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Towards the applied: the construction of ethical positions in stem cell translational research

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Abstract

This paper aims to make an empirically informed analytical contribution to the development of a more socially embedded bioethics. Drawing upon 10 interviews with cutting edge stem cell researchers (5 scientists and 5 clinicians) it explores and illustrates the ways in which the role positions of translational researchers are shaped by the 'normative structures' of science and medicine respectively and in combination. The empirical data is used to illuminate three overlapping themes of ethical relevance: what matters in stem cell research, experimental treatment, and responsible claim making (as contrasted with 'hype'). Finally, we suggest that this kind of 'descriptive' ethical analysis has potential relevance for understanding other substantive areas of stem cell ethics in practice, and we briefly consider the questions our analysis raises about role positions and ethical agency, and the implications for bioethics as a field of scholarship.

Key words: experimental treatment, ethical positions, hype, roles, sociology, stem cells, translational research

Introduction

This paper uses the case of stem cell science to illuminate the uneven ethical terrain of translational research, and aims thereby to make an empirically informed analytical contribution to the development of a more socially embedded bioethics (De Vries, Conrad, 1998; Zussman, 2000; Wainwright et al, 2006a). Those authors who have called for a socially embedded bioethics have a constellation of demands in mind including a greater awareness of how what counts as a salient ethical issue is socially constructed and of the ways in which action is socially and institutionally structured, as well as an interest in the empirical investigation of ethics and in the discursive construction of ethical concepts including, for example, putative 'harms' (Light & McGee, 1998). Our hope is that the discussion of translational research presented here will be relevant to all of these themes but we are especially interested in one dimension of the project to 'sociologise' bioethics: namely the question of how roles shape ethics. More specifically, we are interested in exploring how translational research entails work done inside and across role positions that are constructed within, and defined by, the differentiated ethical spaces of the scientific and the clinical. Hence our use of the word 'uneven' to describe the terrain of translational research, a terrain that traverses the scientific and the clinical – the ethics we are interested in does not occur on an abstract plane in which every actor is similarly placed, rather it is accomplished in a landscape with complex contours and multiple points of engagement.

Our primary purpose is analytical rather than empirical, but in what follows we seek to illustrate, and to ground, the analysis offered by reference to interviews with 10 senior clinicians and scientists all of whom are cutting edge figures in UK or US stem cell research. Five of these individuals are doctors and five are

biomedical scientists, and we will use these two categories of interviewees to set out some contrasts, We take it as read first that these categories are neither clearly distinct nor internally uniform, and second that small scale empirical work of the kind drawn upon here forms a poor basis for large scale generalisations. However we are not primarily interested in producing empirical generalisations but rather in exploring and illustrating how - in the domain of stem cell translational research - the ethical positions and ethical burdens of ideal typical 'doctors' and 'scientists' *might* be institutionally produced. The paper has, therefore, a hybrid character. The broad themes we identify, and seek to illustrate, arose from the analysis of empirical data. At the same time, we are seeking to draw on this analysis to rehearse a more theoretical and speculative argument about the ways in which 'ethical positions' are, in part, socially produced; an argument which, we believe, has important implications not only for reading our data but also for the conduct of bioethics as an interdisciplinary field. We begin by summarising our empirical methods and then go on to summarise the linked problematic and argument.

Empirical methods

The data drawn upon here forms part of the findings from a larger project mapping the scientific, medical, social and ethical dimensions of innovative stem cell research which involved an ethnography of two leading embryonic stem cell laboratories interviews with over 60 scientific and medical staff along with key stakeholders in stem cell research in the UK and US. To preserve anonymity we do not include the titles of doctors or scientists. Following ethics committee approval, interviews were conducted which lasted between 1-2 hours, and with permission, were taped and transcribed. Open-ended questions and an informal interview schedule were used, in order to encourage our respondents to speak in their own words about their experiences.

Transcripts were analysed by content for emergent themes (Weber, 1990) which were then coded (Strauss, 1987). All the research team read the interview transcripts and contributed to the generation of the identified themes. Sections of the transcripts relating to these initial categories were grouped together into broader categories and then into the three major themes of this paper. The paper then underwent rewriting as the team discussed and enacted analysis of our data. There was a broad consensus amongst the team as categories were refined through an iterative process. This enabled the different perspectives of the team to be incorporated, and adds to the richness and validity of our analysis. The respondents and quotes drawn on below were chosen as representative, and illustrate saturated themes. The three themes (i.e. what matters, experimental treatment, and responsible claim making) were identified as areas which our respondents themselves saw as central in relation to the ethics of stem cell science.

