Tonkin, 2001; Manske, 2001; Meyer, 2001; Cooney and Hentz, 2002; Health Quality Ontario, 2016; Brugger et al., 2015; Hedges and Rosoff, 2018), outcomes reports on the first cases of VCA in the “modern” (post-cyclosporine) era of immunosuppression—two unilateral hand transplants in Lyon, France, and Louisville, Kentucky, respectively—celebrated these interventions’ surgical success and the idea that hand transplants under normal levels of immunosuppression could be effective for some patients (Dubernard et al., 1998; Jones et al., 2000). In these initial case reports, published in the first 6-24 months following surgery, “success” in experimental HTX is presented in terms of technical “proof of concept” (the idea that HTX is scientifically possible yielding functional returns and extended graft survival) but not in terms of

HTX patients' own understanding of their postoperative wellness and satisfaction with results (Dubernard et al., 1998; Jones et al., 2000).

Despite the shortcomings of early HTX and VCA outcomes reports, many of these papers were cited as showing proof of concept for performing further HTX and for the diversification of “composite tissue allotransplantation” (an early name for VCA) to other conditions (Kann and Hewitt, 2001; Levi et al., 2003; Wiggins et al., 2004; Ren and Laugel, 2013). For example, HTX pioneers Dubernard et al. write in 1999, “We have confirmed the technical feasibility of limb transplantation” (Dubernard et al., 1318). HTX clinician researchers in Louisville, Kentucky, published similar observations on their own efforts and outcomes: “Our results and those of the first human hand transplantation, performed in France, show that early success in hand transplantation can be achieved with the use of currently available immunosuppressive drugs” (Jones et al., 2000, 472).

While most of the case studies and review articles published by clinical professionals in hand transplantation conclude with some version of the phrase, “hand transplantation is technically feasible... and results are encouraging” (Petruzzo et al., 2008, 491), low numbers of patients and high variability in treatment protocols have made evidence-based assessment of outcomes difficult for clinical researchers, ethicists, and other policymakers and stakeholders. “While these new treatments promise the benefit of better esthetic and functional outcomes, they also expose patients to new types and degrees of risk, not experienced previously in conventional reconstructive treatments,” write VCA providers Barker et al. in 2011. Barker et al. continue: “These risks have generated a heated risk versus benefit debate among reconstructive surgeons, bioethicists, the legal community, and the popular press, and have greatly influenced the clinical introduction of these new treatments” (470). In a similar vein, in the “History and Ethics of Hand Transplants,” HTX

clinicians Errico, Metcalfe, and Platt explain why claims made in the early literature on HTX were difficult to parse in terms of their “on-the-ground” recommendations for patient candidates and providers:

The experimental nature of this treatment ... casts doubt on how informed a patient’s decision can truly be. Our experience in the field is only based on a small data-set collected over a period of 11 years. The true impact of long-term sequelae is not fully understood, and this uncertainty could potentially influence the individual’s decision-making process. In addition, the benefits of such a procedure could be unintentionally exaggerated by an overzealous physician, motivated by the thrill of medical advancement (2012, 4).

Because as of 2019 fewer than 80 hand transplant surgeries have been performed, providers of hand transplantation agree that efforts to evaluate results “objectively” are complicated by the impossibility of generating statistically significant analytic insights from case data. In 2004, bioethicist Françoise Baylis criticized the thin knowledge base among those deploying “success with hand transplants” in arguments supporting new types of VCA interventions: “[These authors] do not show unequivocally that hand transplantation is morally acceptable—the fact that something is done does not in itself constitute evidence of its moral acceptability ... in their haste to persuade others ... they focus on the technical aspects of [VCA] and issues relevant to the research ethics review process” (31). Twenty years after the first speculative discussions of the risks and benefits of hand transplantation, the specific nature of the lifestyle and health-related tradeoffs for HTX patients, and how these tradeoffs factor into the goal of improving QoL in HTX, is not clear.

