Original Article

Ethic of consensibility, subaltern ethicality: The clinical application of embryonic stem cells in India

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Abstract The article interrogates clinical and subjective patient experiences outside the institutionalized conditions of scientific communication. Drawing on the notion of *consensibility* – consensual and circumscribed rules of scientific engagement – the article re-imagines ethicality on the margins of an *ethic of consensibility* as inherently subaltern. The article is based on a multi-sited ethnography focused on a small clinical facility in India offering human embryonic stem cell (hESC) therapies for a spectrum of disorders to local and global patients. The emergence of subaltern ethicality, the article argues, is intimately linked to 'somatic ethics' in the event that a somatic ethical stance is operationalized outside the *consensible* space of science. The article draws on interview material with the clinical director and therapeutic experiences of patients from Germany, United States and Australia undergoing hESC therapy for chronic spinal cord injuries and lyme disease. In so doing, the article shows how subaltern ethicality is an *ironic*, critical stance pitted against demands for (bio)scientific and (bio)ethical *consensibility* while seeking to become incorporated and normalized within its folds.
BioSocieties (2013) **8,** 25–40. doi:10.1057/biosoc.2012.41; published online 14 January 2013

Keywords: stem cells; India; consensibility; subaltern; ethics

Introduction

The use of human embryos for the generation of stem cells is embroiled in protracted ethical, legal and religious debates in much of the Euro-American landscape (Morgan, 2003; Krones *et al*, 2006). The conceptualization of human embryos as sentient beings has mobilized and polarized public opinion for and against such research (Ganchoff, 2004). In many parts of the world, the use of embryonic tissue in the service of generating biotechnological products such as stem cells is viewed less critically (Bharadwaj, 2005; Sleeboom-Faulkner, 2008). In particular, the global spread of research and clinical application of stem cell therapies have further exacerbated criticism (Sperling, 2004; Prainsack, 2006; Bharadwaj, 2009; Song, 2010). There is growing concern surrounding the ethical viability and scientific reliability of these therapeutic interventions (Bharadwaj and Glasner, 2009). The bone of contention is

the perceived lack of scientific scrutiny of these developments (Bharadwaj, 2012). These objections go to the very heart of what Ziman (1996) described as *consensibility*. According to Ziman, *consensibility* is a necessary condition for scientific communication. He argued, 'the general body of scientific knowledge should consist of acts and principles that are firmly established and accepted without serious doubt, by an overwhelming majority of competent, well-informed scientists' (Ziman, 1996, p. 6). While 'science' and 'scientific facts' are inherently unstable, the search for consensus and *consensibility* illustrates the fine-grained adjudication and legitimation of scientific knowledge and practice; we can say science gestates in an *ethic of consensibility*.

The article interrogates demarcations – clinical and subjective patient experiences – outside the *consensibile* circuits of science. The ethnographic focus is a small clinical facility in India offering human embryonic stem cell (hESC) therapies for a spectrum of disorders to local and global patients. This case of clinical application of hESC is deemed problematic – both locally and globally – because it is seen as not conforming to the dominant and normalized view of scientific practice and bioethical oversight. The article re-imagines ethicality on the margins of an *ethic of consensibility* as inherently subaltern. This subalternity is not rooted in oppression or exploitation. As the article will later argue, the subaltern cannot simply be relegated to a space of oppression and exploitation but rather better conceptualized as always occupying a space of difference. Ethicality in a space of difference, to borrow from Veena Das (2012), can be imagined as not oriented to 'transcendental, objectively agreed upon values but rather through the cultivation of sensibilities within the everyday' (p. 3). Subaltern ethicality is inherently ironic and conflicted. It is a vanishing ethicality that disappears without a trace or disappears into the hegemonic. Its emergence is intimately linked to 'somatic ethics' (cf. Rose, 2006, 2008) in the event that a somatic ethical stance is operationalized outside the *consensible* space of science. The resulting ambivalence produces both a critique of an *ethic of consensibility* and a desire to be consumed by it.

The article opens with a reflection on the ethnographic context and goes on to examine the *ethic of consensibility* as normalized within the practice of (bio)science. It is argued that an *ethic of consensibility* within *bioscience* seeks to bind together epistemological and bioethical processes in order to acheive somatic standardisation. This ethico-epistemic benchmarking is related to a notion of *subaltern ethicality*: an *ironic*, critical stance pitted against demands for (bio)scientific and (bio)ethical *consensibility* while seeking to become incorporated and normalized within its folds. Expanding Spivak's (1993) provocative query 'can the subaltern speak?', the article argues that this *irony* is at the core of a subaltern stance.