The problematic and core argument

Our problematic can be opened up as follows: as well as asking "*What* are the ethical problems associated with stem cell research?" we can also ask "*Whose* problems are these?" A number of authors have responded to the former question and developed lists of stem cell related ethical issues (e.g. Holm, 2002; Baylis, 2006). These lists are very diverse and encompass issues such

as: the use and destruction of embryos; the exploitation of donors, sellers or providers; the status of women in society; informed consent; commercialisation and the commodification of bodies; the 'threat' of reproductive cloning; animal rights and species integrity; resource allocation, healthcare priority setting and global justice. From the lofty vantage point of applied philosophical ethics these ethical issues are, so-to-speak, problems for everyone and for no one in particular. And this vantage point is, on the surface, analogous to that of the generalised citizen – the individual abstracted from virtually all particularity. The hypothetical generalised citizen is implicated in these ethical issues and is entitled to, and perhaps even obliged to, take some stance with regard to them. However, if we return to the ground, and focus upon real individuals, the story acquires extra layers. From this perspective, not everyone is equally implicated in the same way, and to the same degree, in every kind of ethical issue. Focussing on the ethical spaces that intersect in stem cell translational research provides one lens to investigate this fact.

To illustrate (and perhaps over-dramatise) the underlying point we will briefly comment on the most notorious of the above examples i.e. the use of human embryos. There are some (at least apparently) significant differences between being someone who is directly working on embryos to derive stem cells, someone who works in a laboratory elsewhere but whose work involves using some of the cells derived from these embryos, and someone who happens to work in this same laboratory on completely different projects. And all of these three are, in some respects, differently placed from the many others who are currently never in proximity to embryonic stem cells. For most purposes there is an acceptance that individuals have a special ethical responsibility for the things that they do as compared with the things they benefit from or which merely 'go on in their midst'. We operate with some kind of division of ethical labour – we do not expect everyone to carry the whole 'ethical burden', instead both psychological health and modes of social coordination seem to be served through the 'ethical burden' being divided up.[i] Our focus – the division of ethical labour between the scientific and the clinical in stem cell translational research – is but one example of a pervasive phenomenon. In this paper we will not be reflecting further on the question of embryo use (see Wainwright et al 2006a) or on any of the 'global' ethical issues signalled above but apart from consideration of the 'ends' of stem cell research we will confine ourselves to a couple of examples of ethical issues that more clearly 'belong' to both stem cell doctors and scientists: the use of experimental therapies and the responsible presentation of claims for innovative therapies or regenerative medicine more broadly. These two issues are chosen not just because they emerged from the data analysis but also because they exemplify the key ethical relationships that exists between doctors and scientists on the one hand and patients and various publics on the other.

It is worth stressing that our discussion is defined largely around 'roles' rather than 'identities', although these notions are related and are both important in the division of ethical labour. We are employing this distinction as it is made by Castells:

> "Roles (for example, to be a worker, a mother, a neighbor, a socialist militant, a union member, a basketball player, a churchgoer, and a smoker, at the same time) are defined by norms structured by the institutions and organizations of society … Identities are sources of meaning for the actors themselves, and by themselves, constructed through a process of individuation. … [Roles] become identities only when and if social actors internalize them, and construct meaning around this internalization." (Castells, 2004: 6-7)

Our core argument – which emerged from, and was suggested by, the data set we analysed - is that the normative structures produced by the 'institutions and organisations' of the scientific and the clinical construct different ethical spaces and role positions, and that translational research has to be understood as a process of movement and negotiation across ethical spaces and not simply across physical and social places and spaces.

In the remainder of the paper we will begin by briefly introducing, and sketching out, some of the contours of the scientific and the clinical. We then develop this account with specific reference to interview data: first, to illustrate how the scientific and the clinical shape what matters in stem cell research; and second, to explore, against this backdrop, the two examples of experimental therapy and responsible representation. These examples are used to illustrate how the normative structures of science and medicine and, equally importantly, the broader discourses and structures that co-constitute them, shape ethical positions in translational research. To conclude we will briefly consider the questions these explorations raise about role positions and ethical agency, and their significance for bioethical analysis.

