

## MEDICINE AND SOCIETY

### What Hand Transplantation Teaches Us About Embodiment

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#### Abstract

While stakeholders in hand transplantation (HTx) recognize the importance of assessing quality of life (QoL), QoL has historically been inadequately defined and measured in such assessment procedures. Current conversations related to QoL in HTx could be enhanced by a phenomenological account of the lived body—namely, by illuminating the ways in which humans develop a holistic QoL through meaningful orientation in their interactions with the world and others. This meaningful orientation involves many factors; this essay considers how QoL is shaped by temporality (how past and future inform present satisfaction), embodiment (habituated, generally unconscious, meaningful attunement to the world), and intersubjectivity (how our identity as selves is constructed through social relationships).

#### Hands-on Phenomenology

Stakeholders in vascularized composite allotransplantation—specifically, hand transplantation (HTx)—acknowledge that standard assessment of quality of life (QoL) and providing long-term enhancement of QoL to hand transplant recipients is essential for the future of HTx.<sup>1,2</sup> However, there is ongoing debate regarding how QoL is to be defined and measured in such assessment procedures and, furthermore, how assessments can be standardized across the unique circumstances of individual transplant recipients.<sup>2,3</sup> Concerns over how to assess QoL are magnified by the tendency among stakeholders and the media to overemphasize cases that have been particularly successful and without incident.<sup>2,3</sup> For example, the website for the Louisville program<sup>4</sup> provides links to the success stories of its 10 HTx patients but does not mention that one recipient completed suicide, 2 have had their hand transplants removed, or that another feels that his hand transplant is effectively useless.<sup>2,3</sup> Furthermore, current tools that are used to track the progress of HTx patients (Carroll; Disabilities of the Arm, Shoulder and Hand, or DASH; and Hand Transplantation Score System, or HTSS, which still needs validation<sup>1,5</sup>) are primarily concerned with functionality of the hand and lack adequate metrics for evaluating QoL.

Current QoL assessments of hand transplant recipients fail to appreciate how our habituated, multifaceted, and generally unconscious facilitation of our

hands provides a familiarity with and attunement to the world that shapes how we comport ourselves toward objects and create meaningful human experience. This article argues that current conversations related to QoL in HTx could be enhanced by the phenomenological method, which insightfully highlights how humans establish a meaningful orientation toward the world. Phenomenology, developed by Edmund Husserl, argues that a descriptive, first-person account of our lived experience can produce essential features about human existence. Phenomenology investigates how humans encounter the world in the immediate and primary modes of being, in contrast to scientific investigation, which is a derivative and secondary activity compared to our everyday being-in-the-world.

One salient observation phenomenologists have stressed is that humans are meaning makers. Martin Heidegger observes that what seems to make humans unique is our thoroughgoing concern to make meaning of our existence, make meaning of our circumstances, and illuminate meaning in our world.<sup>6</sup> Furthermore, phenomenologists observe that we always already expect the world and our experiences to be meaningful. We perceive the world and others within a meaningful orientation, structure,<sup>7</sup> milieu, or directionality<sup>8</sup> that tends toward significance.

This capacity for meaning making is essential for understanding and defining QoL. For example, when one hand transplant recipient “wakes each day to two transplanted hands that he feels are utterly useless,”<sup>3</sup> such uselessness is not merely about function but about meaningfulness. His hands are useless because their presence makes no sense, provides no orientation in his daily life. The phenomenological method has produced extensive insight into how humans interpret meaning and what QoL entails, especially with regard to 3 categories: how humans make meaning from their physical spatiality in the world (embodiment), from their experience of and orientation toward time (temporality), and from their sense of identity and purpose constructed through relating to others (intersubjectivity).

### **Temporality**

Making meaning is only possible because a present moment retains elements of the past and anticipates the future. Heidegger suggests that humans are primarily oriented toward the future, or Being-ahead-of-itself.<sup>6</sup> Consider, for example, how often you are compiling a to-do list in your head while walking, driving, or sitting. More positively, humans find meaning through the imaginative creation of future possibility. We lose all sense of meaningfulness if we sense ourselves to be incapable of imagining new goals or creating new possibilities.

