

Body Shock: Unsettling the Biosciences Through Postconventional Materialities

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Abstract:

The focus of this article is the problematic of data in the life sciences with regard to the supposedly singular event of heart transplantation. In mainstream discourse, organ transplantation is seen as a straightforward exchange of body parts in which fatally deteriorating biological elements are replaced by more competent and enduring components. Post-transplant a variety of biological, immunological, and pharmaceutical data are collected and evaluated, with the success of the operation gauged against the clinical recovery of the recipient as determined by those measures. That simple picture fails to attend, however, to issues such as the historical-cultural context of the biomedical procedure, temporality, the phenomenological sense of self, the psycho-social imaginary, and even disregarded biological dimensions such as cellular microchimerism, all of which can deeply unsettle biomedical certainty. Drawing on my own participation in collaborative research, I rethink what counts as data and demonstrate the need to interweave multiple forms of knowledge in a data assemblage that mobilises new insights into the significance of transplantation and concorporeality.

Keywords: transplantation; hybridity; Deleuze; data assemblage; bioscience.

Introduction

The issue of how to accumulate, process, and interpret data occupies a privileged position in research environments where the influence of effectively positivist methodologies is seldom challenged, and the

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underlying question of what exactly constitutes data is rarely asked. In the social sciences, there has been sporadic progress over the last few decades to the extent that empirical research has developed – and sometimes engages with – self-critique, but in the life sciences there has been little change and in some arenas evidence-based methodologies firmly represent the gold standard. In this article I shall take a critical view of the problematic of data, addressing the field of biomedicine and paying particular regard to the somatechnics of heart transplantation.

In mainstream biomedical discourse, organ transplantation is seen as a straightforward exchange of body parts in which fatally deteriorating biological elements are replaced by more competent and enduring components. The familiar public picture of heroic medicine seemingly interrupting imminent death, not simply by prolonging lives but by restoring recipients to their former selves, is not, of course, quite as straightforward as the authorised narrative would have us believe. Rather the illusion of biomedical certainty may be radically disrupted by attending to issues such as the historico-cultural context, temporality, the phenomenological sense of self, the psycho-social imaginary, and even disregarded biological dimensions such as cellular microchimerism, none of which is customarily addressed in the data. Drawing on my own participation in collaborative research into heart transplantation – a project now in its 13th year – I problematize what counts as data and demonstrate the need to interweave multiple forms of knowledge in a mutually constitutive research assemblage in which no one element can claim priority, even though the fluctuating nature of what comes together ensures that relative attention may shift between elements. The potential is to mobilise new insights into both our understanding of post-operative outcomes and the significance of transplantation and concorporeality.

The *PITH* project (the Process of Incorporating a Transplanted Heart)¹ was originally conceived as a phenomenological enquiry by a multidisciplinary team of medical practitioners, social scientists, philosophers, and artists into the experience of heart recipients with the aim of testing the proposition that the shock of the bodily transformations of transplantation might invoke psychic disruption to the recipients' sense of self. Over the years the project has evolved in multiple directions, taking in the import of the hopes and uncertainties of being on a waiting list, the issue of prostheses through the use of so-called artificial hearts (technically known as LVADs, i.e. left ventricular assist devices), and most recently the experience of donor families. What follows is mostly grounded in the initial research plan, which over time revealed its limitations but more importantly generated its own productive excess.

The aim was to more adequately understand the phenomenological and existential implications of transplantation for recipients themselves by eliciting their own narratives around what it means on a personal level to incorporate an organic prosthesis, or experience the body as hybrid. Unlike some other organs, the procedure of heart transplantation is not put into operation until the intended recipient is already in end-stage heart failure, so there is no question that the intervention, if successful, is life-saving. Following a pre-op evaluation of their medical suitability and a fairly cursory assessment of psychological fitness, recipients are heavily monitored in subsequent years during which biological, immunological, and pharmaceutical data are collected and measured, with the success of the operation gauged against the clinical recovery of the recipient as determined by those data. If, as is most usually the case, the recipient survives the first year, then on average s/he may expect to live for another fourteen years. Our team engaged with recipients between one and ten years post-transplant when anxiety about death is likely to be at its least cogent. For all its publicly avowed success as a life-saving medical procedure, heart transplantation is nonetheless haunted by questions that cannot be addressed by conventionally based research data, but which give rise to cultural phenomena around the transfer of identities.² In short, a current of anxiety continuously disrupts both the reassuring competencies of clinical practice and the public approbation of death deferred.