What matters in stem cell research

Central to the ethical justification of stem cell research is the notion that it has the potential to do some good. In this context clinical benefit is especially important because it provides, for many people, the most telling account of what is at stake, of what really matters, here. But clinical benefits are not the only kinds of goods at stake. Holm (2002), for example, lists clinical benefit as only one of the three main aims of the various stem cell research programmes as follows: "1) increasing our knowledge about basic cell biology, 2) creating new therapies through stem cell culture and control of cell differentiation, and 3) producing commercially viable stem cell products". Individuals who work in stem cell research will place different degrees of emphases on these different kinds of aims, although they are likely, for certain purposes, to foreground the second aim because of this capacity for it to provide a kind of 'ethical backbone' to the field.

Although stem cell researchers may all have some stake in all of the above three (and other) aims, those who work as cell scientists are positioned differently than those who work as clinicians because of the respective normative structures in which their work is embedded. The goals of science are structured around contributions to knowledge, especially to 'basic' or 'fundamental' knowledge. The goals of clinical work are structured around therapy i.e. around curing or benefiting patients. This means that the centre of gravity of the research gaze of the ideal typical scientist and doctor are likely to

be significantly different (see Wainwright et al, 2006b). Crudely speaking cell scientists are more likely to focus on the 'cellular level down' and clinicians on the 'cellular level up'. Epistemological orientations are similarly structured in contrasting ways, with the clinical interest in 'what works' for patients and the scientific interest in 'why and how things work' biologically. Finally, the scientific and the clinical are embodied in different communities of practice with distinct cultures and practices of internal surveillance and review, and lines of accountability to differing constituencies of funders, regulators and stakeholders. In simple terms, certain practices and role positions are closely bound up with the discipline of the professional bodies and watchdogs, others with the peer review mechanisms and hierarchies of the academic disciplines of science. Considered collectively these contrasting normative structures produce contrasting potential role positions which embody different orientations to 'what matters', including differing goals, differing senses and direction of obligation and differing dispositions. These different constellations of role-related 'goals, obligations and dispositions'[ii] make up what we are calling a 'division of ethical labour'.

The empirical data we are drawing upon here contains many instances of our interviewees exploring the distinctions between the scientific and the clinical, and talking about the relationships between scientists and clinicians. This data frequently addresses both the benefits and the challenges of establishing effective collaborative relationships:

I think clinicians and scientists and the scientists and clinicians have to work together because they are in two different fields, and if they don't work together, then their work just remains in those fields. And I think it's important for clinicians to work on the interaction so we get good quality cells to put into patients. Physician 34.

To demonstrate the seriousness to grant giving bodies… that's quite difficult in a diverse team where there are a lot of clinicians and basic scientists, trying to get the mix right as to who decides which direction we go in and how we do that. And the secret is how to encourage people and how to develop the institutional ethos of research, how do you encourage people to be honest and open about what they do, the mistakes and so forth. How do you develop risk taking safely? What does that mean in the scientific world, what does that mean in the clinical world? They're quite different unless there are enough similarities between them, but you need a framework. A lot of my time now is spent thinking how you get people to work together and make people happy working together. Surgeon 32.

The benefits of bringing together 'different fields' is underlined and justified here not least because of the central goal of 'putting cells into patients'. But the surgeon's remarks begin to illuminate some of the accompanying challenges. The challenge of achieving 'happy' relationships is not simply an interpersonal one but arises because central concepts, such as 'risk', have different meanings within the scientific and clinical domains. These ambivalences, as is suggested, raise problems of coherence in relation to credibility and leadership. The scientists interviewed raised analogous issues, indicating, amongst other things, the competing hierarchies at stake - hierarchies that are normative but are nonetheless established and negotiated institutionally and territorially. In particular our translational research scientists frequently reported on the ever

present risk of their work being 'looked down on' by scientists who worked in 'pure' departments, and on the possibility of playing 'second fiddle' within clinical environments:

If you come as a scientist into a clinical environment, there's one overriding thing that you always are going to have in mind, you'll never be top dog because it's always really going to be the clinicians. It might not worry you, but at the end of the day, someone is going to be trying to tell you what to do. And inevitably this would lead to tensions, and where the compromise is reached determines whether you'll be successful or you won't. And if each is aware of the other's ability sufficiently, then you go forward together. But as soon as you start trying to do this dominating thing, it doesn't work. Scientist 35

