Lysaght, Little & Kerridge (2011), Journal of Bioethical Inquiry. 8(2):191-202. Post-review copy.

This is an Accepted Manuscript of an article published in [J Bioethical Inquiry] on 22 Mar 2011, available online at http://link.springer.com/article/10.1007/s11673-011-9294-2

Self-archived in the <u>Sydney eScholarship Repository</u> by the Centre for Values, Ethics and the Law in Medicine (<u>VELIM</u>), University of Sydney, Australia

Please cite as:

Lysaght T, Little JM, Kerridge I. Marginalizing experience: A critical analysis of the public discourse surrounding stem cell research in Australia (2005-6). J Bioethical Inquiry. 2011;8(2):191-202.

Marginalizing experience: A critical analysis of public discourse surrounding stem cell research in Australia

Dr. Tamra Lysaght Research Fellow, Centre for Biomedical Ethics National University of Singapore, Singapore 117597

Professor Emeritus Miles Little Centre for Values, Ethics and the Law in Medicine University of Sydney, Sydney NSW 2050

A/Professor Ian Kerridge
Director of the Centre for Values, Ethics and the Law in Medicine
University of Sydney, Sydney NSW 2050
Bone Marrow Transplant Physician, Haematology Department
Royal North Shore Hospital, Sydney NSW 2065

This study was conducted in accordance with approvals obtained from the University of Sydney's Human Research Ethics Committee and carried out under the auspices of a Premier Postgraduate Scholarship at the Australian Stem Cell Centre. During this study, one of the authors (IK) served as a member of the Legislative Review Committee appointed to review Australia's federal legislation governing the use of human embryos in research and human cloning. We would like to thank Rachel Ankeny from the University of Adelaide, who co-supervised the project and made valuable contributions to the study. We also acknowledge the support of staff and students at the Centre for Values, Ethics and the Law in Medicine and the generous time given by the interview participants.

The authors have no conflicts of interest to declare and all have played a substantive role in writing the manuscript.

Keywords: Stem cells, Cloning, Bioethics, Public policy

Abstract:

Over the past decade, stem cell science has generated considerable public and political debate. These debates tend to focus on issues concerning the protection of nascent human life and the need to generate medical and therapeutic treatments for the sick and vulnerable. The framing of the public debate around these issues not only dichotomises and oversimplifies the issues at stake, but tends to marginalise certain types of voices, such as the women who donate their eggs and/or embryos to stem cell research and the patients

who might benefit from its potential clinical outcomes. This paper draws on empirical research conducted on a recent stem cell policy episode in Australia. From the qualitative examination of 109 newspaper opinion editorials and 23 in-depth interviews, it is argued that these voices are marginalised because they are based on discourses that have less epistemological status in public debate. Our results suggest that the personal experiences of women and patients are marginalised by the alliances that form between more powerful discourse communities and use science as a source of authority and legitimation. It is argued that members of these communities establish legitimacy and assert authority in public debate by discursively deploying science in claims that marginalise other epistemologies. Implications are discussed along with suggestions for a more enriched and inclusive public debate.

Introduction

From the late 1990s when human embryonic stem cell (ESC) lines were first isolated from human blastocysts and mammals were first cloned using a technique known as somatic cell nuclear transfer (SCNT), many governments around the world have implemented legislation to regulate ESC research and SCNT. While there is great variation between, and sometimes within, different countries with respect to its permissibility, there is also a high degree of uniformity in the regulations that govern stem cell research internationally (Hauskeller 2005). Generally speaking, regulatory regimes across nations are developed according to discourses that place priorities on either the welfare of human embryos or the duty to care for the sick and vulnerable (Banchoff, 2005; Gottweis, 2002). Where ESC research is permitted, it is typically under strict conditions that require informed consent from embryo and/or oocyte donors (Waldby and Salter 2008).

In 2002, the Australian Federal Parliament enacted a nationally consistent legislative framework that prohibited the use of SCNT for any purpose and only allowed research on supernumerary IVF (*in-vitro fertilisation*) embryos created prior to April 2002 (Nicol, Chalmers, and Gogarty 2002). A three-year review built into this legislation was carried out by an independent legislative review committee (called the LRC) between 2005 and 2006. The amendment act that followed allowed for the continued use of IVF embryos but permitted the creation of SCNT embryos for research purposes while maintaining the prohibition on human reproductive cloning (Cooper 2006).

The 2005-6 policy episode attracted considerable media attention and, as with stem cell debates elsewhere (Nisbet, Brossard, and Kroepsch 2003; Parry 2003), the Australian media has tended to frame the public debate around issues relating to the moral status of human embryos and potential utility of stem cells (Robins 2005). This framing has dichotomised and oversimplified the social, moral and political issues at stake and has tended to marginalise certain types of voices from the debate (Williams, Kitzinger, and Henderson 2003; Ganchoff 2004), particularly the women who donate their eggs and/or embryos to stem cell research and the patients who might benefit from its potential clinical outcomes (Parry 2003; Williams, Kitzinger, and Henderson 2003; Goggin and Newell 2004).

While the personal narratives and stories of patients often have tremendous emotional power in science policy debates, they seldom have the status afforded to other types of evidence such as scientific data and are often excluded at the point that policy or legislation

is developed (Kleinman and Kleinman 1997, 1-24; Epstein 2000, 15-32). In this paper, we examine the power and legitimacy around different 'voices' in the stem cell debate through the claims participants used throughout the 2005-6 Australian policy episode.