Following an initial and purely speculative theoretical paper, guided by the philosopher, that raised the issue of hybrid identities (Shildrick et al. 2009), the major methodology adopted by the research team, was to video record interviews with a cohort of twenty-five recipients in such a way as to capture not simply their words and – importantly from a phenomenological point of view – their gestures, but also the embodied presence of the interviewer. It took many months to receive approval from the relevant research ethics board – mainly around the issue of the confidentiality of visual records – making us all painfully aware of how formalised and closed to innovation the process has become. As is standard we were forced to provide a putatively rigid research plan with extensive cross-referencing to other published research even though what we were attempting to do was already highly novel within the specific field. We dutifully followed protocol and carefully laid out a set of questions and elaborated the means (including use of NVivo8) by which we would analyse our material. The problem is that if followed strictly, the format imposed – in staying within pre-established normative standards – would be unable to yield radically new insights or produce different forms of knowledge. As Alecia Jackson and Lisa Mazzei

note: ‘Coding takes us back to what is known, not only to the experience of our participants but also to our own experience as well. ... codes might cause us to miss the texture, the contradictions, the tensions’ (2012: 12). Moreover, the convention assumed that the verbal exchange was primary, and that the data collected could be reduced to codes and themes (St Pierre 2014; St Pierre & Jackson 2014) as though it were a simple matter of collating transparent narratives. Given that the REB was hospital-based, that health issues are seen as particularly sensitive, and that many on the team had never previously stepped outside the normative demands of biomedical research, it was a relief to end up with an approval that allowed for some flexibility. Our findings, which I’ll briefly outline later, were startling, even shocking to the team clinicians, but my concern in this article focuses on the *process* that constitutes a data assemblage, not least when it emerges and transmutes from highly diverse inputs over an extended period of time. And as I understand it, the notion of a research assemblage operated in at least two different ways. The data element only makes sense not as a given (done and ready to be dusted) but as performance, and it is there that it imbricates and folds into the assemblage that constituted the team itself.

The *PITH* project was conceived in conversation between a cardiologist, a social scientist, and a philosopher, and quickly grew to encompass another social scientist, a psychiatrist, two nurse-trained interviewers, and four artists, with other participants joining and leaving throughout.³ It was right from the start a somatechnical enterprise in which we intended to explore the complexities of heart transplantation by explicitly entangling research from the arts, biosciences, and humanities without privileging any one methodology or discourse as the fixed point of concern. The common ground initially was no more than an openness to new ideas and a differential fascination with the question of identity in heart transplantation, which for the clinicians was inexpressible in their professional milieu. Rather than allow the putative boundaries between biology and culture to limit our objectives, we wanted to ‘celebrate and develop ... imaginative and creative heterodox qualities and practices’ (Viney et al. 2015: 4). There were inevitable tensions and some mistrust around our decidedly varied expectations of what research would look like, but it has also been highly productive of new insights into both the significance of heart transplantation and the demanding process of close collaboration (Shildrick, Carnie, Wright et al. 2017). Clearly our varying expectations and preferences regarding what counts as data reflects both our own status/condition as an alliance of researchers – coming together, breaking apart – and the task of settling on a fuller understanding of the problematic of heart donation and

transfer. Now some years on, it is perhaps an indication of the success of our collaboration that we have agreed to borrow the term ‘assemblage’ from Gilles Deleuze and Félix Guattari (1987)⁴ and deploy the expression ‘research assemblage’ to circumscribe all the materials – including ourselves – that we bring to our project.