Maybe some of the scientific powers in the University look down upon people who are not doing science on a specific atom, or doing some incredibly clever molecular biology, or understanding what one gene does. Scientist 36

We've always worked as a team [a scientist and clinician], and we've worked rather well. However, I mean, from my point of view as a scientist, it's quite extraordinary, especially in an academic medical unit, that people look down on that, which is totally ridiculous because actually we're much more likely to make it together… For somebody in a University who is a pure scientist, for them to collaborate with somebody in the clinical field, it is like talking two different languages, whereas I have always been looking to the end point, which you could argue makes me a lesser scientist. Scientist 47

The first of these scientists went on to illustrate the competing hierarchies in relation to the 'meaning' of budgets, and the extent to which what matters depends upon which role positions are foregrounded:

Last year I transferred from the University to the [Hospital]. As an inevitable consequence of that, people start asking questions like, where are your grants? Well I've got a big budget but it doesn't quite count as a peer review grant application. Scientist 35

The normative structures of science and medicine are, of course, not 'innocent'. Given their institutional production they are inevitably bound up with what MacIntyre (1981) abstracts out as 'external goods' (i.e. those goods generically associated with 'success' e.g. money, status) and not just 'internal goods' (i.e. those goods which are more specific to, and immanent in, the traditions and practices of science and medicine). There is, for example, plenty of evidence in the data set of 'performance management' pressures shaping what matters to our respondents and of the (differentiated) co-construction of both domains by the increasingly intensified competitive/ comparative arenas of the public and private sectors. We will return to these broader factors – and in particular the effects of institutional competition for funding – later in the paper. However there are also plenty of examples of differential orientation arising from what are arguably internal goods. The starting and stopping points of the clinical and the scientific can be different and can call for different kinds of justification:

The first thing to say is clinicians are not scientists, they're not scientifically trained. Much of my decision making is intuitive. But my personality is, so I would make a poor scientist, I think. Scientists by nature will be questioned about the work that they've done, they will be asked to verify it. I don't think we are in medicine, we are not scrutinised to the same degree. And so by nature scientists are more cautious about the interpretation and the publication of their research. But I think that's also a generalisation. Within that there are personalities for risk taking every branch of research and medicine. Surgeon 32.

You do need to pick certain people who have got to the realisation of what the problem is in terms of translational research. And it doesn't appeal to some people at all because what the scientists will always be trying to do is to define the mechanism so that they can understand that. The thing with translational research is that sometimes it stops short of that, in that the clinical objective is all. If you can get something that works, you don't necessarily need to know exactly how it works because it works. That's the bottom line. And I think that's where the difficulty could come in because it's a matter of translating the knowledge of the mechanism into clinical effectiveness. And there's no doubt that you can reach a stage where more knowledge of the mechanism doesn't necessarily take you forward, because it's very disruptive. Scientist 35

Some of the contestability about what it is worth doing in stem cell research thus arises from the different meanings, perspectives, hierarchies and priorities of the clinical and scientific domains. We suggest, furthermore, that it is a mistake to construct all such differences as representing some kind of distortion of, or distraction from, some non-contestable central purpose. Some elements that constitute the complex value field of stem cell research might be analysed in this way (e.g. some of the 'external goods' mentioned above) but, in large part, what matters here is inherently contestable. That is to say even if we were to place the intrinsic value of science on one side, and to accept the notion that successful treatments somehow provide the 'ethical backbone' to the field, then there is still the conundrum of determining when richer scientific knowledge may ultimately produce richer treatment fruits. But, more fundamentally, and to reiterate, differences of emphasis reflect the contrasting role positions made available by medicine and science. All of the stress in the data upon doctors and scientists 'coming together' and 'working together' in translational research needs to be seen as testimony to the fact that, to put it crudely, they have different jobs i.e. there is an important division of labour between them. This division of labour, we are suggesting, has an ethical dimension to it and not simply because doctors and scientists serve slightly different 'ends' but also because – as will now go on to illustrate – these purposes are linked to slightly different orientations with regard to what it is right for them to do or to say.

