

Phenomenological sociology and the sociology of bioethics: two New Zealand studies

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Abstract

This article addresses several issues raised by social scientists regarding the contribution of sociological research to bioethics, the activities of bioethicists themselves in the social construction of bioethical concerns, and the relationship between the public and bioethicists in establishing and maintaining public trust in medical and scientific research. The primary aim of the article is to demonstrate the value of social science research that investigates peoples' lived experience of modern biomedicine and innovative technology for bioethical debate. In order to do this, we offer snapshots of our research undertaken with New Zealanders from two separate studies respectively informed by phenomenology and the sociology of bioethics. The first study, which focuses on how people experience their self-identity and embodiment in organ donation and transplantation processes as fundamentally intersubjective and social, suggests why phenomenology should be incorporated into contemporary bioethical approaches deliberating issues about the body. The second study, which examines the value of lay perspectives in public engagement with bioethics, draws on research about women's decision-making regarding prenatal screening, to offer critical comment on bioethics as a social, cultural, and intellectual event.

Introduction

This article addresses several issues raised by social scientists regarding the contribution of sociological research to bioethics, the activities of bioethicists themselves in the social construction of bioethical concerns, and the relationship between the public and bioethicists in establishing and maintaining public trust in medical and scientific research. The primary aim of the article is to demonstrate the value of social science research that investigates peoples' lived experience of modern biomedicine and innovative technology for bioethical debate. To do this, we offer snapshots of our research undertaken with New Zealanders from two separate studies respectively informed by phenomenology and the sociology of bioethics.

Sociology and ethics

Despite efforts to constitute itself otherwise, the perception of social science as outside the remit of bioethics is long-standing. In this article, we ask specifically what social science might contribute to bioethical debate. The question may seem straightforward, but it was not until Scott Lash wrote an editorial to *Theory, Culture & Society* in 1996, claiming that the sociology had paid 'insufficient attention' to ethics, that sociologists began to seriously rethink the significance of moral matters in the construction of social life. Although morality has always been on the agenda of classical sociology, and is pivotal to the work of social theorists such as Frankfurt School thinkers, for example, the prevailing view among many sociologists during the twentieth century was of moral life as epiphenomenal. Sociologists, generally speaking, have also viewed ethics in mentalist rather than materialist terms, as codes, rules or principles

that apply to specific problems. By the time Lash made his declarative statement, however, many sociologists agreed that the discipline had largely ignored how “ethics is constitutively linked to corporeality” (Gardiner, 1996) and thus to subjectivity. In the course of the last two decades, sociologists have sought to rectify this.

Notwithstanding moves by sociologists to address the ways moral matters articulate with the body, philosophers have historically dismissed what sociologists might have to offer as peripheral to ethical debate. As Author 1 (Shaw, 2006) has commented elsewhere, primer philosophy texts often characterise sociological discussions of ethics as limited to causal accounts of moral phenomena and thereby confined to descriptive analysis. Sociologists may provide useful background information about social mores and ethical beliefs, but unlike philosophy, sociological research lacks a reasoned account of moral conduct and provides no guidelines for action. In other words, sociologists are not in the business of evaluating or solving ethical problems. Subsequently, when bioethics emerged in the 1970s ethicists assumed sociology’s main contribution to bioethical debate was limited to empirical description.

While biomedical ethics texts still reiterate this age old “is/ought” disjunction (see Beauchamp and Childress, 2001), it remains a point of contention for commentators championing the closer engagement of sociology and bioethics (Borry et al., 2005; DeVries and Conrad, 1998; DeVries et al., 2006; Fox and Swazey, 2005; Haimes, 2002; Hedgecoe, 2004). These scholars variously argue that social science research is always already critically normative.

Social science and bioethics

Since its increasing professionalisation as a field in English-speaking universities, from the late 1960s and 1970s onward, bioethics has slowly attracted the attention of social scientists. From its inception, however, the relationship has been an uneasy one. “Compared to philosophers, physicians, and lawyers”, remark Fox and Swazey (2008, p. 173), “social scientist participants have been relatively few in number; and their outlook, modes of thought, and bodies of empirical knowledge have had a minimal effect on the conceptual framework, premises, value orientation, and agenda of bioethics.” In an earlier commentary, Fox and Swazey (2005) observe the use of sociological insights by leading bioethics’ disciplines simply as illustrative examples or cases to aid the formulation of principles and general theories in the field. Haimes (2002, p. 99) also notes how this ‘handmaiden role’ has plagued sociologists who have undertaken empirical work in medicine and health.

