

## STATE OF THE ART AND SCIENCE

### What's Missing in Our Thinking About Quality of Life in VCA?

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#### Abstract

Drawing on the principles of respect for autonomy and beneficence, many scholars have argued that despite significant drawbacks of immunosuppression and surgery, vascularized composite allotransplantation (VCA), such as hand and face transplantation, has the potential to enhance the lives of patients who meet appropriate criteria and are well supported. This article provides a brief overview of the literature on VCA with a focus on hand transplantation (HTx) and offers a critique of the lack of empirical data on HTx patients' perspectives.

#### Quality of Life in Hand Transplants

Within a few years after the publication of the first journal articles arguing for the ethical and scientific viability of hand transplantation in the modern era of immunosuppression,<sup>1,2,3</sup> hand transplantation (HTx) and other forms of vascularized composite allotransplantation (VCA) had become technically possible,<sup>4,5,6</sup> and they now are viewed as beneficial for properly selected and supported recipients.<sup>7,8,9,10</sup> Because reconstructive transplantation, such as hand and face transplantation, does not afford the lifesaving or life-extending benefits that have so far characterized transplant medicine, the permissibility of VCA resides in the potential of these transplants to enhance recipients' subjective quality of life (QoL) for as long as they have their allograft. Realizing potential gains in QoL is complicated, however, by the burdens of lifelong immunosuppression to prevent graft rejection and loss, which can also potentially limit longevity.

This essay presents a brief overview of QoL conceptions in the literature on VCA, with a focus on HTx, especially in terms of how HTx patients' quality of life has been imagined and represented by stakeholders writing on the ethicality of these interventions. I argue that the sparse characterization of HTx patients' pre- and posttransplant 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.

#### Making QoL a Goal of Transplantation

The emergence of QoL as a goal of organ transplantation has been called "a quiet revolution in organ transplant ethics" by Arthur Caplan and Duncan Purves.<sup>11</sup>

Although some medical and ethical professionals remain skeptical as to the permissibility of HTx and other types of VCA<sup>12,13,14</sup> and many ethicists and health care professionals voiced strong misgivings throughout the early years of human experiments in the field,<sup>15,16,17,18,19</sup> reports on the outcomes of the first cases of VCA—2 unilateral hand transplants in Lyon, France, and Louisville, Kentucky—celebrated these interventions’ surgical success and the idea that hand transplants with a normal level of immunosuppression could be effective for some patients.<sup>20,21,22</sup> In these initial case reports—published 6 to 24 months after surgery—success is presented in terms of technical *proof of concept* (ie, the idea that HTx that yields functional returns and extended graft survival is scientifically possible) but not in terms of HTx patients’ own understanding of their postoperative wellness and satisfaction with results.

Despite the lack of subjective QoL data in early HTx and other VCA outcomes reports, many of these papers were cited as showing proof of concept for performing further hand transplants and for the diversification of composite tissue allotransplantation (an early name for VCA) to other conditions.<sup>4,23,24,25</sup> In 2004, bioethicist Françoise Baylis criticized the thin knowledge base among those arguing that success with hand transplants<sup>24</sup> supported new types of VCA interventions: “Wiggins and colleagues 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.” Baylis concluded, “in their haste to persuade others ... they focus on the technical aspects of facial transplantation and issues relevant to the research ethics review process.”<sup>26</sup>

Because HTx was the original VCA and successful HTx continues to be referenced to justify both performing other types of VCA and continued use of HTx as a treatment for amputees,<sup>24,25,27</sup> the question of the extent to which HTx restores patients’ QoL in the long-term is important to consider.

### **Gaps in the Literature on HTx and VCA**

Although attempts have been made to describe transformations in the health and quality of life of HTx patients using self-reported, survey-based methods or thematic analysis of psychiatric semistructured interviews,<sup>28,29,30</sup> these approaches do not necessarily perform the essential work of representing the viewpoints of recipients and their families before and after hand transplant surgery. In a 2012 review, “Quality of Life Considerations in Upper Limb Transplantation,” Sally E. Jensen and colleagues consulted approximately 250 academic papers on HTx, 27 of which had quality of life as their main topic and were included in their analysis.<sup>29</sup> Only 3 of the 27 papers on hand transplant patients’ QoL included interviews with hand-graft recipients. None of the studies were conducted by nonprogram-affiliated researchers using open-ended questioning techniques, and none of them quoted patients directly regarding their experiences. In some cases, no attempt was made to approach experimental participants for their point of view even when the stated goals of the research were compatible with doing so.<sup>30</sup>

The poor quality of QoL outcomes reporting in the first 2 decades of HTx and VCA experimentation has been remarked on by health care policy and behavioral health researchers and HTx practitioners.<sup>17,19,31</sup> Martin Kumnig and colleagues wrote in a 2014 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.... 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.<sup>31</sup>

According to United Kingdom 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."<sup>32</sup>

### **Why Does What's Missing Matter to the Ethics of HTx and VCA?**

HTx professionals and ethicists agree that objective evaluation of outcomes in HTx is fraught with difficulties,<sup>33,34</sup> in part because fewer than 80 hand transplant surgeries had been performed around the world as of 2013<sup>35</sup> and meaningful statistical analysis cannot be performed on such limited data. Perhaps surprisingly, there has been little interest in preserving and parsing those data that *can be gathered* on outcomes for HTx, including insights from patients describing their experiences. The difficulty of collecting and analyzing subjective observations of hand transplant recipients and family members might account for the absence of patients' voices in the literature on HTx outcomes. Nevertheless, since so few hand graft recipients' first-person accounts have been published, HTx surgeons and ethicists must work from insufficient data to imagine what the particular physiological and subjective psychosocial costs and benefits might have been for HTx patients who faced the trade-offs of HTx in their lives.

### **Justifying the Need for Patient Perspectives in HTx and VCA**

To begin to address lack of subjective outcomes data on HTx and VCA, I conducted oral histories with hand transplant recipients and caregivers (17 interviews total).<sup>36</sup> Hand transplant recipients almost unanimously experienced functional gains with a hand transplant that were impossible with the prosthetics they had tried. However, these gains were made *within the parameters of the posttransplant lifestyle* (including restrictions on diet, lifestyle, budget, and freedom to travel in the short- or long-term). How narrators perceived their QoL pre- and posttransplant depended on several factors, including whether their personal conception of the value of the HTx process evolved with their experiences. Far from the straightforward, ostensibly objective accounting of outcomes of HTx reported in medical journals, the oral history interviews I collected with HTx patients and their caregivers paint a much more complex and deeply human picture of "success."

I argue in closing this essay that short- and long-term QoL trade-offs for HTx and VCA more generally are not yet well understood, especially given the impact of managed complications on QoL for patients receiving these types of grafts. Because

VCA is focused primarily on improving recipients' QoL though such gains are attended by significant risks and long-term challenges, broadening the question of success to include VCA patients' self-reported experiences of (dis)ability and the ongoing construction of their identity—along with insights generated by tests of kidney function and hand strength-motility, for example—would seemingly be appropriate to discussion of the ethicality and value of reconstructive transplantation. Insights from patients' perspectives are needed if the field of VCA is to develop [person-centered knowledge](#) of the effectiveness of different research protocols and the large-scale impact of these surgeries on participants' lives.

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#### **Editor's Note**

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#### **Conflict of Interest Disclosure**

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