Experimental Treatment

The distance between the scientific and the clinical are reflected and refracted in the distance between the bench and the bedside. This distance is constructed in our interview data simultaneously as 'a huge gulf' and as 'tremendous potential'. Applying stem cell research, or thinking about 'what works', means recognising the multiple senses and layers of what counts as 'working':

No doubt there's tremendous potential, but it's still a huge gulf between what is observational experimental stuff and something that's going to be clinically applicable. Scientist 41

My concern is, however, we are not cells. We are a body made up of cells. And to, just to try to study something in a petri dish, does not equate to the human state. There's something in it, but don't extrapolate that just because it works in a dish, it will work in a human. Physician 37.

Despite what many see as the undermining of trust in modern British medicine, brought about through 'the Bristol and Alder Hey Scandals'[iii], there is still arguably more public support for 'experimental work' in the domain of medicine than in the domain of science:

The general population doesn't understand the difference between clinical and research. I don't think we explain it very well as scientists. And I think we're all too happy to allow people to think that research is something in a nasty dark laboratory with people doing scary things, where anything clinical is safe. And neither are correct. It's somewhere in between the two. Physician 37.

Although both the scientists and the doctors that we interviewed were clear about the challenges of making stem cell research clinically relevant and effective there was a rather different emphasis to their concerns about this process. For all the reasons mentioned already the role positions of scientists are oriented towards the horizon of scientific knowledge whereas the role positions of doctors are sharply defined by the immediate presence of patients and the demands of clinical relationships. Given these role positions it would not be surprising if doctors were inclined to look for what might be experimentally applicable today to improve treatment, whilst scientists were more inclined to be sceptical about the knowledge base underlying experimental treatments. There was evidence of both these sets of orientations in the data set; and we will consider each in turn.

In fields like organ and cell transplants it is doctors who have embarked on 'experiments perilous' (Fox, 1998) as they have had 'the courage to fail' (Fox & Swazey, 1992). This ethos, of making bold decisions about potentially life saving treatments can become part of the disposition set of the transplant surgeon:

Who took it [transplantation] *forward? It was the clinicians. People had to bold about it.* Surgeon 46.

In some respects it's easier when you're dealing with patients than when we started out. But your decisions technically are often black or white in that, if you're going to die and you have an experimental treatment, most patients will take it and ethically one feels comfortable offering it, providing that one explains clearly what the risks are and the background leading up to making that decision. Surgeon 32.

However, doctors recognised that cure, especially with novel treatments like cell transplants, was often not currently possible. There was also, amongst

many of the doctors, the associated recognition that offering treatments is much more ethically complex than the quote above implies:

No one has been cured, but every patient has been benefited in his own way… If they survive, they will have mental handicap, that's the sad part. They're alive but there are extreme restrictions on their lifestyle, and despite that, most of them have mental handicap. So if somebody dies … that is tragic, but if you look at the hard fact of life, in a way, that disorder is crippling and in a way it's kind that he died. Obviously it's no good if you die, but living with a severe handicap can be worse. That's the way I look at it. Physician 34.

I mean, for all sorts of reasons. If someone is likely to die it is almost coercive to offer them therapy which is unproven. Because how do you randomise that, because you're going to say, it might work, it might not? It does get quite difficult. Physician 37.

It is, of course, possible that some of the doctors who expressed concern about the use of unproven treatments – who were from the UK - were, in some measure, reflecting a specific national climate in which there is an increasingly high expectation of national and institutional governance and oversight of the use of new treatments through agencies such as the National Institute for Health and Clinical Excellence. Other medical climates may operate with fewer normative pressures of these kinds. Of course our small sample renders it impossible to make any national or comparative claims about the relevant populations of researchers. Here, as with all our examples, we would expect the perspectives of stem cell researchers to be shaped by a complex range of socio-cultural factors and not only the general normative structures that we are concentrating upon.