The Research

The article emerges from an ongoing study focusing on therapeutic application of hESC for two prominent conditions: chronic spinal cord injuries and lyme disease. The larger ethnography revolves around a New Delhi clinic: NuTech Mediworld. Since 2000, the clinic has offered hESC therapies for a range of disorders to patients from over 20 countries. The article draws on data accumulated over a 7-year period in the above research site and

anthropological engagement with the politics, economics and culture of hESC research in India. The ethnography has remained embedded in the clinic since 2003 and the first phase of this study culminated in a research monograph examining the rise of hESC research in India (Bharadwaj and Glasner, 2009).

The current phase of research is studying the terrain occupied by scientific structures and patient agency in the cultural production of hESC treatments in India. Presently, the research is tracking 10 chronic spinal cord injury/paraplegic patients and 2 lyme disease sufferers. The aim is to understand in depth their emerging experience of hESC treatment and expressions of recovery. In total, the research will focus on 20 spinal cord injury and lyme disease patient biographies, respectively, out of 108 spinal cord and 38 lyme patients treated at the clinic. The two lyme disease patients interviewed and followed up for this study registered dramatic recovery post hESC insertions. The experience of spinal cord injury patients was more circumscribed than the lyme suffers given the intractable nature of the condition. However, expressions of healing and recovery – such as regaining bowl and bladder control, being able to walk with calipers – are highly significant as all spinal cord injuries were chronic and 'natural' recovery had plateaued (duration ranging from 2 to 9 years).

The decision to focus on a smaller convenience sample of patients was taken to allow narrative detail to emerge and to understand why these patients continue to seek hESC therapies. The sample size is also restricted to allow for patient follow-up at regular intervals. The resulting longitudinal data promises to offer unique insights into the 'truth claims' of hESC efficacy as well as patient narratives of healing and recovery. All patients were recruited from within the clinic based on treatment cycle-related availability. This convenience sampling strategy eliminated any clinical bias or interference in participant recruitment. The clinic's institutional ethics committee granted full access to all clinical areas including patients so long as they had no personal objection to being approached with requests for interviews. In addition, the empirical backdrop to the argument in this article stems from 3 months of focused participant observation. The exclusive focus in this 3-month period was on narrative production of ethics, morality and experimentation in the accounts of patients and the clinical director. All patient interviews were tape-recorded. Although names were anonymized to preserve confidentiality, where interviewees asked to be identified by their first names, no anonymization was attempted. Similarly, no attempt is made to anonymize the identity of the clinic as the facility has received unprecedented global media coverage for anonymization to succeed. In addition, individual names in the public domain – such as media accounts – are not anonymized. No clinical data or files were accessed, retrieved or stored for this research. The research was carried out according to the University of Edinburgh institutional ethics audit and due informed consent was sought as detailed in the University's research ethics protocol.

Ethic of Consensibility

The philosophical thread connecting the realms of bioethics, biology and bioscience while entangled in the age of reason and the enlightenment project (cf. Shapin and Schaffer, 1989; Good, 1997) remains unencumbered by historical and philosophical specificities as it weaves a universally applicable narrative. This narrative presupposes a universal *bioscientific*

episteme, *biological* corporeality and *bioethical* normativity as necessary preconditions for ontological and epistemological expression. Ethical *consensibility* is continually negotiated on the confluence of these three bio-dimensions. The *ethical* in the production of a *consensible* terrain of praxis and thought is fundamentally institutional, a codified body of abstract knowledge circumscribed by a set of rules and regulations. Social science scholarship has expertly traced the genealogy of this ever-emerging – universal – world of '(bio)science'. And the human biological form is a good place to begin tracing the contours of *ethical consensibility*.

The rise of human biology has rightly been traced back to the Cartesian dichotomous view of the world (cf. Merchant, 1983). As feminist scholars have conclusively shown, this philosophical mediation produced gendered prototypes of the normative body where the masculine ideal type came to typify the biological norm (Rothman, 1982; Martin, 1987; Laqueur, 1990; Oudshoorn, 1999). Digressions from this epistemic construct – most notably visible in the female anatomical form – became legitimate docile objects and pathological subjects in need of active (bio)scientific management (Martin, 1987; Davis-Floyd, 1990). By the middle of twentieth century, this early biological prototype and its concealed philosophical and ideological structure was further refined to enable an imagination of the universalized, biomedicalized body (cf. Lock and Nguyen, 2010, p. 88).

The scientific objectification of the universal body is achieved through an equally familiar and fundamental 'epistemological split that runs like a fault line through modern Western medical thinking – epitomised by the dichotomous distinction between what is biomedical and what is not' (Fox, 1999, p. 4). Fox describes the excluded episteme as falling outside the physical and biological parameters of medicine, falling outside the medicine's 'hard, objective and authentically scientific, and essential core' (ibid.). It is perhaps not surprising that (bio)ethical framing of a universal body and epistemology would necessitate a universal subjective point of departure. In this philosophical schema, ontological complexities resulting from bioscientific interventions into universal biological forms through standardized epistemological practices would self-evidently demand a universal code of ethical principles (Beauchamp and Childress, 1994). Nikolas Rose (2008) lucidly describes this form of bioethical framing as a 'legitimation device within the regulatory technologies of government, as they deal with highly controversial issues of life and its management…[but]…it can [also] serve to isolate researchers from criticism, and from the detailed examination of the nature and consequences of their activities, by bureaucratizing the process whereby they obtain "ethical clearance" for what they do' (Rose, 2008, p. 46).