Even though lack of available data from HTX case studies is an acknowledged problem in the HTX field, there has been little evident interest in collecting and parsing those data that *can be collected* regarding outcomes for hand transplantation, including outcomes data in the form of first-person accounts from patients describing their experiences. A worldwide collaborative data set on hand transplantation and VCA, the “International Registry on Hand and Composite Tissue Allotransplantation” (IRHCTA), endeavors to compile and compare outcomes data from HTX/VCA programs around the world. The quantitative and qualitative tools used to report VCA outcomes in the IRHCTA are derived from existing assessment tools in plastic surgery, hand rehabilitation, and organ transplantation, culled from published VCA case studies and review articles or submitted to the Registry by VCA clinician-researchers on a volunteer basis. The multi-dimensional meaning of hand transplantation as a “quality of life improving” operation is represented in the Registry—and in almost all of the published case studies and review articles informing the Registry—by measurement-focused representations of how well the hand transplant performed on a preselected battery of manual and psychosocial activities. Thus, in decontextualized representations of patient satisfaction and technical “success,” the lifelong and day-to-day impacts of managed complications and the post-transplant lifestyle are not considered.

Authors of a 2008 report of the IRHCTA describe their efforts to create an international record of outcomes in the VCA field as being compromised by the impossibility of “analyz[ing] transplantation functional results in a standardized way” (Petruzzo et al., 2008, 489). The authors go on to characterize the “functional score system” they developed for reporting HTX outcomes: “The Hand Transplantation Score System evaluates six aspects [of HTX outcomes] for a total of 100 points: Appearance (15 points), Sensibility (20 points), Motility (20 points), Psychological and Social acceptance (15 points), Daily activities and Work status (15 points),

Patient satisfaction and General well-being (15 points)” (Petruzzo et al. 2008, 489-490). Although measures for assessing “Psychological and Social acceptance” of hand grafts and for “Patient satisfaction and General well-being” are included on this list, a numerical score representing recipients’ comprehensive experience of HTX function and side effects does not give enough contextual data to inform ethical evaluations of HTX or clinical decision-making in ongoing cases.

The limitations of trying to scientifically depict “success” in HTX makes the writing of person-centered ethical guidelines and best practices challenging for stakeholders in the field. As Louisville-based bioethicist Paul Simmons wrote in the developmental years of hand transplantation:

How does one assess the impact of taking immunosuppressant drugs the rest of one’s life? How does one imagine a life in which undesirable side effects of medication becomes routine: the hair loss, the gastrointestinal distress, the diarrhea, and the constancy of the regimen? ... Knowing the threats to an allotransplant recipient is important but not sufficient in the calculus of when to move forward ... patient perspectives are also vital as risks are weighed against possible benefits (2000, 459).

As Simmons suggests, an evolving, person-oriented bioethics in hand transplantation would take on board the challenge of representing quality of life tradeoffs more accurately by attending to the aspects of life that HTX patients report as mattering to them. Those providing HTX and those providing ethical analysis of HTX need to have accurate data portraying scientific outcomes (including metabolic and immunological outcomes data and measurements of hand function using standardized tools) in addition to psychosocial outcomes data from patients’ point of view, relevant to answering “commonsense” clinical and bioethical questions about the characteristics of a good

candidate for HTX and which support activities or cultural context are most likely to return successful outcomes.

Because HTX is focused exclusively on improving QoL of patients, yet these gains are attended by significant risks and long-term challenges, HTX patients' self-reported experiences of dis/ability and the ongoing construction of their identity would seemingly be more relevant to considering the ethics and value of hand transplantation than decontextualized measurements of function or graft health using standardized tools borrowed from cognate fields of healthcare ("traditional" organ transplantation for assessing graft health and hand-strength motility measurements from hand surgery). The idea that such "scientific" measurements of HTX function could be largely immaterial to quality-of-life discussions on hand transplants' effectiveness has not been extensively considered in debates on the ethics and outcomes of in hand transplantation.

*What is "there" in the HTX literature, and what is not*

While there have been some attempts to describe transformations in the health and quality of life of HTX patients using self-reported, survey-based methods or thematic analysis of psychiatric semi-structured interviews (Bachmann, 2007; Jensen et al., 2012; Kumnig and Jowsey-Gregoire, 2016), these approaches do not necessarily perform the essential work of representing the lived experiences of recipients and their families before and after hand transplant surgery. Surveys are useful for eliciting responses from HTX patients on pre-selected criteria regarding their observations and experiences, but a weakness of survey research is the need for researchers to elicit responses through well-worded, knowledgeable questions, beyond answering which respondents do not have ample room for creative self-expression. And, where semi-structured psychiatric interviews can illuminate much beyond these measures with regard to patient-

participants' self-understanding of their experiences, the unbalanced power structure of psychiatric settings may limit patients' willingness to share the full extent of their observations.