Theoretical Approach: Public Debate as a 'Focused Discourse'

For this examination, we adopted a theoretical approach described by Little (2010) that views public debates around science policy issues as a Type 2 focused discourse. According to Little (2010), this type of discourse occurs in response to an event or affair that is of sufficient political, social and/or cultural import that it reaches the broader communicative field of the public sphere. This public discourse is composed of multiple, heterogeneous communities that coalesce around particular issues. Members of these discourse communities share certain values, commitments and ideological beliefs about the issue in question, which manifest in the 'discourse rules', or lexicon of words they use in public discourse (Little, Jordens, and Sayers 2003). After the issue subsides, these communities usually disperse, although they may reform again as policy events re-emerge in the public domain and transform into an ongoing affair (Little and Lipworth 2007, 10). The public policy issues surrounding stem cell research are events that have developed into an ongoing affair in public discourse as governments continue to consider the regulation and possible prohibition of techniques used in this research.

The Structure of Public Discourse

Public discourses occur within forums that are relatively open and accessible to practically anyone who is interested in a particular issue (Habermas 1989, 27). Forums for public discourse include traditional sources such as the mass media, parliamentary debates, public hearings and inquiries as well as new electronic media (e.g. the Internet). Access to these forums is theoretically open to anyone with the capacity to read a newspaper, watch television or use a computer that has online access. In practice, however, participation in public discourse is limited by many context-bound restrictions.

Public discourses are created and sustained through legitimation processes that accredit speakers with credibility and authority (Derrida 2003, 93). These processes shape the content, structure and dynamics of public discourse by restricting access to those who are allowed to speak for and on behalf of prevailing social institutions (Van Dijk 1996, 84-86). In science policy contexts, powerful institutions (such as governments, the media, science, the judiciary and organised religion) compete for authority to frame and define the rules of engagement. These rules limit the possible outcomes of policy disputes by defining how issues are framed and by prescribing the types of claims that are considered as valid and legitimate forms of argument.

As the most persuasive form of argumentation, participants use rhetoric as an effective means of communicating in public discourse (Tupasela 2007). The use of rhetoric reflects the values, beliefs and opinions of participants and when no other means of legitimation are available, participants in public discourse around science policy may establish credibility and legitimacy by rhetorically adopting the norms, values and ideals of accredited discourse communities (Gamson 1990). Accreditation of discourse communities is negotiated between and within the prevalent social structures of established institutions (Limoges 1993). The institutionalised legitimacy and authority of participants, therefore, not only

restricts access to those who are empowered to speak in public discourse, it also characterises the content, structure and dynamics of science policy disputes.

Science policy disputes manifest in public discourse when decisions concerning the governance of scientific research and its technological applications are contested by those with competing interests in the outcomes of a policy decision. Of the different types of disputes that arise in public discourse, the most relevant to this study are those contested on the basis of what are portrayed as value-conflicts in first principles (Mooney 2001, 4). In such instances, the usual technical and economic considerations of science policymaking are superseded by other political, social and moral concerns (Nowotny 1993). These concerns are vocalised in rhetorically-based arguments that not only question scientific practice, but challenge the basic norms and values that justify the research (Nelkin 1995, 447-448). The types of claims participants use to support their arguments can, therefore, provide important information about the moral norms and social values that are contested in science policy disputes.

Claims that are made about science are thus discursive acts that manifest as statements in the talk (or text) of participants in public discourse. A 'science claim' is one that discursively appeals to the authority of science to support the claim. These claims contain statements about scientific knowledge that participants present in support of their arguments and imply meanings that vary according to the context in which they are used and by whom. This essay examines how these claims were used by participants in the Australian 2005-06 stem cell policy debate.

Methods

Two sources of evidence were examined in this study: 1) opinion editorials that were published in Australian newspapers; and 2) in-depth interviews with informants who participated in the public discourse throughout the 2005-6 stem cell policy dispute. Newspaper opinion editorials ('op-eds') were chosen partly because the mass media is the most accessible and dominant source for tracking public discourse (Kennamer 1992, 6-9). This same method has been used in similar studies (e.g. Nisbet, Brossard, and Kroepsch 2003; Kitzinger and Williams 2005; Williams, Kitzinger, and Henderson 2003). More importantly, op-eds were chosen because authors are explicitly invited to express prescriptive views (Bell 1991, 13). In this way, op-eds are very different to news items, which according to our theoretical frame, are a specialist media discourse. News media discourses embody certain norms, values and perspectives that reflect the discourses communities of the journalists, editors and/or organisations that produce them (Gans 1979, 39-52; Shoemaker and Reese 1996, 82-103). While these values will, to some extent, be reflected in the editorial decisions made in publishing the op-eds of one contributor over another, news items were excluded from the analysis because this study was not concerned with analysing media discourse (i.e. this study was not a media analysis).

Many other forums for public discourse exist and have frequently been included in other similar studies, particularly formal policy documents (e.g. Mulkay 1997; Parry 2003; Banchoff 2005; Gottweis 2002). However, while parliamentary debates and public inquiries are generally held within public forums that are, also according to our theoretical frame, specialist 'policy' discourses. And while Internet sources such as web blogs and posts are public discourses they were not chosen for study because the identity and interests of speakers is often unclear. For these reasons, we examined op-eds published between

January 1, 2005 and December 31, 2006 from two nationally distributed newspapers and twelve major metropolitan newspapers using the Factiva database. The total number of opeds examined was 109.

As has been done in other studies (e.g. Ganchoff 2004; Wainwright et al. 2006), in-depth interviews were included in order to capture a more contextualised and richer account of the public discourse than afforded by the op-ed texts and to better understand why certain claims were used and not others. Twenty-three interviewees were selected using purposive sampling techniques (Merriam 1988, 76-84) from an initial sampling frame of op-ed contributors, which was later expanded to include informants from the official public inquiries. Interviewees were selected according to their self-declared interest group (i.e. scientists, policymakers, religious groups etc) in order to capture a broad range of voices in the public debate. All interviews were recorded using a digital recorder and transcribed for analysis.