Briefly, the conceptual core of *ethical consensibility* is rooted in Euro-American historical, philosophical and scientific experience. There is no denying the fact that despite culture-specific genealogy of these developments, the principles of autonomy, beneficence, non-maleficence and justice – to name a few bioethical tropes – are important conceptual contributions to the process of overseeing welfare and deliverance of the 'good'. However, the (bio)ethical project dilutes the ability to deliver such an outcome because it is less able to adapt to ethical contingencies and uncertainties. The same structural fault line runs through the bio-scientific project that construes the human biological expression and knowledge production in ways that exclude complementing 'local' biological and epistemological articulations. It is against this backdrop that the notion of subaltern ethicality – an ironic position flanked by resistance to and desire for *ethical consensibility* – needs examining.

Subaltern Ethicality

Subaltern is a position without identity (Spivak, 1993, 1999). For Spivak, the subaltern is *not* a 'classy word for oppressed, for other, for somebody who's not getting a piece of the pie' (Kock, 1992, p. 45). At its broadest, subalternity is difference. This difference, unlike in a segment of post-colonial thinking, is not always oppressed (cf. Guha, 1982). Spivak explicitly clarifies how '…everything that has limited or no access to the cultural imperialism is subaltern – a space of difference. Now who would say that's just the oppressed? The working class is oppressed. It's not subaltern' (Kock, 1992, p. 45). The unequal relations of power in a subaltern space are related to issue of *access* to the hegemonic repertoire and not simply a mark of class inequality, oppression and discrimination. In framing her controversial and provocative question, 'Can the subaltern speak?' (Spivak, 1993), she gestures at the segregation of speech from an act of listening. The subaltern can speak, but the act of speaking seldom produces a response. This absence of conversation is not a failure of speech but rather a failure to enunciate from within the confines of hegemonic grammar. In this respect, the subaltern can be understood as an instance of epistemic mismatch. Scholars have argued that the dominant Western episteme has privileged certain ways of knowing as the only valid basis for production of knowledge (cf. Sharp, 2009). From science and religion to art and governance, in order to be heard, the *other* must embrace the dominant epistemic mode of expression (ibid.). The reason 'subaltern cannot speak' is largely because the subaltern is almost always captured in translation, never expressing but rather always interpreted (cf. Spivak, 1993, 1999, p. 272). The only way subaltern can speak, invoke a response, set a conversation in motion is by inserting into the circuit of hegemony. The subaltern craves normativity and normalization. To invoke Spivak again, subalternity is not something to be protected or museumized; 'no activist wants to keep the subaltern in the space of difference … to work for the subaltern, means to bring it into speech' (Kock, 1992, p. 46). In other words, one works against the subaltern status and into the hegemonic discourse. That is, make subaltern part of the hegemonic grammar; end the silence.

Subaltern ethicality can be conceptualized as one instance of failed recognition, an ethical location on the margin of bioethical and epistemic *consensibility*. Subaltern ethicality is a vanishing ethicality. It either vanishes without a trace or vanishes into the hegemonic *ethic of consensibility*. With restricted or no access to recognition in a space of difference, subaltern ethicality continually demands to be heard despite enunciating in a different grammatical register; it asks to be let in without understanding the criteria for group membership. At this juncture, Rose's (2008) concept of 'somatic ethic' becomes useful. Somatic ethic is an act of judging and acting on one's 'soma' in order to make oneself not just physically better but also a better person (Rose, 2006, 2008). In the global realms of biotechnological development, application and patient circulation, *somatic ethics* are more than ever before prone to inhabiting spaces outside the *consensible* limits of science. This could include patients driven by compulsions of 'somatic soteriology' – a sense-making device for one's suffering, its reasons and means of deliverance from it – in order to seek experimental therapies resulting in the production of experimental ethicality. As somatic ethic travels, it also encounters globally dispersed researchers and clinicians producing experimental 'ethics of the bio' – ethical considerations deemed relevant by patients, clinicians and regulators – as they conduct everyday operations on the margins of 'bio-morality', that is, principles and