In a 2012 review titled, "Quality of Life Considerations in Upper Limb Transplantation," Sally E. Jensen and colleagues consulted approximately 250 academic papers on hand transplantation to determine QoL effectiveness, of which 27 were included for analysis in their study having "quality of life" as the main topic. However, only 3 of these 27 papers included interviews with hand graft recipients as part of their methodology. None of the studies was conducted using open-ended questioning techniques by non-program-affiliated researchers, and none of them quoted patients directly regarding their experiences. In some cases, no attempt was made to approach HTX recipients 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 conduct what they call a "phenomenological narrative" analysis 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 conducted their analysis using data collected entirely from news media accounts. Slatman and Widdershoven acknowledge that in their phenomenology of hand transplantation "empirical analysis of embodied self-experience is limited" (2010, 72).

Hand transplant textbooks seem to make more space than peer-reviewed journal articles for patient perspectives. In *The Science of Reconstructive Transplantation*, (Brandacher, 2015), an early chapter featuring exposition on "The Daily Life of a Hand Transplant Recipient" (45) offers an account of HTX as told by a patient recipient. The article is written in first person voice and details the process of evaluation and recovery, including day-to-day challenges and opportunities and general reflections. While it provides some data on the lived experience of the author-patient, it is impossible to generalize from this one account, particularly because no explanation is provided

regarding the authorial decisions regarding what details are included or editorial decisions about why this narrative (or author-patient) was included.

In a chapter for the textbook, *Hand Transplantation*, (Lanzetta and Dubernard, 2007), Daniele Bachmann writes on the topic of “Quality of Life in Hand Transplant Patients.” Although Bachmann did conduct psychiatric interviews with hand transplant recipients, sufficient to yield insights on their motivations and experiences, Bachmann’s chapter spans only three pages of the 400+ page textbook in which it is published. Moreover, it does not offer quotes from patients, and does not include long-term retrospective follow-up on how the side effects and complications from transplant drugs, and the recovery process, balance against gains of psychosocial considerations or manual functionality. In one passage Bachmann alludes to several potential avenues of deep concern and interest regarding the post-transplant lives of people with hand grafts:

[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 (2007, 365).

Unfortunately, the chapter's conclusion follows soon after these revelations that transplanted 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 the interviews are not published alongside professional analysis.

*What is missing and why does it matter?*

"Only time will tell if chronic rejection will preclude the successful long-term outcome of the current reconstructive transplants," write UK plastic surgeons Shehan Hettiaratchy and Peter M. Butler in 2003, "...we will have to wait and see if the current immunosuppression based procedures herald a new era for transplantation or just another false dawn" (2003, 1226-1227). However, despite a flurry of media attention following almost any report of a successful hand transplant surgery, meaningful information that would answer the sincere question embedded in Hettiaratchy and Butler's paper—whether hand transplants have brought a "new era" of reconstructive options or a "false dawn" for vulnerable patients—has not yet emerged from the medical and bioethical literature on hand transplantation. According to UK hand transplant surgeons Simon Kay and Daniel Wilks, "Of the large number of [hand and face] transplants completed now, *outcome data of value is to be found in few*," (2013, 1457, italics added). In 2016 and 2018, the poor quality of outcomes reporting in the hand transplant field was remarked on by HTX practitioners and researchers on healthcare policy and effectiveness in Canada and North Carolina (Health Quality Ontario, 2016, 3; Hedges and Rosoff, 2018, 2). Similar observations on a lack of useful psychosocial data were published by HTX behavioral health researchers Martin Kumnig and colleagues in a 2013 review paper: "Despite a thorough analysis of the literature, the

lack of relevant published information in the psychosocial domain of transplanted patients is a significant limitation of this overview. The majority of articles do not address the psychosocial assessment in any greater than passing detail, so the conclusion that can be made from these highly descriptive, mostly empiric studies in the current literature is limited” (425).