Amongst the scientists we spoke to there was a high level of scepticism, and some consternation, about the 'rush' to experimental treatment in some areas of stem cell research[iv]:

I know a surgeon in x, who has a small trial, a phase one trial[v]. He comes over as a cutting edge 'stem cell researcher' and he doesn't actually know one if it jumped up and bit him on the backside! ... And he's injecting in a rather cavalier fashion, going round and they tried to treat patients first with x, but it's based upon NO good animal models. And he may be exacerbating the situation, he may be causing more [complications]. I don't know. He's now going back and doing some animal model work, but the clinical trials have gone ahead! Okay, he hasn't killed anyone! He's Cavalier. Scientist 40

The way forward in research is normally you've got something you do in vitro, then you maybe have some preclinical models whether you're doing fish, flies or rats and mice. And then go on to maybe a human trial. It seems to me that often now, such is the anxiousness of people to become known in this field, and get on, that the clinical trials are coming before any decent animal experiments. Maybe to their detriment… [A scientific colleague], *who's from* [another university] *actually said 'These guys are an embarrassment to the stem cell community'.* Scientist 40.

They basically said, 'Oh we've got some sick patients, got some cells, chuck one into the other and see what happens.' With absolutely no biology behind it at all! And, of course, it didn't work. It's not surprising. So a lot of trials were done, in a completely sub optimal fashion, and nobody tried to do the biology first. Scientist 47[vi]

These sceptical remarks point, once again, to some possible 'external goods' in play; in this case the reputational drivers of experimentation, which have both internal and external faces. But they also highlight the differences reviewed above between the 'internal' imperatives of science and medicine – the imperative of finding treatments versus the imperative of validating truth claims.

Making claims

As some of the quotes above indicate the ethical dilemmas surrounding experimental treatment are not just about what is 'done' but also about what is 'said' – in particular about what counts as responsible claim-making. This is just one example of a much wider phenomenon – namely the complex economy of trading on expectations in stem cell translational research. Short and long-term prospects are traded on by many parties including not only commercial organisations but also the institutions of medicine and science, health-related charities, the media as well as by scientists, doctors, patients and publics. Unsurprisingly the doctors we spoke to had particular concerns about managing the expectations of actual and potential patients. The interviews indicate something of the public and patient generated pressure that doctors are under to deliver treatments and how doctors as well as scientists take seriously the difficult task of negotiating expectations. In this context some of the doctors also raised concerns about the role the media can play in raising unrealistic expectations:

You could put highly speculative trials for cancer patients and get huge numbers of volunteers in what would be ethically unacceptable, just simply because people are desperate and will take any potential treatment, no matter how unrealistic it may be. Funnily enough I think there would be this impedance to carrying out unethical studies, not from the public, it's the scientists and doctors, who do have ethical standards, which don't actually necessarily match up to the public. We see ourselves as protectors of the public and I'm not really sure the public sees us the same way. Surgeon 32.

They have to think about what they eat every time they eat. And there's a whole, you live around your diabetes. And to say to someone like that, 'We could get rid of this for you,' they would sell their souls for that, and you do have to manage that very carefully, because I don't think we can do that for a long time. Physician 31.

I do see it [stem cells] as a potential future therapy. I think the media has hijacked it, as the media hijacks everything, in that this is going to be a cure for tomorrow. No it isn't. You know, in a small subset of people it is a support mechanism... So, it's not yet cure, but fascinating, and yes, over the next 5 to 10 years it might well become a real possibility. I think my concern is that it's been sold a bit too hard by the media. Physician 37.

Many of the scientists we spoke to talked both about the role of the media in representations of stem cell prospects and about the broader and deeper sources and causes of 'hype' in the field. Some helpfully reflected on possible explanations for hype including what might be seen as the inherent 'hypeability' of the developing field of regenerative medicine which seems to promise so much, not least the growing of whole organs (kidneys, lungs) in the laboratory:

There's lots of interest and excitement in the stem cell world, but an awful lot of exaggeration and over interpretation perhaps and hype. Scientist 41.

I think with stem cells, the reason they can hype them is that the concept is easy. Someone with any understanding of science, the idea that you get a cell which can make your liver or a heart or a brain, is easy to take on board. And so you can very easily to on television and say, 'We're going to cure everything.' It just depends on what you want the stem cells to do. There's a whole range of clinical applications from producing a beta cell for a pancreas for diabetes, through to making a kidney in a dish. When people say a) it's round the corner, and b) that you can grow things in a lab, grow bits of liver or bits or bits of kidney or whole organs then that's probably nonsense. Isn't it? I mean you couldn't – if you think of the structure of a kidney - all the cell types, the arteries, the veins, the lymphatics etc…. Even it were a possibility to grow a kidney in a test tube, you may as well forget it, because of the expense. Scientist 38