codes framing the conduct of research and clinical work (Rose, 2008, pp. 46–48). As these global circulations gain traction, actors *can* find themselves failing to work around or work into the *consensible* space of science. Rose observes that 'biological and ethical are intertwined' (ibid.). This intertwining is predicated on the entwining of another kind: 'bio-morality' and 'somatic ethic'. However, in a global order characterized by increasing levels of proactive therapeutic mobility to contexts and demarcations outwith the *ethic of consensibility*, we can expect to witness conflict between purveyors of 'bio-morality' and agents espousing a 'somatic ethic'. In these fraught global encounters, their entwined destiny is prone to unravel as they – personal differences and agendas notwithstanding – seek to 'justify the decisions they must make when human vitality is at stake' (Rose, 2008, p. 48). It is in this zone of conflict where a space opens between 'somatic ethic' and 'bio-morality' we can expect to find subaltern ethicality exploring routes into the *consensible* space of science, searching for the harmonious entwined world of 'bio-morality' and 'somatic ethic'. Subaltern ethicality in other words is a transitional, vanishing ethical space that emerges and disappears as 'somatic ethic' and 'bio-morality' entwine and unravel. This is not a (dis)position opposed to *consensible* hegemony even though it may rile against it unrequited. Subaltern ethicality can seldom oppose that which it seeks in order to speak.

The Clinic

There is worldwide scientific and media interest in India's stem cell research programmes (Bharadwaj, 2005; Bharadwaj and Glasner, 2009). The Indian state, and both public and private initiatives aim to 'lead' the world in the culture, production and eventual application of hESC entities (ibid.). Although the Indian state in particular is striving to combine its strategic investment in stem cell research with the prevailing global scientific norms and ethical protocols as a conscious strategy and sound commercial investment in the emerging 'global moral economy' (cf. Bharadwaj, 2009), notable departures to this policy do exist. The ethnographic focus on NuTech Mediworld offers a compelling illustration of one such facility that has forged ahead with clinical application of hESC despite domestic and international regulatory unease at the rapid translation from bench to bedside (cf. Jayaraman, 2005).

Since 2000, the clinic has offered hESC therapies for a range of disorders to patients from over 20 countries. The stem cells at the clinic were derived from one leftover embryo from an IVF cycle. With due consent from the couple, the embryo was put through a series of tests, including medical and genetic history of the donors, to determine the viability of any resulting stem cell lines. The clinical director controversially claims that theoretically one human embryo can generate enough cell lines to treat the entire human population. This suggestion puts a very different perspective on the prevailing 'panics and ethics' surrounding the use of human embryos for stem cell generation (Bharadwaj, 2012) and what Lawrence Cohen(2003, 2010, pp. 253–254) describes as 'supplementarity', an ability of individuals or populations to constitute their longevity through access to the organic forms of other persons. If indeed a single embryo can divide in perpetuity to supply cells for therapeutic use, a breakthrough of this magnitude could potentially rewrite the rules of 'supplementarity'. However, the boldest clinical claim to date involves the suggestion that human embryonic

stem lines do not show any immune rejection in the body nor do they have any antigenic proteins necessitating immunosuppressant drugs or indeed any issues around cross-matching irrespective of age, ethnicity and gender. Thus far, there are no reported side effects in any of the patients and the range of conditions currently treated at the clinic are as diverse as diabetes, multiple sclerosis, Parkinson′s disease, cardiac conditions, lyme disease and chronic spinal cord injuries.

The hESC therapy at the clinic was first introduced in 2000, in keeping with the Indian Council of Medical Research (ICMR) ethical guidelines for biomedical research on human subjects (ICMR, 2000). In total, four patients volunteered to undergo stem cell therapy. At this stage, the objective was to test for safety. In the second year, six patients underwent hESC insertion to consolidate safety and ascertain efficacy. There was an increase to 24 in the third year to determine further the safety and efficiency of the intervention. Eventually, the figure snowballed into the current cohort of over 900 patients. The clinic has adopted the Helsinki Declaration, at least in essence, as the foundational ethical register governing its everyday practice and its institutional ethics committee. In addition, the clinic is Good Manufacturing Practice (GMP), Good Clinical Practice (GCP) and Good Laboratory Practice (GLP) compliant. These practices can be read as visible attempt to co-opt standardized baseline operational structures on which *consensible* scientific practice is predicated. However, prevailing regulation structuring scientific practice in India is proving to be a 'soft touch' given the rapid pace of development in the red biotechnology sector in India and beyond. In many respects the clinic, like the Indian state, is caught up in a 'governance limbo'. The prevailing ethical guidelines on stem cell research are 'snarled up' by slow paced, often excessive, bureaucratic procedures. This has further delayed the long-awaited transition from 'guidelines' to 'robust legislation'.