The spectrum of function for hand transplants is broader than for the available alternative of bionic and aesthetic prostheses, and includes return of touch sensation, warmth, and “human”-ness. Nevertheless, hand transplants do not necessarily work better than prosthetics to improve their users’ quality of life. While hand transplants and bionic prosthetics both require extensive learning and rehabilitation periods before they are useful for even the most basic tasks, many who pursue hand transplantation after using bionics emphasize that the work needed to maintain a hand graft and the demands of post-care protocols are far more intense than any physical therapy they had previously experienced. Additionally, because hand transplants can bring dramatic functional returns but are also biological gifts from another person, all functional and psychosocial gains can be set back by immunological complications at any point in time. VCA providers J. Rodrigo Diaz-Siso et al. explain why providers need grounded, up-to-date information on utilization factors in hand transplantation: “Because of the associated risks of lifelong immunosuppression, a critical responsibility of multidisciplinary vascularized composite allotransplantation teams is to educate candidates about the alternative surgical and nonsurgical reconstructive options available to them” (2018). Alternatives to HTX must be considered and compared across the full spectrum of known potential risks and benefits (including impact on health, impact on relationships, potential for therapeutic return) while keeping in mind that, unlike a prosthetic, a hand transplant is a constant lifelong presence on the body both affording and the recipient’s action and movement through the world.

In an oral history project which informs my dissertation on the “rhetoric of success” in hand transplantation (17 interviews total), narrators almost unanimously report experiencing functional gains with a hand transplant that were impossible with the prosthetics they had tried (Herrington, 2019). However, these gains were made *within the parameters of the post-transplant lifestyle*, including restrictions on diet, activities of daily living, budget and freedom to travel in the short or long term. The threat of rejection—which must be constantly monitored and protected against—and the specter of life-threatening complications from immunosuppressant drugs attend all gains to lifestyle and self-perception following HTX surgery. During rejection, a hand transplant can swell, develop spots or lesions, itch, or burn. Therefore, the social and manual function of hand grafts decreases during rejections, as the graft(s) might be too swollen or painful to use, (and the aesthetic presentation of rejection can be off-putting to others (Herrington, 2019). Far from the straightforward, ostensibly objective accounts of outcomes comprising assessments of hand transplantation in medical journals, the oral history interviews I collected with hand transplant patients and their caregivers paint a much more complex and deeply human picture of how “success” is established in hand transplantation (Herrington, 2019; Herrington and Parker, 2019). How narrators perceived their QoL pre- and post-transplant depended on several factors, including whether their personal conception of the value of the HTX process evolved or not with their experiences.

The need for consistent, person-centered outcomes reporting has been emphasized by the leading surgical and scientific figures in HTX/VCA—however no strategies have been agreed upon for filling empirical gaps. The International Registry is not complete or up to date and lacks insights from many programs and patients. Furthermore, patients who have lost their hand grafts are not followed at all. Complications, including patient deaths, are not discussed in the academic

literature with as much regularity as successful surgeries or milestones. James L. Benedict, an ethicist who has studied informed consent issues in HTX/VCA, noted the lack of meaningful cooperation towards knowledge generation in hand transplantation and VCA at the 2018 meeting of the American Society for Reconstructive Surgery (ASRT) in Chicago:

“One recognized challenge in the field is a lack of regular data sharing. While the OPTN VCA Committee provided a partial remedy to this problem with its requirement for data collection and submission for transplants from September 2015 forward, this remedy falls far short of international ethical standards for reporting the outcomes of research and deprives those in the field, potential patients and the public of critical information. In the absence of this information, it is difficult to argue convincingly that the knowledge base, skills and systems are in place to consistently produce good to excellent outcomes and that the field thus deserves the trust of patients and third-party payers.”

Even when outcomes of hand transplants are published in a timely fashion and patients followed over time, what is typically discussed—e.g., manual function (grip strength, etc.) and the clinical management of immunosuppression or rejection/infection—is not presented in the frame of asking questions about patients’ *lived quality of life* post-transplant. For instance, commonsense factors contributing to HTX patients post-transplant QoL that are not reported in HTX papers—and that therefore cannot be formally shared or even widely known—include the QoL impacts of travel to and time spent in the hospital or at (scheduled and unscheduled) medical appointments, the intermittent loss of manual and psychosocial function during recovery from infections or rejections, and how the long-term (metabolic and immunological) effects of immunosuppression on recipients’ health affected HTX patients’ understanding of their quality of life. After 20 years

of hand transplantation, we can learn almost nothing about patients' lives and challenges from the literature and even conferences are thin on this aspect.