Data in the Life and Social Sciences

Before laying out more specifics of the research project, I want to consider what is meant by data in the life sciences and why we might need to get our hands dirty. In general terms, data are sets of quantitative or, less frequently qualitative, variables that have been extracted, collated, and quantified. As part of the process, information that is identified as relevant in the operative context is represented or coded – typically in graphs, charts, flow diagrams, macro-databases – in a form that enables further usage and (usually statistical) evaluation. In the form of big data, the aim is to reach saturation that eliminates differences and yields instead categories of sameness, so the bigger the input the greater the reliability. Barring unexpected contamination, data in the biosciences are assumed to be neutral givens, even brute ‘facts’ – supposedly gathered without interference such as observer bias – that provide self-evident veracities or lend themselves to confident interpretations that provide new extensions of existing knowledge. The idea that knowledge production is constitutively partial and ambiguous, contextually situated, and temporally specific – all familiar notions in postconventional theory (Jackson & Mazzei 2012; Gitelman & Jackson 2013) – is unthought for many researchers, and what characterises published articles in bioscientific journals is usually detailed description, but sparse analysis or consideration of the implications of findings. As I have outlined elsewhere (Shildrick et al. 2017), and aside from a few, often feminist, researchers such as Donna Haraway (developmental biology), Gillian Einstein (neuroscience), and Diana Bianchi (genetics and neonatology), there is little interest in flagging up inherent (as opposed to accidental) uncertainties, or indeed in any interpretative commentary – still less in speculation. All that counts as credible in the reporting of data are the design of the acquisition process, the observations and the measurements. In the desire to protect the putative purity of the data, and prevent contamination from extraneous inputs, the explication of how they have been collected and how different elements fit together is considered a necessity, but the question of what it all means, the other factors with which they may interact (what Karen Barad calls ‘reading insights through one another’ 2007), or the wider

significance are rarely broached within mainstream research in the life sciences.

There is, of course, a danger of unfairly stereotyping the process as though data gathering in biomedicine just is of less value than the methodologies used in the humanities. The normative standards of data-driven bioscientific research, and particularly when it is reliant on quantitative methodologies, are often anathema to many researchers with a background – as is my own – in the arts and humanities, but I do not want to suggest they do not have a part to play. Indeed, the preference of social scientists for qualitative data is scarcely less limited. Conventional approaches in the social sciences are marked by a grounding assumption of the integrity of the subject, and of the stability of interpretation and of categories themselves (St Pierre, Jackson & Mazzei 2014). Rather than acknowledge that specific ontological and epistemological beliefs from multiple sources can feed into and influence data output, such disruptive aspects are disregarded in favour of a static and unvaried notion of an evidential reality. Moreover, the focus rarely goes beyond the human to consider the influence of non-humans, both organic and inorganic (Nordström 2017), although science and technology studies, environmental studies and feminist new materialism are moving away from that limitation. The point is that data can never be clean and proper, an aspect tacitly acknowledged by any research that makes prior choices. These may be centred on what constitutes necessary and sufficient data sets, the boundaries of inclusion, the location and temporal frame of collection, and the methodology employed, but also extend through to any consideration of the disciplinary expectations of an audience, or the research standards of favoured journals, and so on. If we really want to produce knowledge of value then we must start by acknowledging the impossibility of keeping our hands clean, by accepting uncertainty, and recognizing that data does not provide any once and for all answer to research questions but is part of a changing and changeable process. As Susan Squier puts it: ‘the material objects scientists study are really processes, always changing in response to their surroundings, on micro and macro levels, and always in turn changing them’ (2013: 6). Moreover, far from being disinterested researchers, we all inevitably come with baggage, bringing to data collection a mostly unacknowledged array of ‘preconceptions, theoretical biases, personal experiences, and spatio-temporal situatedness even before accessing any of the putative “raw” material’ (Shildrick et al. 2017). All of these considerations played out in the *PITH* research and its later offshoots.