The clinic has taken out a global patent on its unique embryonic stem cell extraction technique, which is available in the public domain (internet) and open to scientific scrutiny. This is the clearest indication yet that the clinic and its scientific director are gearing up to participate in the emerging global bio-economy. On legal advice, the clinic withheld all publications until such time as the patent is granted. At present, there is no independent verification available that can ascertain the exact provenance of this legal advice save the clinic's own submission on the issue. However, existing industry norms as well as some universities' guidelines on publishing (for example, the German University system) appear to suggest that withholding publications is not an uncommon strategy when patent applications are pending. The clinic has systematic data on stem cell extraction technique, treatment protocols together with a working paper on chronic spinal cord injury covering 108 patients (40 quadriplegics and 68 paraplegic patients) who have undergone hESC therapy between 1 January 2004 and 31 December 2009. However, the absence of publications in scientific journals is accentuating criticism, as lack of peer review is seen as further evidence of dubious scientific practice. In this respect, the clinic is missing one of the key 'obligatory passage points' (Epstein, 1996) as it attempts to navigate its way to the *consensible* core of stem cell science. There is accumulating evidence to suggest that this accentuating criticism – emanating from regulatory agencies and fellow scientists – is curiously being articulated through media channels (cf. Bharadwaj and Glasner, 2009). However, this is not entirely unusual given mass media is playing an ever-increasing role in determining the outcome of scientific controversies (ibid.). Following Cohen, these

developments can be recapitulated as a fine illustration of 'ethical publicity' (Cohen, 2010) and a form of 'scandal publicity' (Cohen, 1998).

Clearly, the prevailing scenario can be read as a straightforward show of clinical belligerence and resistance. However, upon closer inspection a lot more than a simple digression from the norm appears to be at stake. Through the course of an interview in 2010, the conversation with the clinical director deviated to the upcoming Geron hESC stem cell trials in the United States. While the clinical trial eventually failed and the entire project was scrapped, in 2010 the Geron trial generated much excitement and was hailed as a landmark step forward in treating spinal cord injury.

> Q: You must have heard that there is a new clinical trial in the United States, what are your views?
> A: All the best to them.
> Q: It is just that first it was on and then it was off and now it's back on again … (interrupted).
> A: What happened, this, I don't know too many details, what I read that Geron got this clinical trial go ahead from the FDA which they withdrew when they saw that there was some cyst formation, I think their cell line is GNROC1 something like that. Unfortunately, I think, this is the one that is derived on animal products. It is unfortunate, but I think the first phase is only for safety so they are doing it on I think a 2-week-old spinal cord injury which is in acute phase so obviously they cannot talk about efficacy. Efficacy cannot be ascertained if you are transplanting cells into an acute injury because natural recovery occurs if you can show the stem cells are working in a chronic case that is what is required, I do not believe that Geron can show efficacy but they will be able to show safety aspect which I think had FDA concerned a few weeks, few months ago, which is why they had withdrawn the support…

The clinical director was not alone in making this critical observation. As early as November 2005, Jerry Silver, a neuroscience professor and stem-cell researcher at Case Western Reserve University in Cleveland, criticized Geron for moving too fast (Ertelt, 2011). The Geron clinical trial was finally given the go-ahead based on lab studies on eight rodents. The clinical director was further probed on the ethical viability of the Geron clinical trial compared to the clinic's ongoing and seven year old therapeutic interventions in patients from around the globe:

> Q: What makes this trial ethical and your clinical application of hESC unethical?
> A: It is not unethical! I am in a different country I am ethical, I practise under all international guidance with all good practice in place.
> Q: I am referring back to the criticism one hears about you in the media. What they are saying is that it is unethical because there is no clinical-trial data so what makes the clinical trial itself ethical where they are putting untested embryonic stem line into humans?
> A: No they won't call it untested, they [are] tested on mice. They are tested on mice and it makes it ethical for human trial.
> Q: What are your views on that?
> A: No comments (laughs). My comments are…

Q: Is that all it takes to make it ethical, it has to be tried on an animal?
A: Yes, and then you have to follow certain protocols which scientists have in place and you have to conform to those things and then you have be part of their lobby and then you are alright. As I am from another country though I am absolutely following whatever this country has to offer and I have international patients who speak highly of this therapy.
Q: So the criticism is that you have not followed these protocols?
A: No, I have followed every protocol, that is what I am trying to say, I have followed every protocol only thing is whatever you hear about me is from the media, if a journalist who comes across sits across or doesn't even sit across and passes a judgement (sic) … it is scientists sitting in London, like Stephen Minger, I am not ashamed to use his name because he did not behave like a scientist he had the audacity to challenge me or call me, I forget the words he said (sic), something weird, I question him as a scientist if he is so interested why doesn't he come and see, and he meaning the scientist, if I am a quack come and show me, I have gone on air and invited people over why don't they do it ….