So far in this thesis I have introduced HTX and the idea that hand transplants are complicated QoL interventions about which knowledge of patient-participants' lived experience is sorely lacking. Below I will develop the argument that—in addition to survey-based self-assessment of HTX outcomes and analysis of patient interviews conducted in psychiatric or media settings—systematic “grounded” qualitative research on HTX patients' experiences is needed to advance bioethical discussions of potential risks and benefits of HTX interventions. Collecting and parsing such data may require teams of bioethicists and clinical researchers partnering with scholars whose research orientation is toward descriptive or narrative ethnography, medical anthropology, social studies of health and medicine, medical oral history, or other methods of parsing and authentically portraying lived impacts of medical interventions from the “grounded” perspective of patient-participants.

## **2.0 The Ethical Warrant for Integrated Approaches to Assessment of Outcomes in HTX and VCA**

Because hand transplantation and VCA are only performed to improve recipients' quality of life, broadening the assessment of "success" to include VCA patients' self-reported experiences of dis/ability and the ongoing construction of their identity would seemingly be appropriate and critical for discussion of the ethics and value of reconstructive transplantation. Grounded insights from patients' perspectives must be integrated with standardized "scientific" assessment tools (such as tests of kidney function and hand strength-motility, for example) if HTX providers are to develop person-centered knowledge of the comparative effectiveness of different research protocols and the large-scale impact of these surgeries on patients' lives—especially because any immediate or emerging gains to QoL realized through HTX are attended by significant risks from immunosuppression whose serious side effects could disrupt the risk/benefit balance for patient families at any time.

In this second section, I argue that, for those writing about the outcomes and ethics of hand transplantation, a more collaborative or "grounded" critical/analytical role may be warranted where QoL tradeoffs in HTX are being considered or measured over an extended period of time (as they must be to understand these operations' longitudinal effects). In such situations patients' own words about their experiences can help bioethicists and providers tease out factors relevant to ethical analyses of events and ongoing practices in the field, wherein the initially idiosyncratic vocabulary of first-person experience can gradually come to replace the (necessarily) less-contextually specific language of pre-experimental discussions. My call for this type of interdisciplinary empirical work is supported by recent theoretical and empirical work by

bioethicists and scholars in related fields of research (see especially: Shildrick and Mykitiuk, 2005; Newell, 2006; Caenazzo et al., 2017; Svenaeus, 2017; Baylis and Dreger, 2018)

Because hand transplantation is naturally interdisciplinary, uniting knowledge and practices from hand surgery, transplantation, hand rehabilitation, transplant behavioral health, and bioethics, the author list for ethics articles in HTX typically includes at least one bioethicist writing with clinicians of various specialties. This typical (in HTX bioethics) blend of disciplinary perspectives elicited by clinicians and ethicists working together can effectively produce discussion of the scientific and analytical tools relevant to parsing the ethicality of HTX/VCA, or what outcomes might constitute “success” in a hypothetical frame. However, ethicist-clinician partnerships that do not include HTX patients as partners have not been—and will *never* be—effective at developing practical knowledge of whether and how HTX can be successful at producing QoL benefits for patients (the central driving question of pre-experimental ethics debates). As I will show, perspectives from patients, their caregivers, and other workers in the daily activities of living with HTX/VCA would substantially improve the relevance and productivity of the interdisciplinary ethicist-clinician collaborations that have so far dominated debate on HTX outcomes.

In the early experimental years of hand transplantation, Louisville clinicians Gordon Tobin et al. write, “Although the immunologic concerns seemed more formidable to many in the beginning, a substantial portion of these issues have been resolved by the immunologic successes and graft survivals in the early clinical experience. The ethical issues, however, have emerged as sources of ongoing concern” (2005, 1392, italics added). A 2019 paper titled, “Emerging Ethical Challenges Raised by the Evolution of Vascularized Composite Allotransplantation,” discusses contemporary bioethicists’ response to evolving (rather than diminishing) concerns about the

risk/benefit balance in hand transplantation and VCA. An objective of the paper includes informing readers about the authors' efforts towards "developing an ethical framework for the future of VCA" (1241). Bioethicist Arthur Caplan and colleagues explain, "Leaders of each program performing and/or evaluating VCA in the United States were invited to participate in a working group to assess the state and future of VCA ethics and policy. Four meetings were held over the course of 1 year to describe key challenges and potential solutions" (1240). Notably for Caplan's group, the removed-from-reality, "expert opinion" of VCA clinicians and bioethicists provided the starting point for this ethics initiative—not the grounded experiential knowledge and concerns of VCA patient-participants and their families or caregivers. The authors write, "Participating members were asked to provide expert opinion and react to drafts of a proposed ethical framework ... Members met for 4 [workshop-style] sessions ... Following the third session, discussion points and comprehensive meeting notes from all sessions were compiled and synthesized by the NYU/Hopkins leadership team to serve as the starting point for drafting an article" (Caplan et al., 2019, 1241).