A further major consideration in empirical research involving human respondents concerns the putative ‘truth’ of their own accounts.

The convention persists that respondents are both transparent to themselves and reliable witnesses, and that that their words can be taken as unproblematic facts. In the specific context of the *PITH* project it was clear from the start that even in the open approach adopted by the two interviewers, the data collected was deeply shaped by the existing *biomedical* narratives around heart transplantation that almost universally view the procedure as a biomedical success and a personal and social good. Death from heart failure is very common in the global north and those over the age of forty have a one in five lifetime chance of developing the condition. Twenty-five to 40% of those who are diagnosed will die within the first year – often by effectively drowning in their own congestive fluids. For such patients, transplantation is a way to prolong life, and regain the semblance of health by easing breathing and possibly returning to work. According to standard quantitative measures, recipients do flourish, with 90% reporting no breathing limitation after transplant such that at an unproblematised level, heart transplantation is a highly effective life-saving treatment. So far, so factual: these are the kind of non-contentious data that secure continued funding for both research and surgery, confirming biomedicine's own sense of success and assuring politicians and the public of the value of the procedures. Yet the heart is not simply bloody muscular tissue to be cut from the body at will, but carries with it a whole host of spiritual, religious, and sentimental connotations. The details of anatomical functionality – which are just one arm of the biomedical narrative – are overlain with all sorts of symbolic meanings and finally the sense that the heart is the core of human selfhood and personal identity. The narratives of heart transplantation, both biomedical and lay, demonstrate a strange, even contradictory, conjunction of discourses that, on the one hand, emphasize a symbolic significance that eludes bioscientific explanation and, on the other, celebrates the apparent mastery of our capacity to intrude at will into the human body. Nonetheless, to the extent that all complex surgery remains a mystery to the lay public, patients are generally content to accept the claims of heroic medicine that our fragile, disorganised and diseased bodies can be restored to well-being by the intervention of highly skilled experts. Failures in the procedure do occur, and in my own limited experience are deeply felt by clinical staff, but there is little recognition that positive biomedical outcomes constitute only one element of what might count as success. The popular view is that heart transplantation is an intervention with certain relatively small biomedical risks (ones hugely outweighed by the certainty of death for those with end-stage heart failure), but no existential consequences. Yet for all its avowed success, contemporary heart transplantation continues to be haunted by

questions that cannot be addressed by conventional data: there is always a current of anxiety that in various ways breaks through both the reassuring competencies of the clinic and the surface gloss of heroic medicine.

In the *PITH* approach, the recipients' own video and audio recorded narratives were frequently ambivalent (Abbey et al. 2011) but however much they verbally repeated the positivist authorized narrative of the clinic, most interviewees also displayed significant distress in their body language – such as slumped posture, agitated hand gestures, and, above all, tearfulness – about the experience of incorporating the donor organ. Without doubt, the team's interpretation was subjective and culturally constrained by our own range of affiliations, but despite some disagreements about exactly what was being conveyed, the very evident visual distress of the respondents added an important layer to our data assemblage. In many jurisdictions, information relating to the provenance of the transplant organ including the donor's age, gender, sexual preferences, or ethnicity is withheld, yet many recipients expressed strong connections to the donor both through the ubiquitous gift of life discourse that dominates transplant transactions (Shildrick 2012; Shildrick et al. 2017), and through a sense of the hybridity of their new embodiment. Though it is rarely spelled out to recipients, the DNA of the donor heart remains *in situ* for life and may also circulate in the peripheral blood supply. Despite encouragement to own their 'new' organs and see them as simply spare parts, a high proportion of recipients were fully aware of the phenomenon of transferred identity that haunts popular discourse on transplantation, although most distanced themselves from such beliefs by giving proxy accounts. While the cultural hype is widely dismissed and certainly not recognised as research data, what engaged the recipients was not the dry scientific data, but films like *21 Grams* (2003), *Heart of a Stranger* (2002), *Blood Work* (2002) or *Return to Me* (2000), or the novel *Change of Heart* (2008), which gave voice to cultural anxieties about organ transplantation. So long as the transplant is medically successful, the emotional and psychic responses of recipients typically remain hidden and unspoken, but came tumbling out, both consciously and unconsciously, once the research methodology allowed it to do so.