One of the most trenchant and vocal critics of the clinic, Dr Stephen Minger, formerly from King's College London, is often quoted in leading international daily papers. Breaking news on the dramatic recovery of a 45-year-old Australian woman, Sonya Smith, who crushed both 'T11' and 'T12' bones in her spine and had, since her treatment at the clinic, begun to regain sensation and walk with calipers, the report concluded: Dr Stephen Minger, a leading stem cell scientist at King's College London, said: 'I think it's dubious to say the least. She might be Mother Teresa [taking a swipe at the clinical director], but I'm skeptical' (*Telegraph*, 2007). Personal criticisms such as these have become commonplace in media renditions and expert testimonies embedded in media reports (cf. *The Guardian*, 2005; Sky News, 2006, 2007; *Telegraph*, 2007, 2008). The main source of exasperation expressed by the clinical director is not directed towards 'trial by media', but rather for being judged unethically while following 'all international guidelines' as currently practised and interpreted in India. While the clinic claims to follow the guidelines laid down in the country, emerging moves in India, especially those sponsored by the ICMR, are proactively seeking integration with a normalized view of *consensible* science (ICMR, 2006). The ICMR in this respect remains unimpressed by the clinic introducing hESC into an ever-increasing cohort of national and international patients (cf. LifeSiteNews.com, 2001). However, as argued earlier, the ICMR-sponsored proposals are mere guidelines and cannot be legally enforced. As and when these guidelines become law, they are highly likely to mirror the prevailing 'hyperethicality' (Sunder Rajan, 2008) that governs the clinical-trial industry in India. Despite one of the most robust and stringent laws overseeing clinical trials in the world, the clinical-trial subjects in India remain vulnerable and an exploitable resource. This is not because legal and ethical oversight is inadequate or not properly enforced, but rather because the liberal contract between the clinical research organization (CRO) and the trial subject enables *ethical appropriation* of 'merely risked' subjects (ibid.).

There is another crucial implication in the clinical director's assertions. The science and therapeutic interventions are unwittingly explained by the clinical director as lying within the 'geography of blame' (Farmer, 1993). The assertion not being part of 'their lobby' is first

a veiled admission that access to *consensible* science is all but blocked and second this exclusion further accentuates the stigma of otherness and breaching the *ethic of consensibility*. Thus far, the clinic's attempts to engage with research laboratories and experts around the world have yielded little success. Obviously, this seems self-inflicted, as withholding publications and data – otherwise prime signifiers of adherence to good scientific practice – would inevitably produce such isolation. However, when asked to explain how the clinic engaged with peers and participated in a well-delineated scientific public sphere, in the notable absence of publications, the clinical director replied:

> I have tried to speak at the International Society of Stem Cell Research, once it was held in Brisbane or Queensland and other one held just recently in the States. I applied for speaking at the World Stem Cell Summit and so many other conferences and each one of them came out with a refusal to allow me the space to talk (sic). Now, that was my attempt to get it out, now if scientists don't want to hear and want to comment I won't call them scientists, I will call them politicians, I am not going to call them scientists, if they were, they will be out there helping, understanding, coming here and checking out (sic) … if tomorrow someone said I wanna come, you are most welcome.

While deepening isolation and exclusion from a community of local and global peers continues unabated, a steady stream of patients is arriving at the clinic from around the world. As the clinic continues to withhold scientific papers, patient testimony and experience of incremental recovery are beginning to have a supplementing effect. This contingent, stopgap measure, while an inadequate response to structural and ethical demands embedded in the *ethic of consensibility*, provides access to the world of patients and their 'somatic' struggles.

The Patients

A growing number of spinal cord injury and lyme disease patients from the United States, Australia and Germany are taking their somatic struggles to the clinic. These moves are straining relations between 'somatic ethics' and 'bio-morality'. Patients interviewed thus far had proactively spent time and effort researching treatment options around the world, kept abreast of ongoing breakthroughs in the lives of fellow spinal cord injury and lyme sufferers, as well as faced up to a lot of criticism and well-meaning advice from scientists and clinicians in their home countries before opting for hESC treatment in India. Interviewing an Australian patient, Andrew (pseudonym), who sustained irreversible spinal-cord damage in a bungee jumping accident in Thailand, clarified how professional validation of hESC treatment outcome was a difficult terrain to negotiate:

> … first week I had a procedure here and I could wriggle a toe I didn't believe it was happening … I feel pretty great I have sensation in my legs and use of bowel and bladder …
> Q. There is a medical ethics debate going on, should people embrace experimental therapies, is it ethical to offer such therapies?
> A. The doctors back in Australia there is a lot of debate that this is dangerous, 'you might die of tumours' and in my mind I rather die of tumours than sit around for the

> rest of my life … I don't buy into this stuff at all … it would be so much better if this were available in Australia …
> Q. What do you think are the impediments to that happening?
> A. I think the local opinion is changing and there have been a few stories on the news, positive news, but professionals have been against it. Every time they put a positive story, there is a negative opinion against it … overall it is changing. The rehab doctors are all negative so my GP I see didn't really know, he was interested but he didn't know … I wouldn't go to specialist just because they are negative …

Andrew, like many other patients and carers at the clinic, struggled to make sense of the suggestion that hESC therapies were problematic because they could potentially harm people. Drawing on everyday experiences and sensibilities of paraplegic and lyme sufferers, he found this stance to be a non-choice, amoral if not immoral and unethical as opposed to ethical. Andrew found the professional negativity towards patients opting for hESC interventions particularly disheartening. He had spent a lot of time seeking professional validation of improvements he was experiencing post stem cell treatment. However, faced with persistent 'negative' assessments of hESC therapy in his native, Australia, he eventually gave up. Simon (pseudonym), another Australian chronic spinal cord injury sufferer, encapsulated this sentiment in his characteristically blunt but cheerful manner.