Texts from both sources were examined qualitatively using content and thematic analysis techniques to identify participants and examine their use of science claims. Science claims were defined as discursive acts that appeal to the authority of science. It was assumed these claims would vary according to the interests and commitments of participants when used to support a policy position¹. Participants were categorised as either advocating or opposing the liberalisation of Australia's existing legislation governing stem cell research. Of the fifty-six participants identified as op-ed contributors, twenty-six were categorised as policy advocates and twenty-five as policy opponents. The position of five contributors was unclear. Of the twenty-three interviewees, fourteen advocated the policy proposal while nine were opposed.

Both datasets were analysed for themes relating to the legitimacy and authority of science and expertise and the use of rhetoric in public discourse. Rhetoric was identified in statements containing tools and devices commonly applied in discourses of science (e.g. Gross 1996; Waddell 1997; Prelli 1997; Mulkay 1997). Deference to, and contempt for, science or technical expertise were regarded as an appeal to authority, and legitimation processes were captured in statements participants used to establish legitimacy for their position and/or diminish the authority of others. Participants' personal and professional interests were also examined for any inconsistencies between their declared commitments and their use of science claims in the public debate. Results of the op-eds are presented first

¹ We do not assume that the interests and commitments of participants are fixed and do not change over time or develop as the debate progresses or changes direction as new information emerges. We do, however, assume that participants generally enter these debates with pre-formed views about what issues are important and about how they would prefer to see the policy episode resolved and that these views generally reflect their interests.

followed by the interviews² and discussed with respect to the relevant literature under the following headings.

The Authority of Science, Expertise and Marginalisation in Stem Cell Policy Debates

The results of this examination revealed that the public discourse surrounding the Australian stem cell debate was replete with claims that appealed to the authority of science. These claims implied meanings and values that varied according to the stated policy position of participants and were used discursively to achieve a desired moral outcome. For example, the comparable meanings of SCNT and IVF embryos, and the rhetoric used to convey those meanings, was associated with the different moral arguments participants used to support their position. As seen in this op-ed statement, rhetorical devices were used in comparing SCNT embryos with other types of objects known to lack moral status:

...the committee ultimately concluded that embryos created in this way have a different moral status from those formed from an egg and a sperm by a couple trying to have a baby. Where an embryo is formed to produce stem cells compatible with the person whose body cell is used, that is more akin to growing skin cells for a skin graft than to having a baby and there are fewer objections to creating an embryo for the purpose of using its cells in research and treatment. [Loane Skene] *The Melbourne Herald Sun*

The simile in this statement made by Professor Loane Skene, who co-chaired the LRC, makes clear that the moral status of SCNT embryos is "more akin" to that of human tissues, rather than to whole human beings. In support of this ontological claim, Skene appealed to the authority of science to imply that 'cells' not created from the fusion of an egg and sperm for the purposes of reproduction have less moral status. SCNT embryos, therefore, were dehumanised in a discursive process that shifted the focus away from questions regarding their moral status onto the technical issue of whether these are "just" cells or viable embryos (Parry 2003; Williams, Kitzinger, and Henderson 2003).

Opponents of ESC/SCNT research employed similar processes in their claims. For example, opponents often argued that there were no differences between embryos created for research and reproductive purposes. At the same time, however, they attached very different moral significance to different sources and types of stem cells. This sometimes created situations where the moral status of SCNT embryos was claimed as being sufficient to protect them from research, but implied as being less than that of fertilised embryos. In the following statement, SCNT embryos are equated as "offspring" but classified as a "subclass" of humans:

To clone is to create a human offspring with no mother -- just an emptied out female egg -- and no father, for the donor of DNA is not father to the clone, but its identical twin, and could be as anonymous a donor as a piece of human tissue from the laboratory fridge. Cloning creates a subclass of humans who are absolute orphans with no mother to defend their interests, mere laboratory animals, meat for the consumption of science. [David van Gend] *The Herald Sun (Melbourne)*

-

² Quotes from the op-eds are transcribed verbatim and attributed to their respective authors. However, interview texts have been de-identified and edited according to standards for using verbatim quotations in reporting qualitative research (Corden and Sainbury 2006).

In this statement, Dr Van Gend, who fronted the "Do No Harm" campaign (established to oppose research on human embryos) suggests that the moral status of SCNT embryos is less than human because they lack the genetic connectedness of 'normal' parental relationships. At the same time, he implies that the interests of SCNT embryos should nonetheless be protected from "the consumption of science". This type of rhetoric has been used by opponents of ESC/SCNT research elsewhere in appealing to the emotional disposition of public audiences (Parry 2003; Williams, Kitzinger, and Henderson 2003). In other opponent's claims, the moral status of human embryos was heightened by contrasting them with mature adult stem cells:

Better still, there is no ethical dilemma about the harvesting of mature stem cells. They come from a scrape of your nose, so a human embryo does not have to be destroyed. [Angela Shanahan] *Sydney Sunday Telegraph*

The enthymeme in Angela Shanahan's statement implied moral status by assuming that there is "no ethical dilemma" in destroying tissues from non-embryonic sources, even though research on human tissues is highly regulated and does raise important ethical issues relating to privacy and ownership. Along with industrial metaphors of "harvesting" stem cells (rather than 'deriving' cell lines), these claims were nevertheless likely to carry emotional appeal and were generally made in the context of comparing the potential medical utility of embryonic and non-embryonic sources of stem cells. They were used to argue against SCNT on the grounds that a less morally relevant source of stem cells was available and undermine the science supporting ESC research:

Despite similar misinformation to the contrary, adult stem cell research is a viable and vibrant path to new medical therapies. Even calling them an alternative to embryonic stem cells misinforms the public. Why? Because embryonic stem cells provide no path at all. [James Sherley] *The Australian*.