Novel Methodologies

The initial motivation for the *PITH* project was to investigate through a phenomenological approach whether heart recipients are likely to experience psychic disruption to their sense of self as a result of their bodily transformation, to ask what it means to incorporate an organic

prosthesis, or to experience the body as hybrid. From the start it was clear that even where we used the conventional social sciences route for qualitative research that data would never be enough, and there would be nothing 'clean' about any of it. Each semi-structured interview with recipients lasted on average between 90 minutes to 2 hours and was video-recorded. As we understand it, the recipient narrative emerges not just verbally, but through the body itself, and even through contextual artefacts. As Christian Heath notes: 'Through gesture, bodily comportment and talk, they render visible what would otherwise remain hidden and unavailable for inspection' (2002: 615). Because we understand the production of knowledge as an intermeshed and fully embodied somatechnical enterprise, we also wanted to catch the bodily encounter between the researchers and participants, and any other incidental visitors, such as family members and pets, as well as non-living material. The two highly experienced interviewers always prioritised the respondent's experience but were not compelled to position themselves as neutral and hide their own feelings as interactive research usually demands (Shaw 2011). The whole team watched the videos together at least twice, and individually many more times, and the data was coded (with some misgivings)⁵ using NVivo8 software to kickstart analysis. This sounds like a conventional way to deal with data, but with the difference that our own emotions played a part in the process, and there was no pretence of objectivity (Thoresen & Öhlén 2015). It was far from unusual for us to be moved to tears watching the videos, or to engage in a perverse humour to offset the emotional intensity of the experience. The group discussions and analysis of the videos – each usually occupying half a day – were highly productive in their cross-cutting interests and disruptions. Whatever the nature of the recorded material, we were working with and as a data assemblage.

Many metaphors could describe our kaleidoscopic working practices, but it is the Deleuzian term 'assemblage' that most closely expresses the dynamic process of not just simply creating new patterns but of recognising that each element fluctuates in its importance. New conjunctions form and disperse even as they are explored, just as the experience of heart transplant can never be pinned down. The elements of a data assemblage do not merge, but remain in flux, profoundly disrupting expected singularities, as reflected in much of the digital art work that contributed to the project. As Deleuze and Guattari note:

On the one hand it is a *machinic assemblage* of bodies, of actions and passions, and intermingling of bodies reacting to one another; on the other hand it is a *collective assemblage of enunciation*, of acts and statements, of incorporeal transformations attributed to bodies. (1987: 88, original emphasis)

In the Deleuzian mode, what matters is not the ‘content’ of any particular assemblage but the provisional moments of insight – this is how it works – that emerge from the intermeshing of multiple forces. The point – which is widely endorsed in art and postmodernist philosophy, less so in the social sciences, and is remarkably absent in the context of bioscience – is not to aim for definitive answers to research inquiries so much as to generate new questions. This is not to say that some of the medical questions around transplantation did not invoke decisive answers, but they were just one part of the assemblage, not its primary force. As we understood the research process, imposing strict methodological categories in the expectation of generating unambiguous answers would greatly limit the productive possibilities. The most creative approach in the life sciences, as elsewhere, is likely to be inherently messy and never finalised, generating constantly new questions that are as nomadic and slippery as the living matter they investigate. In embracing both philosophical and sociological enquiry, together with bio-medical investigation and visual explorations, we were able to embrace a non-reductive style reliant on different perspectives that rather than being oppositional or simply adopted in parallel, offered a conjoined approach. Going beyond the ‘and...and...and’ model of mixed methods, each perspective lost its singularity and became interwoven – and certainly impure – on an ad hoc basis. Undoubtedly there were instances of discordances, discomfort, and doubt, but this is what a research assemblage looks like. As the team worked through the issues of organ transplantation each member brought a particular expertise but was willing to respond to and incorporate novel materials and methodologies.