> Q. Medical ethicists are of the view it is (hESC therapy) unethical and it is wrong, exploitation of desperate patients?
> A. If someone said this to my face I will punch them in the face! (laughs). Spend couple of years in a wheel chair, losing your legs changes everyone's mind…I can show you visibly I am improving and inside I am happier. I had a lot of back pain, now I am getting improvement, the more improvement you get the happier you get…

Simon worked on a farm, and it was there that he sustained the injury that left him paralysed in December 2007. He too, like Andrew, was at the receiving end of a lot of advice to wait for credible treatment options to emerge at home. Like all chronic and paraplegic spinal cord injury patients interviewed for this research, Simon considered his happiness within and the visible improvement without the key contingencies to be considered in formulating a response to hESC treatment. The proactive deployment of agency to resist medical objection 'back home' was the dominant strategy through which patients actively produced accounts of healing and relief. Placed in the context of everyday flickering sensations and twitching movements to taking first tentative steps in many years, the proponents of *consensible* science and 'bio-morality' appeared at best indifferent to their physical suffering and struggles. Cynthia from Las Vegas is a good example. Cynthia sustained chronic spinal cord damage in a car accident over 9 years ago. Interviewed on her first ever trip to the clinic, Cynthia felt flickering sensations running down to her toes for the first time since the fateful day she sustained life-altering injuries to her spine. Asked to deliberate on the question of ethics and the fact that the therapy she had turned to was considered largely unregulated and unsafe prompted the following comment:

> They are saying we haven't found any cases of anybody improving in our scientific minds lets put it that way and we found that them going to other countries has not

> worked out and you need to wait till this comes to the US and its FDA approved … I couldn't get it FDA approved what does that mean? Who is FDA? Have they been in this situation, do they know anything about science? … I don't see them knowing that much more than anyone else … and it takes them forever to approve anything you know, a drug you know, let alone stem cell things they were more like no don't go, don't go it could put you backwards ….

Travel to other parts of the world to seek out therapeutic alternatives unavailable in Euro-American countries was the only option for many patients at the clinic. Cynthia, like other spinal cord injury patients at the clinic, did receive help and support back home but only to re-orient life to accommodate a wheelchair. A carer mother, looking after her paraplegic son, summed it up succinctly: 'it seems to me the problem with ethics is that they seem to be saying we rather you die than try!'. This response, in large part a dig at the disciplinary modality of 'bio-morality', was an untenable option that galvanized many of the therapeutic journeys from around the world to the clinic. The patients at the clinic struggled to cope with their failing bodies. These struggles were not simply confined to the ethical work humans do on themselves in the name of health and longevity, core concerns are animating somatic ethics (Rose, 2008), but rather acting to survive, reclaim simple somatic functions such as walking and voiding the bladder. Christine, a lyme disease sufferer from Germany, was one such patient who was seeking to escape 'bio-morality' of *consensible* science that seemed to her, and many others, as an invitation to 'die' as opposed to 'try':

> … the doctors told me you are lucky if you have 5 years remaining to live so I decided that there is [a]chance to get out of this nightmare … Many of them [doctors in Germany] have treated thousands of lyme disease and they said you are the second worst case we have seen, just about every organ was affected, it was three years and if the diagnosis comes too late it is very difficult especially if it goes through the brain blood barrier it is very difficult … (sic)
>
> Q. It is often suggested that there are no animal studies and clinical trials. This therapy is tantamount to human experimentation, post Nuremburg and post Helsinki, this seems deeply problematic.
>
> A. … I see many studies I do not believe in studies. I am very sceptical of many studies why should we waste time while people are dying and I find comparing mouse to human being difficult (sic). Many, because we have too many laws holding up scientist from going ahead … (sic). So much ignorance about lyme. There is a medical debate, some doctors believe in chronic lyme, some mainstream doctors say it doesn't exist! They are not willing to treat, they are not willing to help the patient, to me this is a disaster! How can somebody be a scientist and medical doctor and send the patient home … With me they were saying, 'I don't know what you have when lyme is not existing'. I was getting paralysed and getting into the wheelchair they tried to tell me this is psychosomatic we have SPECT scan that was highly inflamed we had inflammation and damage all over the body and heart muscles and this was not psychosomatic but damage caused by lyme bacteria so the worst thing in medical history is ignorance …

Faced with the harrowing prospect of imminent death, Christine embarked on the long road to hESC therapy to rid herself of debilitating lyme parasite. Christine was clearly incensed at the 'bio-morality' shaping the *consensible* world of science and biomedicine. She was also elated at her dramatic recovery as her symptoms began to retreat through the course of hESC treatment. She had pulled numerous threads together that produced a tangled and confused relationship to ethics. Her deep scepticism at how globally science worked, both as a therapeutic intervention and industry, posed many, as yet, unresolved ethical questions haunting the rapid rise of bioeconomies around the world.