*And suddenly 'Scientists Create Human Lung!' It's complete cobblers! It's not their [*the scientists'*] fault, they just said, 'Maybe one day.' 30 different cell types in the lung, and suddenly they've made a few little Type-2 pneumocytes. And, you know, people are saying they've created a lung, it's absolute rubbish!* Scientist 40

Although our respondents do not necessarily attach blame to fellow scientists for hyping stem cell advances (see "its not their fault" above), the responsibility cannot simply be laid at the door of the media either; rather there are major institutional/organisational normative structures which help to produce 'over-interpretation' and hype. In particular those arising from the competitive/ comparative arenas in which stem cell research is conducted, especially the competition for resources. These powerful institutional norms cut across medical and scientific domains and co-constitute them:

So there's a lot of people that have seen things happen once and then they make a general claim about it, and that gives a rosy impression… I just think they're too quick to rush into publication. They want the money, they know there's a lot of money out there and the government is saying there's so many millions for stem cell research, that I think people are rushing ahead and publishing prematurely. Scientist 40

*And we got the same thing…. Sometimes, even with the best intentions, research gets hyped. We're allied with [*a medical charity*], they have a publicity department and they know that when they get a bit of publicity, if they just get somebody talking for 15 seconds on the news, they know that they can identify significant upsurges in funding. And so it's a question of keeping the balance right and not making it too hyped, but on the other hand, keeping it in the public eye*. Scientist 40

These scientists and doctors on the TV say stem cells are going to cure this or that, and I think that sort of approach is sensationalism really…. And that's made me a lot more cautious about these things. I mean maybe these days our kind of culture says that you've got to have your publicity and hype, and the hospital wants you to do this too. Scientist 36

One of the doctors interviewed also underlined this thesis, indicating in very clear terms the temptation for stem cell researchers to trade on the promise of future community well-being and, in the process, highlighted the interpenetration of scientific 'truth validating' discourses with other discourses:

In my opinion it's [cures via cell transplants] *a long way away… And you can't get a paper published now unless you make some outrageous statement about its value to the greater community. And a lot of that comes from the pressure of* [research funding]*. You need an exciting opening sentence. It's like writing a novel. And often it is writing a novel, let's face it!* Physician 31.

Thus although the role positions of doctors and scientists are structured differently with the doctors being much more preoccupied about the dilemmas of mediating accounts of what is scientifically possible to particular patients or prospective patients rather than simply to 'the public' at large, there are some strikingly similar factors structuring these contrasting role positions. These factors are clustered around the pressures from funding and other indicators of institutional success and they create more general and shared dilemmas about the proper balance between responsible representation and hype.

Conclusion

We hope to have shed some light on the ethical spaces that are being constructed, contested and traversed in stem cell translational research. Although we have used a small empirical data set to explore some very large issues we believe that this data helps to illuminate some of the ways in which the normative structures of medicine and science shape the ethics of stem cell research. In some instances, at least in the case of the 'cutting edge' researchers we interviewed, it is possible to see how the normative structures of medicine and science can produce somewhat different ethical positions i.e. different emphases in relation to what matters and associated sets of priorities and dispositions (for example, sensitivity to patient demands 'versus' sensitivity to 'over-interpretation' of trials). In other instances it is possible to see how the ethical positions of both doctors and scientists are seemingly constructed by similar, or strongly analogous, factors arising from broader social and institutional norms (e.g. the norms of institutional and financial competition). Our focus has, quite deliberately, been upon relatively routine and pervasive ethical dilemmas and the mundane ways in which their management is shaped by both the 'internal' and 'external' interests of science and medicine. But we see no reason why similar accounts could not be produced in relation to some of the more dramatic and 'global' ethical issues – listed in the opening to the paper – raised by stem cell translational research. Applying science is not, as it is sometimes conceived, a move from 'theory' to the 'thorny ethics of practice' rather it is series of negotiations and collisions between value fields in which thorns are everywhere present.