In the light of our interdisciplinary entanglement of ideas, voices, images, agreements, and disagreements that cut across status and hierarchies, what exactly was the group working with that generated the commitment to data assemblage? One major factor was that the videos themselves demonstrated that 80% of the respondents had very significant forms of distress, far in excess of what is traditionally cited in heart transplant literature. And interestingly this was a clear-cut example of where a quantitative look at our results provided a richer appreciation of what we had uncovered. There were high levels of guilt, fear, and anxiety regarding their relationship with both deceased donors and donor families, and about themselves. None of this would be apparent in standard biometric tests: Mary Dew et al. (2005), for example, used a self-report checklist to identify substantial distress in just 33% of their sample. Despite the degree of distress and dysphoria that we encountered, all the interviewees were regarded as medically

and psychologically stable in terms of pre-transplant psycho-social assessments and post-transplant clinic follow-up. Our own figures were so unexpectedly high that for methodological comparison, we also measured our respondents on the quantitative Atkinson Scale – a standard health-related Quality of Life instrument – where they duly scored *satisfaction* levels over 70%, close to the international average (see Abbey et al. 2011). Obviously the qualitative and quantitative data yielded completely opposing results. Interestingly it was the transplant cardiologist and psychiatrist on the team who were most shocked by what they were learning of the recipients' hidden distress which seemed beyond words. Our conclusion was that the standard opening question in post-transplant clinic consults – 'How are you?' – would invariably be met by recipients adopting the authorised discourses of the clinic to simply list the ups and downs of their physical markers of recovery – breathing, pulse rate, weight, antigen levels, medication compliance etc. – that the medical professionals relied on to monitor recovery. Yet whenever I – a non-medical outsider – was alone with them, a different discourse emerged, and many would start to tell me about their mood, anxieties, changed preferences, and the like, of which the professionals heard nothing.⁶ Similarly, even in interview encounters, body language indicated high levels of existential disruption that words alone did not convey.

Fuller considerations of our findings have been published elsewhere,⁷ so I will briefly summarise here. The issue is that the heart recipients in our study – as typical modernist subjects – enter into the procedure expecting to be restored to their former selves and have little anticipation of the changes they will encounter.⁸ Even if we put aside the phenomenological understanding of the self as coming into being through embodiment, and thus having no fixed originary self to recover, in the case of transplant the materiality of the body is not only prosthetised, but also becomes irreducibly hybrid for life. In biomedical terms specifically, the donor's DNA, present in the transplanted heart, represents an alien other literally at the heart of the self. The new form of embodiment is irreducibly hybrid, but not as an integrated and comfortable new whole. Instead, in the metaphorical understanding of traditional immunology the recipient's immune system goes on incessantly trying to reject the alien invader, but with the twist that that intrusive material is in fact keeping the embodied self alive. It is difficult to see how any recipient could be expected to effortlessly negotiate the conundrum and regard their 'new' organs as unexceptional. What the *PITH* study shows is that most recipients do want to express their unfamiliar embodied experiences, and many are very invested in

knowing or guessing the personal characteristics of their donors precisely because they feel that some characteristics will carry over. It matters not at all whether such reports are 'true' in the sense that the transplant has indeed caused such a change – what matters is that recipients *report* such phenomenological changes and attribute them to the graft. It was not simply the physical difficulty of integrating organs that causes dysphoria in recipients but ontological anxieties in relation to the donor, to their own identities, or to both (Shildrick et al. 2009). Even recipients who overtly hold on to a rigid machine model of the body and reject any thought of a personal connection, are highly likely to show distress, anxiety, and disturbance in their bodily comportment. In other words, beyond the *surface* expression, we are able to show that the vast majority of recipients do, in fact, experience a significant degree of ontological unease. It was not our purpose to privilege one mode above the other but demonstrate the complexity of all the elements that constitute a research assemblage. Altogether seventeen of the twenty-five respondents showed some adherence to the mechanistic vocabulary of pumps and spare parts, but fourteen of those 'common sense' accounts also referred to the heart in emotive terms. Few recipients actually regarded the heart of the deceased donor as merely a transferable and disembodied organ that has shed all vestiges of its prior location. Typically psychic unease was expressed through dreams, a sometimes-acute desire for recognition from the donor family, or an evident confusion over which pronoun to use when referring to the heart. Is it now 'mine' or still 'his' or 'hers'?