In the authors' exposition on their process of developing recommendations for hand transplantation and VCA ethics, they report having conducted interviews with patients and their family caregivers. However, very little information is given about the content of these interviews in the working group's first publication, nor do they illuminate their methods for data collection and analysis. Also not described is how the authors generated conclusions based on their exchanges with HTX patients (including how many interviews were performed over what period of time, who performed the interviews, how long the interviews lasted, whether patients and family members were interviewed separately, and whether or not they were interviewed in an institutional or public/home context). Although the NYU/Johns Hopkins VCA ethics working group is calling for

more systematic research with clear methods of data collection and analysis across the field, they do not include methodological details regarding the exchanges with HTX recipients that informed their own study, and thus the paper is less informative than it might be. It is ironic that academic publications, like this one, arguing for greater attention to patient perspectives in the VCA field generally fail to include substantive accounts of patients' perspectives. The following sentences raise concerns about how the evidence of "technical success" in hand transplantation has overshadowed collection of evidence the about improvement in QoL of recipients as the actual goal of VCA:

[P]atient-provider relationship challenges are evident throughout the full lifecycle of a VCA. Surgeons and teams spend extensive time with VCA recipients in part due to the complexity and long-term risks. This may result in unhealthy attention, priority, or favoritism of the patient, or *a patient having unrealistic expectations of the provider* ... the temporary celebrity status that many VCA patients acquire from media coverage, [could also] leave them disappointed and angry with their medical team when the media loses interest (Caplan et al., 2018, 1241).

The framing of key ethical issues in this passage—and in much of the bioethical literature regarding HTX—gives preference to the physicians' point of view. Caplan et al., for example, refer to patients' having "unrealistic expectations of the provider" and seem to overlook the fact that the singular goal of a hand transplant surgery is improvement in patient recipients' quality of life. That goal makes central the expectations of the recipient and makes central to candidate evaluation and informed consent both the accuracy of the recipient's understanding and the degree of realism of the candidate's expectations. In another section, the authors write that "despite early skepticism, the [HTX/VCA] field has demonstrated feasibility and success" (1240). However, this

conclusion is inadequately supported in the absence of empirical studies examining QoL outcomes, particularly the subjective and nuanced outcomes that candidates seek. The paper also does not show how the working group's observations are supported through their own critical analysis and grounded inquiry of VCA outcomes. The conclusion that the VCA field has demonstrated "success" employs a physician/surgeon-centric, medicoscientific-centric notion of "success," which is inadequate for a medical intervention that seeks to improve quality of life as patients themselves conceptualize that quality.

*How can bioethicists help the situation in hand transplantation and VCA?*

The current situation of the ethics of hand transplantation offers an opportunity to consider how clinical bioethics can or should work to elevate the perspectives of patients in the HTX field, and what types data gathering represent the essential work of producing knowledge on the ethics of QoL-enhancing operations. In this thesis I have argued that sparse characterization of HTX patients' pre- and post-transplant QoL in papers reporting outcomes data for HTX is an obstacle to knowledge generation and ethical analysis in the field. Systematic efforts to describe and understand patients' lived experiences are needed to ground professional discourse on the ethicality of HTX and VCA more generally.

Even after 20 years of experience in the hand transplant field, low numbers of geographically isolated patients make analytic insights on case data impossible. As I argued in section 1, there has been an apparent lack of interest among hand transplant professionals—including bioethicists—in parsing the subjective embodied knowledge of hand transplant patients to guide experts' discussions of HTX ethics in realistic and relevant directions. Such "grounded" qualitative research questions are not outside the acceptable and even necessary data-gathering activities of HTX clinicians and others who work on these issues. As feminist bioethicist and

disability scholar Margit Shildrick and research collaborators on the topic of heart transplantation have written, “transplant professionals need to question the limits of what is seen as unproblematically therapeutic, and to look beyond conventional data.” Shildrick et al. explain:

[So-called “raw”] data itself can never be clean and proper. ... At the outset of all research, choices have already been made about what constitutes necessary and sufficient data, what is to be included and excluded, the place and the time frame of collection, the methodology employed, and so on. Moreover, rather than the data sets of bioscience and social science being in opposition, they may tell a similar intersecting story (2017, 53).