In the by-line of this op-ed piece, Professor Sherley, a US-based researcher who was in Australia during the policy debate, appealed to his credibility as a scientist working with adult stem cells to support his claims. While Professor Sherley is a member of an alliance with several religious groups who recently filed an injunction in the US District Court against President Obama's changes to federal funding for ESC research (*Sherley v. Sebelius* [2010] DDC 686), in the Australian context, he used only his scientific credentials to establish his claims to authority. This is not to accuse him of dishonesty in any way, rather it simply reinforces the point that scientific credibility could be seen to secure persuasive access to public debate, ahead of any other grounds. In this regard it is noteworthy that those who argued for ESC legislation also did not disclose their religious affiliations, their agnosticism or their atheism – their claims to scientific validity were of far greater discursive significance.

Arguments over the 'plasticity' or potential clinical utility of different stem cells were an important feature of the public discourse surrounding ESC research. Such arguments are essentially moral in nature because they appeal to the *necessity* of using human embryos in research. Those used by opponents of ESC research are largely made in response to arguments advanced by advocates of this research who claim that it is necessary to pursue because ASCs do not offer the same potential in terms of medical and therapeutic benefits. A research advocate in this debate provided one such example:

While adult stem cells do offer the promise of treating some diseases, there is a very widely held view among experts in this field that their usefulness may be limited. [Bernie Tuch] *The Sydney Morning Herald*.

Credibility for this claim derived both from Professor Tuch's standing as a stem cell scientist and from his assertion that it was the "very widely held view among experts" that ASCs have limited use. This statement implied that there is scientific consensus on the relative merits of different stem cell sources. Scientific consensus is the combined opinion of experts. When used in public discourse, the concept of expert consensus becomes a rhetorical term that conveys legitimacy, regardless of whether it represents the 'truth'. In this context, it was likely to have conveyed both trust and authority in the claim that ESC research was necessary.

Similar statements were made by non-scientists who drew on the expertise of others to substantiate their arguments. The claims of non-scientists contained comparable normative evaluations of human embryos and stem cells, and conveyed similar assumptions about the authority of expertise and scientific consensus. These similarities emerged as evidence of the discourse alliances that formed between scientists and non-scientists. The use of science by those arguing both for and against ESC/SCNT research conveyed meanings that were normatively consistent with the overall objectives of each alliance. For example, journalist Wayne Crawford drew on science claims to link SCNT embryos with their ethical and social value as useful objects that lack moral status:

As scientists have stressed, therapeutic cloning is not about copying people, but copying cells. It may mean eventually that, for example, bone marrow grafts could be made with perfectly immunologically matched cells which would, therefore, not run the risk of mismatch and rejection... Any human embryo clone created would be purely to extract stem cells -- linking its moral significance closely to the research to develop potential treatments for serious medical conditions, rather than a potential as human life. [Wayne Crawford] *Hobart Mercury*.

These strategies appeal to the scientific ethos and are a discursive means of establishing credibility: that is, they allow speakers to convince their audience about their knowledge of the technical issues and establish a trust relationship with them (Prelli 1997, 88-89). By aligning themselves in this way, the claims made by those opposed to ESC/SCNT on technical grounds were invested with meanings that were normatively distinct from those used by the advocates of this research. Such distinctions became the dominate narrative throughout the debate and were indicative of the 'rules' different discourse communities have regarding the meaning and use of words such as "stem cells", "cloning" and "embryos" in public discourse.

Marginalisation of Personal Experiences

Narratives that fail to fit within either the specialist or critical discourses that surround science often struggle to find a voice in public debates around its governance. During the Australian debate, people with disease that may, in theory, benefit from ESC/SCNT research, some of whom represented patient advocacy groups, were invited to describe the hardship of their daily lives and hopes for medical interventions that might arise from stem cell research. Their stories were often articulate and moving. Being allowed to speak in public about their experiences was a highly personal matter for these participants, whose personal feelings and emotions were in need of legitimation. The emotional power of these narratives was, however, often resented or devalued by opponents of ESC/SCNT research.

At times, patients were dismissed by opponents to the policy proposal as having been misled into believing there was hope in the potential of ESC/SCNT research:

I think they are the classic dupes in all this... they get all the patient groups together and get someone in a wheelchair 'yes we'll cure you, are you behind us?', 'yes, we're behind you!'. You've got Parkinsons, you've had a stroke and the patient advocate groups will advocate anything that gives them hope. And I think that is a misuse of those people personally. [Opponent A]

As suggested in Professor Sherley's op-ed, supporters of ESC research were accused of making overhyped, exaggerated and misleading claims about the realistic prospects for benefits. In an apparent response to these criticisms, many policy advocates were seen toning down the language used in their claims about potential benefits. For example, the CEO of the Australian Stem Cell Centre at the time of the debate claimed that, "it should be understood that cell cloning technology is not a guarantee of a cure" and "at this stage, no scientist would guarantee its potential as a cure" (Steven Livesey, Australian Financial Review). Indeed, the false hopes being raised by doctors who exploit the vulnerabilities of patients in so-called 'stem cell tourism' is receiving increasing attention in the scientific and bioethical literature as a moral concern (i.e. Murdoch and Scott 2010). However, undermining the testimony of patients in the context of a public debate based on assumptions about their ability to form rational judgments was described by a patient advocate interviewed for this study as offensive:

They represent people like me as dupes... [like] we are just duped by these cavalry scientists who are giving us false hope. That really gives me the willies, because I am an intelligent person and everybody I know on this debate is pretty intelligent. We're not expecting overnight cures. I mean, I'm aware that this disease will probably kill me before any therapies are developed, but I never give up hope. [Advocate A]

In this quote, Advocate A has responded to the opponents' assertions of misguidance as an insult to their intelligence. This perceived lack of respect for the patients' voice in public debate is what Little et al (2002, 1081) refer to as "dysempowerment". Dysempowerment is a process whereby an individual interprets an event as an affront to their dignity and in ways that debilitates their ability to respond (Kane and Montgomery 1998). In the policy arena, this process results in the dysempowered being marginalised to the outer fringes of public debate as the more powerful 'mainstream' discourses of science, law and politics take precedence (Little et al. 2002). Dismissing the hopes held by patients as false is one possible means of achieving this: another is to undermine the generalisability of their accounts by providing counter-experiences of disease and illness. For example, by claiming that not all those who suffer from serious illness supported ESC/SCNT research, as indicated in the following quote from an interviewee whose close relative had recently deceased from a chronic disease, some opponents were able to assert that the patients' testimonies were either irrelevant or provided only limited insight into the issue:

Some people think somebody with that sort of background might have a different view and would be prepared to support any and all research that may assist people with, you know, Type 1 Diabetes, Motor Neurone Disease or like diseases. I guess my philosophy is good science requires good ethics. You have to draw a line somewhere. Even somebody such as myself who has so much to gain, potentially to gain, or my kids have so much potentially to gain, you've got to draw the line somewhere so the question is where do you draw the line on these matters in terms of the ethics. [Opponent B]

The quote from Opponent B implies that the experiences of those suffering from disease and illness ought not to have authority in ethical decision making around science policy. Not because they have been 'duped' – indeed, this opponent appears to acknowledge the potential for

benefits – but that their views are not *representative*. This lack of generalisation, and the subjectivity of personal experience, does not fit well with the other, purportedly more, objective discourses that sit at the policy table. And so while patients can reveal the most, and know best, about what they are experiencing, they do not speak with any authority in policymaking contexts as their stories almost invariably disappear from policy documents and legislation – they are dysempowered (Little et al. 2002). To establish their legitimacy, patients must, therefore, form into organisational groups (as patient advocates) and build alliances with other actors who speak on behalf of politically powerful institutions, such as science, medicine and the law.

Individuals are vulnerable when they speak about their personal experiences in the public domain, far more so than if they are speaking from a professional or political narrative. They are especially vulnerable when they are not institutionally supported or are without a discourse that protects them from personal attack. And while personal narratives can touch audiences emotionally and engender empathy from others who identify with their circumstances, they can also expose people to marginalisation through torment, humiliation, persecution and exclusion from other social groups to which they belong.

One such vulnerable group in the Australian debate were the embryo donors. Women who already donate their embryos, or will be called upon to donate their embryos and/or oocytes for ESC/SCNT research, play a crucial role in its future. Yet these women are in an extremely vulnerable position because they may often have strong emotional attachments to their embryos (De Lacey 2005; Haimes et al. 2008). According to an IVF patient interviewed in this study, many feel judged for making decisions about the fate of their embryos and particularly for speaking about their decisions or beliefs in the public domain.

I'm a Christian. I'm a member of a Church and... we had to sit and listen to these people, the right-to-lifers, say that if we were to consider using our stored embryos for research that we were treating them like frozen vegetables. Others accused us of treating them as a commodity. Some quite callously suggested that they were not surplus but unwanted and the Social Committee of the Anglican Church in Sydney said that anyone wishing to donate them into research were treating them as a commodity and that our guardianship of them should be withdrawn. [Advocate B]

Reflecting on the rhetoric employed by some opponents of the policy proposal, Advocate B makes explicit references to members of the Church who sought to silence her and other former IVF patients from participating in the debate. As she went onto explain, "I am a member of the Anglican Church in the Sydney diocese no more... I just pretty much felt an outcast there because I felt that I was in error". The treatment experienced by Advocate B, both in the public debate and as a member of this particular Church, and her subsequent actions is evidence of what Kane and Montgomery (1998) describe as the outcome of dysempowerment: that is, feelings of humiliation, indignation and hostility that that ultimately lead to an impairment in trust, motivation and commitment to the discourse community in question.

Patients of IVF programs are members of other discourse communities, which have their own rules about what its members can and cannot discuss in public discourse. For members who speak in terms that are not accepted within the discourse rules of a particular community are required to either modify their views or keep them private, else they risk expulsion (Little and Lipworth 2007, 10-11). These sanctions can threaten the identity of members because identification is part of the process in which they subscribe to the values,

beliefs and ideologies of a discourse community (Gee 1999, 32-34). Thus, when asked why more couples from IVF programs do not participate in public policy debates that affect decisions concerning their embryos, Advocate B replied that "it is very difficult for people to be open because they are afraid that judgments will be made about the way they want to have children". It is arguable, therefore, that fear of retribution and exclusion from other communities they are members of, as well as society more generally, has marginalised past and potential embryo donors participating as legitimate actors in the public debates around stem cell research. More often, their interests are represented by the more powerful and established voices of the IVF industry.

