

Radical Revealing of Cognitive Dissonance in Transplant Participants

El-Sheikh, Tammer (ed.) 2020. *Entangled Bodies: Art, Identity and Intercorporeality*. Vernon Press Series in Sociology: York University. (213 pages)

ENTANGLED BODIES: ART, Identity and Intercorporeality is the long-awaited scholastic culmination of nearly two decades of international interdisciplinary collaboration between artists, humanities scholars, medical scientists and psychiatric researchers. The book endeavours to represent as fully as possible the lived experience of those most intimately impacted by organ transplantation: transplant recipients and donor families. The anthology's seamlessly interconnected accounts of the biggest philosophical issues with prevailing cultural narratives attached to heart transplantation belie just how radical the insights in the work are. Philosophically, everything from the singular notion of human selfhood to the efficacy of demarcated intellectual disciplines for an accurate understanding of lived reality is questioned and upturned. Stitching together the book are an assemblage of the following themes: repair, brokenness, imperfection, cure, care, sameness and difference, consent, representation, replacement, space, identity and hybridity. The collaborators' radical guiding principle of encouraging emotional vulnerability is best

expressed through the fundamental question which the anthology is centred upon: “How does it feel to be a heart transplant recipient [and donor family] ?”(2020: 5).

The most important insight which emerges from the *Entangled Bodies* book is the discovery of the deep cognitive dissonance which transplant participants experience. The team’s innovative practice of using visually-coded interviews, in contrast to the normative practice of using audio only interviews, reveals the incongruencies between words spoken in the voice of the Clinic and expressed through the body of the transplant participant interviewee. The overwhelmingly positive words spoken, when placed beside the equally frequent occurrences of bodily affect indicating distress, are shown to indicate a shocking difference between authorised narratives and lived experiences. These disjuncts would have been missed completely without the study’s unique method for data collection. While previous quality of life studies report that only a fifth of transplant participants report distress in traditional questionnaire measurements of wellbeing, when body language was analysed “over 80% showed negative affect” (62). This reveals that the scale of emotional complexity – indeed suffering – following transplantation has been vastly underestimated. *Entangled Bodies* suggests this is likely the norm rather than the exception, and that this finding is, for all involved and any witnesses: “heartbreaking” (104). Furthermore, the veracity of most conventional qualitative studies which typically omit the visual aspect of interviews, is at stake with the *Entangled Bodies* teams’ validation that the body is an essential source of knowledge of lived experience. The various moving and poetic representations of the recipient and donor family interviews throughout the anthology make it clear that transplant centres need to more accurately understand the complexity of participants’ lived experience, in order to facilitate the best possible outcomes for psychological wellbeing.

The global pandemic of 2020 has put biopolitics and the need for mass understanding of medical ethics centre stage. Given this, Donna McCormack’s utilisation of imaginaries otherwise usually drawn upon to minimise the reality of immunological medical complexity post-trans-

plant by the promise of greater biotechnological mastery as a psychological salve, is brilliant. We learn that with transplantation – like with many cultural artefacts which are emblematic of human ingenuity and achievement – the default cultural approach is to undermine, avoid and subtly argue against the existence of both good and bad within the lived experience. McCormack, as well as other contributors' demonstrations of how the artistic and the scientific, as well as fact and fiction, are intrinsically intertwined, allows for a palatable facing of ethical and emotional complexity. They make possible the dissemination of otherwise potentially taboo lived experiences, such as how "care may be a form of violence" (172).

The anthology predominantly refers to a "white" lived experience of transplantation. One of the book's contributors, Jennifer Poole, critiques the team's methodology using critical race theory. This lays bare the need for the hidden voices of black, indigenous and other non-white people to be uniquely understood and represented within future research as researchers and interview participants. The omission of direct engagement with the lived experience of transplants which happen through human trafficking, save for Margrit Shildrick's reference to it as an "uncomfortable spectre," (60) highlights it as a taboo topic which also requires further exploration. By comparison, the only other interdisciplinary transplant anthology that seems to exist – a 2012 Scandinavian-Baltic collection edited by Martin Gunnarson and Fredrik Svenaeus – boldly includes an account from a kidney transplant recipient who procured transplantation by illegitimate means. Neither collection explores the unique kinds of lived experiences of transgender and queer transplant participants; transplantation medico-culturally contains assumptions of cis-ness, despite being a medical process which more than most kinds, navigates the realm of hybridity.

Yet, these critiques on the grounds of inclusivity ought not overall detract from the unprecedented achievement of the *Entangled Bodies* anthology in mapping the terrain of conceptual complexity with transplantation. All contributors rocked the professional boat in pushing, indeed crossing, intellectual boundaries whilst simultaneously being bound by

institutional limits which sought to reinforce traditional divisions between emotions, intellectual concepts, and biomedical transformation.

The *Entangled Bodies* team's recognition of transplant participants' body language and feeling impressions as valuable markers of quality of life generates a radical rethinking of assumptions which the culturally predominant account of transplantation propagates. The cognitive dissonance that arises between transplant participants' expectation and reality is uncovered by the body itself. When "listened to" – *seen* – via visually recorded interviews, the faculty of feeling is a litmus test for checking conceptual coherency. It becomes visible when exhaltation of gratitude are accompanied by despairing tones, tearful shaking, and stiltedness, that the transplant participant's body contradicts the(ir) mind's exclusively positive representations of transplantation. Another way of articulating this, is that the intellectual artistry which knows how to stitch tissue and compartmentalize trauma by anaesthetization is insufficient for psychological recovery. Indeed, a more holistic approach, with acknowledgement of the inevitable feelings of loss, grief, and frustration which accompany transplantation – where the faculty of feeling and the language of the body are embraced – is necessary for more effectively understanding transplant lived experience.

Fascinatingly, embracing of feeling must occur in the researchers themselves – affect must effect – to enable the uncovering of hidden signals of distress which otherwise would have been missed : "the team absorb[ed] entire seas of pain" (117). This methodological practice contests the prevailing view that feeling obscures knowledge and goes far beyond the field of transplantation. The *Entangled Bodies* team teach us that in order to make leaps in our understanding, in particular our understanding of the psychological wellbeing of patients, researchers have to be willing to be transformed by what they encounter in order to transcend their disciplinary and cultural blind spots. The anthology teaches us that the idealised "scientific" approach, where objects of study are separated from the observers, does not generate the supposedly pristine contemplative icons for frozen display in our cultural chest of curiosities. Separation creates only illusions of fixed

understanding; *fata morganas* of drying up pools of water which reflect only the ideals of the observer. Only by being receptive to our own transformation can we facilitate the transformation of our understanding of others.

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REFERENCES

Gunnarson, Martin & Fredrik Svenaeus, (eds.), 2012. *The Body As Gift, Resource, and Commodity: Exchanging Organs, Tissues, and Cells in the 21st Century*. Stockholm: Södertörn Studies in Practical Knowledge.