In July 2011, Christine was back at the clinic and gave a follow-up interview. Her husband and two children who were all suffering from lyme accompanied her. In her first interview in 2010 (cited above), she spoke at length about the guilt of 'infecting her family'. However, Christine and her husband had made dramatic recovery. Through the course of an excited exchange in the clinic waiting area, Christine's husband described his 'new life'. Christine as indeed many of the clinic staff recalled the day she arrived in a wheelchair. She described how she routinely 'showed off' her 'before and after SPECT scans' to the utter disbelief and amazement of doctors in Germany. In her case, another dramatic outcome was the complete reversal of glaucoma triggered by the lyme parasite. She excitedly recalled being tested no less than four times over a period of weeks as the specialist in Germany could not understand nor explain the dramatic recovery stem cells had brought about.

Conclusion

Subaltern ethicality is a vanishing ethicality that either disappears without a trace or disappears into the hegemonic *consensible* space of science. This ethicality is cultivated in response to sensibilities populating the everyday. It appears in the cracks that emerge when 'somatic ethics' stray beyond adjudications of 'bio-morality'. Subaltern ethicality, its unrequited riling notwithstanding, is not an ethical stance against *consensible* scientific hegemony. It actively looks for ways to meld into an *ethic of consensibility*, to become normalized and absorbed within its folds. In the event, it fails to co-opt successfully or elicit hegemonic tropes and techniques to its advantage and, subaltern ethicality disappears as utterly illegible and illegitimate. Subaltern ethicality in other words is a transitional, vanishing ethical space that emerges and disappears as 'somatic ethic' and 'bio-morality' unravel or entwine.

The protagonists in this research occupy an anomalous space between 'somatic ethics' and 'bio-morality' while waiting to gain a foothold in an entwined variant of the two. They remain incoherent to an *ethic of consensibility* that sees: (i) the clinic as violating the basic rules of *consensible* engagement, such as not publishing results of hESC interventions and (ii) the intrepid patient ontology as inherently psychosomatic or susceptible to placebo (cf. Bharadwaj, 2008). For example, Christine's lyme ravaged body deemed psychosomatic or aspersions of placebo that Simon and Andrew endured back in Australia are all illustrations of deepening cracks between the somatic and the normative. The clinic and its clinical director, not unlike the many patients, are becoming increasingly inaudible to an *ethic of consensibility* trained in filtering speech acts in a different grammatical register. The subaltern ethicality on the other hands speaks and protests in the *interpolated voice of difference* hoping to get absorbed within the folds of *consensible* science. For the clinical

director, this amounts to being recognized by the scientific community as ethical and practising *good science*. The treatment seekers, on the other hand, crave that their experience of healing and recovery is not belittled by the prevailing scientific consensus on stem cell treatments. Although the clinic and the patients successfully craft a 'soteriology' centred around stem cell therapies that animates their subaltern ethicality, they nevertheless fail to garner any tangible response from within the *ethic of consensibility* that looks to 'bio-morality' to promulgate not only codes and rules of bioscientific practice, but also adjudications on the probable results and outcomes of hESC therapies. Not surprisingly, none of the patients interviewed received clinical validation of discernable and incremental improvements in their home countries. The focus reportedly nearly always remained on reiterating the impossibility of such an outcome, a clear consequence of 'somatic ethic' straying beyond the circuit of 'bio-morality' and into the zone of 'subaltern ethicality'.

The transition from a space of *subalternity* to *consensibility* is likely to produce one of two outcomes for the clinic: (i) it will disappear as the schism between 'somatic ethics' and 'bio-morality' closes to the point of entwinement and (ii) get absorbed into the burgeoning global bio-economy. In the latter case, compulsions of commercial logic and global circulation of capital are highly likely to render the entire hESC therapeutic platform *consensible* via one of two possible routes: (i) retrospective clinical trial or (ii) 'orphan drug' status. The engineering of such 'ethical biocapital' (Franklin, 2003), an embedding of ethical concerns into business practices and products, is not too dissimilar from the prevailing conditions of 'hyper ethicality' normalizing 'structurally violent' activities like clinical trials (Sunder Rajan, 2008). In the end, the clinic and its patients will either disappear without a trace or an expedient solution will emerge from within 'bio-morality' that will entwine a 'somatic ethic' in its fold. In either scenario, subaltern ethicality will have played a role in shaping the space of conflict, difference and otherness.

Acknowledgements

I wish to thank the anonymous referees for their extremely generous, detailed and valuable comments. I am grateful to the special issue editors for their editorial input and for keeping me within the word limit. Last but not the least, I remain indebted to the research participants who so openly and unconditionally shared their everyday experiences and struggles.

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