Legitimation of Discourse Communities

The legitimacy of medical doctors and scientists in science policy contexts is determined by norms and processes that draw sharp boundaries around, and assign status to, different types of expertise (Jasanoff 2005, 28-29). These boundaries are negotiated between experts (Gieryn 1999, 4-5) by drawing on terms that are situated within a preferred discourse (Little, Jordens, and Sayers 2003). Hence, in contexts such as stem cell research, scientists draw on the specialist discourses of science by providing the 'hard facts' and other experts, such as bioethicists and theologians draw on the critical discourses of bioethics in normatively justifying or refuting the research. However, while very distinct, our analysis of the Australian stem cell debate clearly shows how the two discourses are interdependent.

Throughout the Australian stem cell debate, moral and technical experts negotiated their legitimacy by drawing on multiple discourses that crossed into each other's domain of expertise. These processes were observed in the way participants deployed discourses that extended beyond the presumed boundaries of their expertise. At times, this fusion of moral and technical discourses often made it difficult to tease them apart. It was also indicative of how the rhetorical strategies adopted by participants reflected the different understandings discourse communities have about the ontology of human embryos, as highlighted in the following statement from a stem cell scientist:

It comes back to the definition of when life begins. If you were to take the view that says life begins when an egg and sperm are fertilised, or when an embryo is created by other means, then I completely understand that point of view about why you might have difficulties. I personally have some problems about giving the same credence to something which is less than the size of full stop comma dot or whatever, to put it colloquially. Compared to someone like yourself or myself, basically, I find it very difficult to see how you can equate the two together. [Advocate C]

Several factors emerge to suggest why expert discourses cross into multiple domains. First, like everyone else, experts belong to multiple discourse communities and may have numerous interests in the outcomes of a policy dispute (Irwin and Michael 2003, 95-97). Moral, technical and legal experts can each have simultaneous interests as employees, shareholders, parents of sick children and concerned citizens, as well as being professional researchers, academics, ministers, lawyers and so on. As they seek influence in public debate, experts will thus employ discourses from the domain(s) in which they have power (Ganchoff 2004). However, certain discourses may prevail because of priorities that are set in the mobilisation of discourse alliances.

Alliances invariably form between members of discourse communities who share some common goal in achieving a particular outcome. Perhaps the most notable alliance that arose during the Australian debate was that between the Catholic Church and conservative

sections of the Australian Federal Government at the time, which led directly to the funding of research into adult stem cells and the establishment of the National Adult Stem Cell Research Centre with non-competitive grants (Dayton 2006). Generally though, these alliances tend to be informal and loosely governed by an implicit set of rules that *guide* the types of arguments and claims participants may use in public debate.

In the Australian debate, informal alliances formed between scientists, patient advocates and other political supporters of stem cell research. This alliance primarily concerned itself with establishing and defending the technical viability of ESC/SCNT research. This strategy not only reinforced the 'genuine' potential of this research but also shifted attention away from the moral issues concerning the embryo by forcing opponents to respond to these technical issues and deny its potential utility. In the interview with Opponent C, the technical issues were seconded to the moral questions central to the opponent's position:

That's the heart of it. That it is wrong as it was unanimously felt to be in 2002 and remains so now. If that is wrong, then even if there are unique benefits to be gained scientifically from cloning that is too bad because it is an ethical aisle that cannot be crossed no matter how attractive the prospects are on the other side of that line. We simply have to find other ways as we are as we are, beautifully, with adult stem cell science. We need to find other ways to obtain those good goals. And therefore the scientific question is almost irrelevant. At the very best it is strictly secondary. [Opponent C]

As explained below by Opponent D, a Sydney religious identity, opponents felt they had to respond to claims the advocates made about the comparable utility of ESC and ASC research because the debate had focused on its potential benefits. Commitments to other moral imperatives did not allow them to acknowledge that benefits might potentially be gained from research on ESCs and SCNT:

The question isn't which one of these two will engage in therapy because there is a fundamental question behind one of them that doesn't allow me to say that embryo research is a good way to go, whether it will benefit or not. So, at that level it is not relevant. It is relevant in the sense that if you are claiming something, if you're claiming a lot for something, then you need to be able to at least make a good case as to why you are claiming so much. [Opponent D]

As SCNT is now permitted in most parts of Australia, this counter-strategy was unsuccessful in preventing the laws governing ESC/SCNT research from being relaxed for several reasons. First, it gave research advocates space to justify their case, which diverted the public's gaze from the opponent's main concern – the welfare of human embryos (Lynch 2009). Its efficacy was also weakened by the emphasis given to technological solutions in Australia's science policymaking context (Harvey 2008). Ultimately, however, the objections to ESC/SCNT research were ineffectual because issues that are framed as technical questions do not generate moral solutions (Jasanoff 2005, 195). Legitimacy in this debate was, therefore, contingent upon the participants who were able to access the debate, put forward their arguments and respond to the claims of others through their various social networks and allegiances.

The personal experiences of women and patients were marginalised in this debate by the alliances that formed between more powerful discourse communities. Members of these communities established legitimacy and asserted authority by discursively deploying science in claims that legitimated expert discourses while marginalising other types of epistemologies. The public debates surrounding stem cell research have thus come to be dominated by consideration of a relatively narrow range of arguments and issues to the

exclusion of other concerns that may be held by broader sections of the community who either do not or are unable to align themselves with institutionally-accredited discourse communities.

Conclusion

Examination of the debate around ESC/SCNT legislation in Australia found that participants in these debates use science claims rhetorically as a means of achieving a desired moral outcome and deploy them strategically as a source of authority and legitimation. Generally speaking, those opposed to the liberalisation of Australia's stem cell policy used science claims to state their opposition in terms of the immorality of creating and destroying human embryos for research purposes; while supporters of this policy proposal used science claims to position their arguments within the ethical framework of medicine and the moral good of pursuing outcomes associated with medical beneficence. The preferential use of science claims implied that the status attached to scientific knowledge was weightier than other epistemologies and that the personal narratives and stories of those most likely to be affected by the outcomes of the policy episode were relatively marginalised.