Moving away from this highly simplified version of the empirical research, what transplantation invokes in theoretical terms is a very old philosophical problem about the persistence or loss of identity in the face of change. The experience of the body that is not one and an intuitive sense of hybridity evokes precisely the kind of psychic disturbance that haunts respondents' narratives. If transplantation does raise fundamental questions of identity, then these entail issues of age, ethnicity, sexuality, and gender – the very data that is withheld from participants on both sides. Does it matter if a male receives a female organ, a black person the heart of someone white, a teenager that of an old person? Or moving away from phenotype, how would it be for a straight man to be transplanted with the organs of a gay woman? In our good liberal ethics, we would assert that these are differences without significance, and, in particular, that things like sexuality and gender are just social constructions and would therefore have no impact. But the point is not to capture verifiable reality, but to attend to underlying anxieties. And in any case, biology itself is highly plastic. Although we

might strongly reject the biology is destiny line, we need to see – as feminists like Donna Haraway, Elizabeth Wilson, and Anne Fausto-Sterling have been telling us all along – that the fluidity and construct-
edness of the material-semiotic world interacts with the body as understood by bioscience. Perhaps bioscience and critical theory do not have conflicting data sets but are actually pointing to enmeshed phenomena as, for example, in recipients' feelings of otherness being mirrored in the incorporation of non-self DNA. As it becomes clearer that the body can no longer be organised according to humanist principles; as it makes novel connections and is exposed as already participating in machinic assemblages of the organic and inorganic – human, animal and machine alike; we need to reimagine not just the components of human identity, but the data needed to express it. At very least we need to re-*envisage* the problematic of data in the life sciences, and specifically with regard to organ transplantation.

In the context of modernist biomedicine, which conventionally adheres to binary categories such as self and other, the confused heart transplant recipient may seek certainty in a normative body and is understandably disturbed by hybridity. Given a series of powerful external discourses that privilege restoration to wholeness, the recipient's capacity to negotiate post-operative dysphoria is severely constrained by a system that makes recipients feel that they cannot voice their anxieties to clinical and health care professionals. With no 'official' outlet for the expression of psychic distress, recipients are reluctant to acknowledge disturbed feelings that go beyond the feel-good narrative of life restored, and most were relieved to speak openly to our researchers. Given that all interviewees are required to give consent, they can become in effect self-selecting, but across the number in the eligible cohort, we met with just two refusals.⁹ What seemed to be at stake was a strong desire to communicate an account that the clinic suppressed.

Conclusion

On a simple level, then, we need to rethink which data are relevant and what recipients should know. Alongside the usual biomedical information that grounds consent, the potential disruptions to identity should be discussed from the outset as anticipated rather than abnormal. Recipients need space in which to express their intuitions of internal difference, but the wider issue for all of us is how to rethink the cultural imaginary of a singular embodied subject who is autonomous and distinct from her others. In place of ontological separation, there is an ethical imperative to think through at least concorporeality, but more radically

assemblage where diverse elements conjoin – and split apart – in never settled processes of becoming. The insistence in current practice, that the pre-existing subject will live on essentially unchanged seems to me profoundly restrictive of alternative modes –and let’s call them data – that might better express the recipient experience.