Finally, this paper is intended as a study of applied ethics as well as of applied science. We hope that it will serve as an example of the ethical work done by role positions - i.e. the ways in which various kinds of ethical burdens and ethical baggage are embedded in role positions and have effects, to put it crudely, 'before' role occupants begin to act. We have suggested that the social and institutional production of role positions serves to reflect and thereby reproduce what we have called a division of ethical labour between medical and scientific research. This is, of course, a claim from empirical ethics but, we believe, it is one that has normative, and not just descriptive significance. In

saying this we are not suggesting that agents ought to be defined by their roles but merely underlining the fact that agents cannot simply and entirely 'float above' their roles, and that the ethical appraisal of agents must take into account facts about their role positions.[vii] It is no part of our intention to undermine the place of personal agency in understanding, analysing or appraising ethics. The desire to help 'sociologise' bioethics, which informs this paper, is not a desire to reduce ethics to the effects of normative structures. Any sociology worth the name will accept as a central problematic the business of working with the structure/agency relationship in ways that - even when it is focused upon an explanatory project - envisages a role for agency in both *explanans* and *explananda*. If we are interested in understanding the ethics of stem cell research – or anything else for that matter – we need to pay close attention to the commitments, deliberations and choices of individuals as they navigate difficult fields. But at the same time we need to pay equally close attention to the conditions which help structure these stances, deliberations and choices. Thus the construction of role positions in ethics is not merely important from a descriptive or explanatory point of view. It is our contention that it is central to substantive ethical analysis and appraisal. Unless we understand the social construction of ethical positions, and the divisions of ethical labour thereby produced, we will be unable to sensibly understand or attribute responsibility, or make judgements about what is defensible, or make informed recommendations about how things might be done better.

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[i] We will leave aside here the discussion of exactly when, where and how these facts from 'descriptive ethics' correspond with what *ought* to be the case – but our discussion depends on the assumption that there is some degree of correspondence i.e. that even if responsibility for practices ought to be more equally diffused there are limits to how far this is possible or ethically desirable. There are at least two reasons to embrace this assumption: (a) there is arguably something ethically special about first person engagement - in the end we can only be wholly responsible for our own actions and the things we do arguably speak for us differently and more definitively than the things we accept; (b) there is a crucial second-order component to ethics – we can exercise our ethical judgement and integrity not only through our first order commitments but also through tolerating (up to a point) others exercising their own different, and to some degree incompatible, commitments.

[ii] Here we are using this short list of 'goals, obligations and dispositions' as a deliberately oversimplified way of marking the domain of ethics. It gestures towards the traditions of consequentialism, deontology and virtue theory by reference to these three crude organising ideas. An explanation and defence of this simplification is found in Cribb and Ball (2005).

[iii] This refers to two very major and highly publicised and debated hospital scandals in the UK. The Bristol case centred on the death of 29 children during or following heart surgery at Bristol Royal Infirmary, reflecting a death rate much higher than the national average. This led to a major inquiry and three doctors being found guilty of professional misconduct by the doctors' regulatory body, the General Medical Council, for failing to call a halt to the operations. The Alder Hey case centred on the retention of deceased children's body parts without consent. Over a thousand families were affected and, following legal action, received official apologies and more than five million pounds compensation,

[iv] It is important to stress that these scientists are not talking about the work of the doctors interviewed or indeed even of the same lines of research. Here we are only seeking to highlight some of the differences in the *kinds* of concerns raised by the two groups.

[v] Experimental treatments undergo three phases of testing on humans involving increasingly large numbers of human subjects. Phase one trials concentrate primarily on the potential safety of the treatment and involve small numbers of healthy volunteers (e.g. 20) typically in very controlled (e.g. hospital) conditions being used to see how a drug is absorbed and metabolized in humans and to investigate possible side effects and dose effects.

[vi] This scientist, and others, gave us specific examples of what they regarded as non-scientifically informed clinical experiments that we are not able to reproduce here for reasons of confidentiality. However it is also worth noting that the kind of language used here of 'chucking cells into people' also plays an important metaphorical and symbolic role, and thereby acts as part of the struggle over the normative environment of stem cell research.

[vii] We should note, once again, that the exact implications of role positions for normative ethics is beyond the scope of this paper. But we should also stress that it cannot be merely 'read across' from descriptive ethics. To think otherwise would often produce ethically bizarre conclusions e.g. that because no one person or group is, as a matter of fact, solely responsible for producing and using a weapons system that no-one can be blamed for the harm that it does. (We are grateful to one of the reviewers for reminding us about this kind of vivid example). On the other hand it is equally clear from mundane examples that we believe it is often right to apportion praise or blame in ways that take roles into account.