As Shildrick et al., point out, there are no “rules” governing how much doctors and ethicists should attend to, rely on, and represent empirical data from their patients’ point of view in published reports and even in internal documents.

Although bioethics discourses regarding hand transplantation have been unclear so far with regard to their ability to effectively represent the needs and desires of HTX patients and candidates, this need not be the case for the next 20 years of human research in this area. Because there are not enough data to make normative statements regarding success of HTX, or the balance of its benefits over its burdens, it would seem imperative to engage the work of empirical knowledge generation to confirm and augment published outcomes, in order to be able to inform analyses of the permissibility of HTX. Those skilled in normative analysis—bioethicists and policy analysts—should partner with qualitative researchers to develop the body of empirical data necessary to address their normative questions and to inform the ethically critical components of HTX itself—namely, informed consent, candidate evaluation, and provision of support to patients and their informal caregivers.

Because the rehabilitative potential of hand transplantation can only be realized within the constraints of the post-transplant lifestyle, including increased medical surveillance, health risks, and potentially burdensome care activities—the ethical impact of HTX must be considered in terms of the specific benefits patients felt that they received in the short or long term through their participation. Such grounded research questions are not necessarily outside the natural data-gathering activities of bioethicists, transplant researchers, surgeons, and others who work on these issues. Given the deeply person-specific nature of the goals and outcomes in hand transplantation, ethical analyses of risks and benefits of HTX would be aided by a “lifeworld-led” approach to treating, representing, and conceiving of transplant candidates and recipients.

As described in paper by philosophers of science and medicine Dahlberg, Todres, and Galvin:

[Lifeworld-led healthcare] ... acknowledges differential levels of expertise and understanding between patient and professional. The patient can understand her/his journey better than any other and in that sense is an expert. Professionals need to acknowledge but not relinquish their expertise, and lead their care from an expanded view of knowledge as articulated above, and not just from ‘technical’ knowledge. This lifeworld knowledge is different from ‘technical’ knowledge, in that it is always on the way, whereas technical knowledge is fixed until the next new evidence becomes available (2009, 2).

For hand transplant patients, the commonsense idea that patients are the experts on their own experiences finds particular salience due the inherently risky, deeply personal, interpersonally demanding, lifelong challenges of these procedures and the physical,

emotional, and interpretive work HTX patients and their caregivers do to bring successful outcomes to fruition.

In closing this thesis, I argue that ethical analyses of risks and benefits in hand transplantation should take into account and indeed give priority to how HTX patients experience and weigh the burdens and benefits of HTX. There is need for the systematic collection of data regarding this experience, including subjective QoL outcomes, that are more nuanced and personal in their robustness than (for instance) the data that are typically included in papers on the HTX experience, such as lists of activities of daily living accomplished by patients, quantitative functional and sensory measures of graft hands, or descriptions of successfully managed complications and measurements of how long grafts persisted on patients' bodies (see section 1; also Herrington 2019 gives an extended critique of the largely unsubstantiated "rhetoric of success" and its operations in the HTX field). Given the personal, and frequently socially-mediated and identity-related, nature of this experience, it may be said that what is needed is the construction of a body of "lifeworld knowledge" that, as Dahlberg, Todres, and Galvin write, "differs from 'technical' knowledge, in that it is always on the way, whereas technical knowledge is fixed until the next new evidence becomes available" (Dahlberg et al., 2009, 270).

The QoL outcomes in HTX are realized by patients and their family members within the lifestyle constraints and the ongoing risk-state of transplant patienthood, which lasts as long as a hand graft is viable or the rest of the recipients' life. Clinical interactions that respect this lifeworld knowledge respect and integrate the knowledge of both medicoscientific (technical) experts and patients, who are expert with regard to their experience and values (Dahlberg et al., 2009, 270). Moreover, the decision-making by patient candidates and professionals in the field—during candidate evaluation, informed consent, and post-transplant follow-up—should be informed by

understanding of not only technical knowledge, but also the lifeworld of HTX recipients. Therefore, more data about recipients' experience and quality of life, both pre- and post-HTX, and about their experience with the processes of candidate evaluation and informed consent, need to be collected and used both to ground ethical analysis of HTX and to inform the processes of evaluating candidates and obtaining their informed consent.

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