The terms participants use in public discourse, and the context in which they choose to speak, reflect not only their value preferences, but their membership of particular discourse communities. When participants speak 'out of turn' or in ways that conflict with the overall commitments of the communities to which they belong, their authority may be eroded and they may become marginalised. While such outcomes seem severe for individuals, they may be an inevitable consequence of attempts to force public discourse into domains where particular participants have dominant legitimacy and authority. These domains are represented in the stem cell debates by the expert communities that make up the specialist discourses of science and the critical discourses of bioethics.

The dominance of discourse alliances between Judeo-Christian religious groups, biomedical researchers, academic bioethicists, and the biotechnology industry, not only explains the observed uniformity in the global stem cell policy debates: it accounts for the dysempowerment of patients and women's groups. The dominant discourses within these alliances are institutionally-accredited and influence the public debate by generating the discursive resources that convey a unified message with a limited set of policy options. These resources are adopted by other, less powerful groups to gain legitimacy and reflexively influence the terms and framing of the debate. While this process provides access for groups who lack institutional legitimacy, it also entails a delegitimation of ambiguous meanings and conflicting values. Alternative viewpoints and positions are systematically marginalised by the institutions that compete for authority over the legitimation process, and whose interests are best served, by limiting participation to those who share similar values and ideals. As such, public debate around science policy is more likely to reflect the normative preferences of the prevailing social structures that control the legitimation process rather than the needs of those likely to be most affected by its outcomes.

More enriched and inclusive public debates about the governance of stem cell research may be encouraged by shifting focus away from the outcomes of particular policy decisions and onto the processes by which participants and their arguments are legitimated. These processes are moral, political and rhetorical, and operate in empirical and contextual practice. Science has an important role to play in these processes, not as means of silencing

others from discussion, but to explore possible meanings and novel solutions to policy problems. The point is not to win the debate at all costs, but to clarify and deepen our understandings of science and its social, moral and political implications.

- Banchoff, Thomas. 2005. Path dependence and value-driven issues: The comparative politics of stem cell research. *World Politics* 57 (2):200-230.
- Bell, Allan. 1991. The Language of News Media. Cambridge, MA: Blackwell Publishers.
- Cooper, Donna. 2006. The Lockhart Review: Where now for Australia? *Journal of Law and Medicine* 14:27-44.
- Dayton, Leigh. 2006. Unease stems cell research funding joy. The Australian, 13 May, 31.
- De Lacey, Sheryl. 2005. Parent identity and 'virtual' children: why patients discard rather than donate unused embryos. *Human Reproduction* 20 (6):1661-1669.
- Derrida, Jacques. 2003. Autoimmunity: real and symbolic suicides: A dialogue with Jacques Derrida. In *Philosophy in a Time of Terror: Dialogues with Jurgen Habermas and Jacques Derrida*, edited by G. Borradori. Chicago: University of Chicago Press.
- Epstein, S. 2000. Democracy, expertise and AIDS treatment activism. In *Science, Technology* and *Democracy*, edited by D. L. Kleinman. Albany, NY: State University of New York Press.
- Gamson, William A. 1990. The Strategy of Social Protest. Homewood, IL: Dorsey Press.
- Ganchoff, Chris. 2004. Regenerating movements: embryonic stem cells and the politics of potentiality. *Sociology of Health & Illness* 26 (6):757–774.
- Gans, H J. 1979. Deciding what's news: a study of CBS Evening News, NBC Nightly News, Newsweek and Time. New York: Pantheon Books.
- Gee, James Paul. 1999. An Introduction to Discourse Analysis. London: Routledge.
- Gieryn, Thomas F. 1999. *Cultural Boundaries of Science: Credibility on the Line*. Chicago: University of Chicago Press.
- Goggin, G, and C Newell. 2004. Uniting the nation? Disability, stem cells, and the Australian media. *Disability & Society* 19 (1):47-60.
- Gottweis, Herbert. 2002. Stem cell policies in the United States and in Germany: between bioethics and regulation. *Policy Studies Journal* 30 (4):444-469.
- Gross, Alan, ed. 1996. *The Rhetoric of Science*. Edited by T. Enos, *Encyclopeodia of rhetoric and composition: Communication from ancient times to the information age*. New York: Garland Publishers.
- Habermas, Jürgen. 1989. The Structural Transformation of the Public Sphere: An Inquiry into a Category of Bourgeois Society. Edited by B. Thomas. Cambridge, MA: MIT Press.
- Haimes, Erica, Rouven Porz, Jackie Scully, and Christoph Rehmann-Sutter. 2008. "So, what is an embryo?" A comparative study of the views of those asked to donate embryos for hESC research in the UK and Switzerland. *New Genetics and Society* 27 (2):113-126.
- Harvey, Olivia. 2008. Regulating stem cell research and human cloning in an Australian context: The Lockhart Review. *New Genetics and Society* 27 (1):33-42.
- Hauskeller, Christine. 2005. Introduction. In *Crossing Borders: Cultural, Religious and Political Differences Concerning Stem Cell Research*, edited by W. Bender, C. Hauskeller and A. Manzei. Munster: Agenda Verlag.