Temporality is critical for evaluating QoL. It illuminates the fact that, by its very nature, QoL is comparative and ongoing. QoL cannot be measured in a discrete moment; it requires an evaluation of the past and future. For example, the first

hand transplant recipient of the Pittsburgh program initially had a “successful” HTx. In 2009, not long after his transplant, his new hand provided him a positive futural orientation. One reporter asked the hand transplant recipient, “What do you see in this different future?” He responded, “The same future I saw before I got hurt. I don’t feel broken anymore.”<sup>9</sup> However, when he requested the removal of his transplanted hand in 2013, he perceived the hand as inhibiting the meaningful future he had imagined—of becoming a mechanic and spending his time differently than driving to hospital visits and undergoing therapy.<sup>10</sup> Similar **narratives** have been shared by at least 3 separate hand transplant recipients who did not or could not imagine a meaningful future.<sup>2,3</sup> If a recipient’s QoL goals or future desires dramatically change over time, when can one say whether an HTx was successful?

Temporality adds a qualitative element to quantitative metrics of hand functionality. On average, hand transplant recipients in France have achieved 69% functionality in dominant hands and 55% functionality in nondominant hands, based on Carroll scores.<sup>1</sup> But percentages alone fail to capture whether such functionality translates into a sense of meaningfulness. Furthermore, there is no clear relation between degree of functionality and individual satisfaction with hand transplants. For example, one hand transplant recipient reported that he is quite happy with his hand transplant, yet he only has 55% functionality compared to his original hands.<sup>11</sup> Doctors predicted the first hand transplant recipient in the Pittsburgh program would regain about 65% functionality in his hand, and he initially exceeded that; however, despite that quantitative measure of achievement, 4 years later he still chose to have the transplanted hand removed.<sup>10</sup> Another hand transplant recipient, deeply dissatisfied with his hand transplant, reported that years of weekly sessions and grueling physical therapy could yield only 50% to 55% functionality.<sup>2</sup> And yet another patient completed suicide because the functionality of his hand transplant failed to afford him renewed life “purpose.”<sup>2</sup> If patients’ hand functionality plateaus, proves limiting, or fails to meet their expectations, patients have difficulty creating meaning out of their circumstances as their future possibilities become diminished.

### **Embodiment**

As humans, our encounter with the world is thoroughly embodied. René Descartes claimed that the body is merely a machine that does whatever the mind tells it to do and that thinking is a task distinct from the body.<sup>12</sup> For Maurice Merleau-Ponty, however, I do not merely have a body; I am my body.<sup>7</sup> My perception of the world is situated by the physicality I inhabit. A growing body of research suggests that cognition itself is embodied and extended. Within this framework, much of what qualifies as *thinking* is not merely brain function; our bodies are part and parcel of the process.<sup>13</sup> Thinking is full-bodied and multidirectional, a continual body-brain feedback loop.<sup>14</sup> Memory and trauma are stored in the physical body.<sup>15</sup> The habituated and unconscious activities we perform throughout the day without thinking reflect a form of

body intelligence or embodied know-how, suggesting that the body is as “smart” as the brain.<sup>16</sup>