In moving to a more intersectional approach to organ donation that accepts the need for a data assemblage and leaves behind the narrow positivism of biomedical advances, all sorts of difficult questions that take account of the shock to the body’s putative unity and identity-to-self are able to emerge. The post-operative patient knows that something fundamental has altered, that their sutured bodies intend a transformed mode of being-in-the-world, and they need support in thinking through how to live well in a hybrid, prostheticised body. Even in conventional approaches, the need to revamp healthcare practices to enable heart recipients to express their actual embodied experiences, without fear of ridicule, or being thought ungrateful or psychiatrically unstable, is clear. And that means transplant professionals need to rethink what is seen as unproblematically therapeutic, and to take a more critical approach to conventional data that opens up new forms. If we recognised more widely the symbiotic and unfixed intersection of biology and culture in the meaning of embodiment and rethought the epistemologies that dominate bioscience and its restrictive data habit, then it might be clear that it is precisely fixed boundaries that are the problem – not just for those undergoing radical interventions into the body, but for all of us. In any case, in postconventional thought, there is no pre-existing pure form of embodiment to restore – we are already hybrid, already more than one, already more than human. We are always in a process of becoming-other, even when appearing the same. In the age of technological transformations that contest the nature of human embodiment, the bioscientific approach alone is inadequate; and perhaps it would be better to start from the phenomenological point of disturbance.

Thinking through research assemblages in relation to the issues uncovered by recipient accounts mobilises the need to explore at least two major paths. First, we need innovative research methodologies that give up the search for incontrovertible quantifiable evidence, or indeed for qualitative data, that asserts the truth of any one discourse, including that of the respondent. Second, we need to radically rethink the relation between self and other by engaging with the notions of hybridity and concorporeality, and embrace the Deleuzian notion of assemblage. Whatever entangled data paths are taken, and they cannot be defined in advance, it is clear that outcomes will remain provisional at best and constantly open to transformation. If the conventional search for a

coherent sense of bodily normativity is deeply damaging in its disavowal of the radical instances of disarray and disorder that embodiment may entail, then body shock requires new forms of data that do not close things down. The need is for novel modes of knowledge production for meaning-making that mobilise new relations with the embodied materialities of biomedicine. Such perspectives take heart transplantation out of the narrow confines of the clinic and into an entangled sphere where recipients, donor families, clinicians, academics, artists, and the general public come together to make their own meanings about the procedure. The exploration of new questions and possibilities facilitated by a critical engagement with multiple modes of intertwined data may unsettle the life sciences only to creatively reimagine them.

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Notes

1. PITH project REB File #07-0822-BE.
2. I mean here 'identity' mainly in its philosophical meaning as a sense of self, but also in the social world where it roots what others see of us.
3. The core team: Heather Ross, Susan Abbey, Oliver Mauthner, and Enza De Luca from the clinical side; social scientists Pat McKeever, Jen Poole; Margrit Shildrick from philosophy; and artists Ingrid Bachman, Andrew Carnie, Catherine Richardson, and Alexa Wright.
4. The notion of assemblage, as developed by Deleuze and Guattari (1987), refers to the conglomeration of multiple component parts that constitute what are often seen as single entities. Assemblage theory, however, is concerned with uncovering ontological and social complexity, and forefronts the fluidity, interconnection, instability, and provisionality of such forms.
5. As Elizabeth St Pierre warns: '(empiricists) too often ... strip the words from context, manipulate them, order them in binaries and hierarchies and categories, label some words with other words (code data), and even count words' (2014: 224).
6. This is the more striking in that as I was simply introduced as an observer and did not have ethical clearance to engage verbally with such patients in clinic, the 'conversation' was entirely one-sided.
7. See, for example, Ross et al. (2010); Abbey et al. (2011); Shildrick (2012a and b); Mauthner et al. (2014).
8. We specifically engaged with one cohort of those on the waiting list prior to transplantation, who showed a remarkable degree of optimism about their post-operative capacity to return to their previous lives that had been overtaken by ill-health. A small number were worried about the operation itself but not about its aftermath. The strongest anxiety was that an organ would not become available in time to avert death.
9. Twenty-nine recipients were approached, of whom twenty-seven gave consent for the interview process. On two occasions, a technical problem prevented recording.

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