- Irwin, Alan, and M Michael. 2003. *Science, Social Theory and Public Knowledge*. Maidenhead: Open University Press.
- Jasanoff, Sheila. 2005. *Designs on Nature: Science and Democracy in Europe and the United States*. Princeton, NJ: Princeton University Press.
- Kane, K., and K. Montgomery. 1998. A framework for understanding dysempowerment in organizations. *Human Resource Management* 37 (3-4):263-275.
- Kennamer, J David. 1992. Public opinion, the press, and public policy: an introduction. In *Public Opinion, the Press, and Public Policy*, edited by J. D. Kennamer. Westport, CT: Praeger Publishers.
- Kitzinger, Jenny, and Clare Williams. 2005. Forecasting science futures: Legitimising hope and calming fears in the embryo stem cell debate. *Social Science & Medicine* 61 (3):731-740.
- Kleinman, A, and J Kleinman. 1997. The appeal of experience; the dismay of images: cultural appropriations of suffering in our times. In *Social Suffering*, edited by A. Kleinman, V. Das and M. Lock. Berkley: University of California.
- Limoges, Camille. 1993. Expert knowledge and decision-making in controversy contexts. *Public Understanding of Science* 2 (4):417-426.
- Little, J M. 2010. Is there a real nexus between ethics and aesthetics? *Journal of Bioethical Inquiry* 7 (1):91-102.
- Little, Miles, C F C Jordens, K Paul, Emma-Jane Sayers, J A Cruickshank, J Stegeman, and K Montgomery. 2002. Discourse in different voices: Reconciling n=1 and n=many. *Social Science & Medicine* 55 (7):1079-1087.
- Little, Miles, Chris F C Jordens, and Emma Jane Sayers. 2003. Discourse communities and the discourse of experience. *Health* 7 (1):73-86.
- Little, Miles, and Wendy Lipworth. 2007. Focused discourse: an exploratory essay. Vol. 2, VELIM Occasional Monographs Seriers. Sydney: Centre for Values, Ethics and the Law in Medicine.
- Lynch, John. 2009. Stem cells and the embryo: biorhetoric and scientism in Congressional debate. *Public Understanding of Science* 18 (3):309-324.
- Merriam, Sharan B. 1988. *Case Study Research in Education: A Qualitative Approach*. San Francisco, CA: Jossey-Bass Publishers.
- Mooney, Christopher Z. 2001. The public clash of private values. In *The Public Clash of Private Values: The Politics of Morality Policy*, edited by C. Z. Mooney. New York: Chatham House.
- Mulkay, Michael. 1997. *The Embryo Research Debate: Science and the Politics of Reproduction*. Cambridge, UK: Cambridge University Press.
- Murdoch, Charles E., and Christopher Thomas Scott. 2010. Stem Cell Tourism and the Power of Hope. *The American Journal of Bioethics* 10 (5):16 23.

- Nelkin, Dorothy. 1995. Science controversies: the dynamics of public disputes in the United States. In *Handbook of Science and Technology Studies*, edited by S. Jasanoff, G. E. Markle, J. C. Peterson and T. Pinch. Thousand Oaks, CA: Sage Publications.
- Nicol, Dianne, Donald Chalmers, and Brendan Gogarty. 2002. Regulating biomedical advances: Embryonic stem cell research. *Macquarie Law Journal* 2:31-59.
- Nisbet, Matthew C, Dominique Brossard, and Adrianne Kroepsch. 2003. Framing science: the stem cell controversy in an age of press/politics. *Harvard International Journal Of Press/politics* 8 (2):36-70.
- Nowotny, Helga. 1993. Socially distributed knowledge: five spaces for science to meet the public. *Public Understanding of Science* 2 (4):307-319.
- Parry, Sarah. 2003. The politics of cloning: mapping the rhetorical convergence of embryos and stem cells in parliamentary debates. *New Genetics and Society* 22 (2):145-168.
- Prelli, Lawrence J. 1997. The rhetorical construction of scientific ethos. In *Landmark Essays* on *Rhetoric of Science: Case Studies*, edited by R. A. Harris. Mahwah, NJ: Hermagoras Press.
- Robins, Rosemary. 2005. Biomedical innovation or bioethical precaution: The stem cell debate in Australia. In *Crossing Borders: Cultural, Religious and Political Differences Concerning Stem Cell Research*, edited by W. Bender, C. Hauskeller and A. Manzei. Munster: Agenda Verlag.
- Shoemaker, Pamela, and Stephen D Reese. 1996. *Mediating the Message: Theories of Influences on Mass Media Content*. 2nd ed. White Plains, NY: Longman.
- Tupasela, Aaro. 2007. Re-examining medical modernization: framing the public in Finnish biomedical research policy. *Public Understanding of Science* 16 (1):63-78.
- Van Dijk, Teun A. 1996. Discourse, power and access. In *Texts and Practices: Readings in Critical Discourse Analysis*, edited by C. R. Caldas-Coulthard and M. Coulthard. London: Routledge.
- Waddell, Craig. 1997. The role of pathos in the decision-making process: A study in the rhetoric of science policy. In *Landmark Essays on Rhetoric of Science: Case Studies*, edited by R. A. Harris. Mahwah, NJ: Hermagoras Press.
- Wainwright, Steven P, Clare Williams, M Michael, B Farsides, and Alan Cribb. 2006. Ethical boundary-work in the embryonic stem cell laboratory. *Sociology of Health & Illness* 28 (6):732-748.
- Waldby, Cathy, and Brian Salter. 2008. Global governance in human embryonic stem cell science: standardisation and bioethics in research and patenting. *Studies in Ethics, Law and Technology* 2 (1):Article 12.
- Williams, Clare, Jenny Kitzinger, and Lesley Henderson. 2003. Envisaging the embryo in stem cell research: rhetorical strategies and media reporting of the ethical debates. *Sociology of Health & Illness* 25 (7):793-814.

Cases Cited:

Sherley v. Sebelius, 686 F. Supp. 2nd 1, 5-7 (D.D.C. 2010)