Embodiment is essential in QoL discussions. We don't just have hands like we have a tool; we identify with them, and seeing a transplanted hand as part of oneself is critical.<sup>3</sup> With our hands, we extend our thinking into space and illuminate both ourselves and the world. Common references to our hands in figures of speech, as well as the myriad ways we communicate nonverbally and symbolically through hand gestures, suggest how deeply essential our embodiment is for creating meaning and communicating with others. One hand transplant recipient alludes to the profound symbolism of handedness, stating: “There's so many figures of speech and whatnot that relate to our hands and our feet... If you don't have them [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?”<sup>2</sup> Or as Rosemarie Garland-Thomson states, “Hands appear to help us conceptualize our world. Available items are on hand, handy, or in hand.”<sup>17</sup> To heap praise on another, we offer a “thumbs up.” A handshake symbolizes peace, agreement. My friend is “handy” because he can facilitate tools to perform mechanical tasks. We express ourselves with countless hand gestures: pointing, shushing, or a stiff palm meaning, “Stop!” People who use American Sign Language wield not only an entire grammar, syntax, and vocabulary with their hands but also conceptualize an entire world. Similarly, the extent to which hand transplant recipients see their new hand(s) as their own, express themselves by using their hands, and communicate gesturally with others dramatically affects their ability to make meaning of their world. Given the pivotal role hands play in human expression, it is astonishing that none of the assessment tools used for hand transplant recipients ask about gestures.

Embodiment is relevant to QoL for another reason: because our [lived experience](#) is direct and immediate to us, which means it is not captured in assessment tools, many of the ways we create meaning often go unnoticed. We are so adept with our hands that it often takes injuring them for us to fully appreciate them. As Boris Ladwig notes of a Louisville program hand transplant recipient, “Rickelman said people who have two hands don't realize how often they use both hands, from putting on clothes in the morning to eating with knife and fork to operating a mobile phone. ‘It's a two-handed world,’ he said. ‘You say you can (do anything), but you can't.’”<sup>18</sup>

When we are attuned to the world around us, we do not really have to think about our hands and their affordances to achieve daily tasks. Hence, while current metrics for assessing HTx patients evaluate limb functionality and difficulty in performing tasks, they do not quantify the additional mental burdens hand transplant recipients carry that are not manifested in conventional handedness. With conventional handedness, I don't have to think about whether these hands are mine, worry about constant infection, worry

about whether I can do something, worry about whether people will notice the scars, or spend extra time recalling how to shape my hand to perform particular tasks. Hence, the mental exhaustion the task exacts, the extra amount of time that's required to achieve it, and the difficulty in developing the intuitive recall to perform the task are obfuscated or ignored in assessment questions related to difficulty in performing tasks.

### **Intersubjectivity**

Discussion regarding QoL also requires acknowledging intersubjectivity. Phenomenologists highlight that our being-in-the-world and individual identity are thoroughly shaped by our intersocial relationships. We are not autonomous subjects; rather, our sense of self develops within an interwoven array of familial, social, and cultural networks. Emmanuel Levinas stresses that one's subjecthood is not an established fact or foregone conclusion; it is an event realized through one's ethical attunement toward others.<sup>19</sup>

Intersubjectivity has numerous implications for QoL, but given space constraints, I will mention one. Meaning making happens in community, alongside others, with others. Our sense of identity and belonging is developed through relationships. And yet, on my reading of articles on the "success" of HTx, researchers appear to be thoroughly concerned about whether individual hand transplant recipients have achieved independence<sup>5,20,21,22</sup> in tasks like eating or driving—ignoring that these are thoroughly social activities that we regularly perform with or alongside others and that we learn to perform by watching others. While a certain level of autonomy is critical for personal satisfaction, an holistic assessment of QoL requires not only close proximity to hand transplant recipients and an evaluation of what tasks they can perform, but also evaluation of their ability to derive meaning from intersubjective and social encounters as well as ongoing conversations with their support community.

### **More Complete QoL Deliberation**

While discussion regarding defining and assessing QoL in HTx is ongoing, this paper has highlighted factors that are essential to illuminating one's psychosocial health or QoL and that are not currently included in QoL assessment tools. These factors include our capacity to make meaning, particularly in relation to temporality, embodiment, and intersubjectivity. Without attention to these features of the human condition, assessment of hand transplant recipients' functional capacity and psychological sense of satisfaction will remain incomplete.

### **References**

1. Bernardon L, Gazarian A, Petruzzo P, et al. Bilateral hand transplantation: functional benefits assessment in five patients with a mean follow-up of 7.6 years (range 4-13 years). *J Plast Reconstr Aesthet Surg*. 2015;68(9):1171-1183.

2. Herrington ER, Parker LS. Narrative methods for assessing “quality of life” in hand transplantation: five case studies with bioethical commentary. *Med Health Care Philos.* 2019;22(3):407-425.
3. Dobbs D. The devastating allure of medical miracles. *Wired*. February 18, 2019. <https://www.wired.com/story/devastating-allure-of-medical-miracles/>. Accessed April 1, 2019.
4. Hand Transplant Program. Composite tissue allotransplantation. <http://www.handtransplant.com/>. Accessed April 3, 2019.
5. Shores JT, Malek V, Lee WPA, Brandacher G. Outcomes after hand and upper extremity transplantation. *J Mater Sci Mater Med.* 2017;28(5):72.
6. Heidegger M. *Being and Time*. Macquarrie J, Robinson E, trans. New York, NY: Harper & Row; 1962.
7. Merleau-Ponty M. *Phenomenology of Perception*. Smith C, trans. New York, NY: Routledge; 2010.
8. Morris D. *The Sense of Space*. Albany, NY: State University of New York Press; 2004.
9. Andrews W. Experimental hand transplant shows promise. *CBS News*. July 30, 2009. <https://www.cbsnews.com/news/experimental-hand-transplant-shows-promise/>. Accessed March 1, 2019.
10. Defense Lodging. Wounded marine offered bittersweet opportunity. *Defense News*. April 9, 2013. <http://defenselodging.com/marine-corps/wounded-marine-offered-bittersweet-opportunity-categories-corps-connections-features/>. Accessed March 1, 2019.
11. Woolsey E. Nation’s most successful hand transplant recipient marks 20 years since surgery. *WDRB*. March 5, 2019. [https://www.wdrb.com/news/images-nation-s-most-successful-hand-transplant-recipient-marks-years/article\\_8b4193d4-3f5f-11e9-8c96-eb01435578c2.html](https://www.wdrb.com/news/images-nation-s-most-successful-hand-transplant-recipient-marks-years/article_8b4193d4-3f5f-11e9-8c96-eb01435578c2.html). Accessed April 2, 2019.
12. Descartes R. *Meditations on First Philosophy*. Cress D, trans. Indianapolis, IN: Hackett; 1993.
13. Rowlands M. *The New Science of the Mind: From Extended Mind to Embodied Phenomenology*. Cambridge, MA: MIT Press; 2010.
14. Kahneman D. *Thinking, Fast and Slow*. New York, NY: Farrar Straus & Giroux; 2013.
15. van der Kolk BA. *The Body Keeps the Score: Brain, Mind, and Body in the Healing of Trauma*. New York, NY: Viking; 2014.
16. Bahler B. Merleau-Ponty on embodied cognition: a phenomenological interpretation of spinal cord epidural stimulation and paralysis. *Essays Philos.* 2016;17(2):69-93.
17. Garland-Thomson R. *Staring: How We Look*. Oxford, UK: Oxford University Press; 2009.
18. Ladwig B. Transplant recipient stresses need for organ donation. *Insider Louisville*. October 12, 2016. <https://insiderlouisville.com/economy/big-business/transplant-recipient-stresses-need-for-organ-donation/>. Accessed March 2, 2019.

19. Levinas E. *Totality and Infinity*. Lingis A, trans. Pittsburgh, PA: Duquesne University Press; 1969.
20. Jablecki J, Kaczmarzyk L, Domanasiewicz A, et al. Unilateral hand transplant-results after 41 months. *Transplant Proc*. 2013;45(1):440-443.
21. Singh M, Sisk G, Carty M, et al. Functional outcomes after bilateral hand transplantation: a 3.5-year comprehensive follow-up. *Plast Reconstr Surg*. 2016;137(1):185-189.
22. Singh M, Oser M, Zinser J, et al. Psychosocial outcomes after bilateral hand transplantation. *Plast Reconstr Surg Glob Open*. 2015;3(10):e533.

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