The undervaluing of sociological contribution and insight in this way has much to do with the dominance of philosophy and medicine in an otherwise interdisciplinary field. The privileged place accorded to these disciplines has led to on-going cross-disciplinary debate over what subjects to privilege in the bioethical arena and what methodological approaches to adopt. Without denying its importance, a current focus for bioethical inquiry, as well as availability of research funding, has tended to be on and around studies in genetics, stem cell research, xenotransplantation, and so on – the high-tech end of medicine and health care. For some, the focus on these ‘cutting-edge’ topics has, as bioethicist Leigh Turner (2005, p. 374) remarks, occurred at the expense of what could otherwise be “bioethical” issues, but are not (see Fox and Swazey, 2005, p. 363). Although Turner makes the point that bioethics has not entirely neglected ‘ethical issues related to what are often called the “social determinants” of health and illness’, he nonetheless argues that the preoccupation has been with issues ‘at the bedside’ (2005, p. 377).

As sociologists interested in exploring the lived experience of morality in health care, and the discussion of these perspectives in the public domain, we also focus on issues ‘at the bedside’. Unlike the application of mainstream philosophy and medicine in bioethics, our research is primarily concerned to document how people negotiate and manage their identities as moral subjects in medicalised and biotechnological situations that challenge their experience of embodiment as bounded,

autonomous and universally applicable. We maintain that recognition of this experience as culturally and socially diverse can provide guidance for public policy and health care practice.

The following discussion, which draws on examples from two separate sociological studies, implicitly questions the construction of the normative bioethics' subject as individuated, bounded and closed. In so doing, the first study, which focuses on how people experience their self-identity and embodiment in organ donation and transplantation processes as fundamentally intersubjective and social, offers a reason for incorporating such accounts into the contemporary bioethical corpus. The second study, which examines the value of lay perspectives in public engagement with bioethics, steps back from ethnographic description in this article to offer critical comment on bioethics as a social, cultural, and intellectual event.

Underpinning both research approaches is the belief that the views and experiences of research subjects regarding the practices they participate in can usefully add to, and enhance bioethical understanding. There is precedent for this stance in bioethics. In an early paper, Hoffmaster (1992) suggested that ethnography could help to "save the life of medical ethics", and qualitative research methods including feminist and narrative ethics have increasingly been adopted as approaches in the field (e.g., Lindemann et al., 2009). However, what bioethicists generally call ethnography may not be what social scientists say it is (anthropologists especially), and while ethnographic methods may be deployed by phenomenologists ethnography does not exhaust phenomenological sociology.

The body in bioethical debate

Phenomenological sociology, as Author 1 defines it, emphasises the social and cultural character of embodied existence and being-in-the-world. As a descriptive and interpretive approach to the study of lived experience, it theoretically informs the first research project discussed in this article. This study draws on data from one-to-one interviews with New Zealanders designed to investigate perceptions of organ donation and transplantation processes. The interviews took place from 2008 to 2010 and involved talking with 24 organ and tissue recipients, 13 living organ donors, and 9 donor family members who identified as New Zealand (NZ) European or Pakeha. Two separate studies with health professionals and members of stakeholder groups were undertaken (27 participants in total) as part of the larger study, as well as interviews with 15 donors and recipients in a connected study with Māori and whanau. The aim of the overall study was to determine how the respective roles, beliefs and understandings of different groups of New Zealanders toward human embodiment and identity shape and frame their attitudes and moral experience of organ donation and transplantation.

All the participants in this study were self-selected adults, recruited through advertisements in national newspapers, magazines, and websites associated with organ donation and transplantation during 2008 and 2009. The interviews for the study, which usually occurred in participants' homes or at a location convenient to the interviewee, took between 1 ½ to 2 ½ hours. The interviews were audiotaped with participants' consent, transcribed, sent to participants for checking and editing, and then coded and analysed thematically.

The study interviews were narrative in style and built a picture of how participants made sense of their experience of organ donation and transplantation. An objective of the overall study was to determine the extent to which discourses circulating in the public domain and popular press influenced and shaped the ways people described their experiences and the context in which organ transfer occurred.

Several dominant representations of organ donation circulate in the public domain in New Zealand. These descriptions and images, documented in the media as 'human interest' stories, draw on personalised anecdotes promoting donation and transplantation as a moral good (e.g.,

Loates-de Roles, 2009). At the same time, some media figures promote a number of misconceptions about New Zealanders' reticence to donate organs and lack of generosity as donors of body tissue (e.g., Laws, 2009).

Deceased organ donation rates in NZ are relatively low, compared to other western countries. In 2009, there were 9.9 deceased donors per million population in NZ (<http://www.anzdata.org.au/anzod/v1/AR-2010.html>), compared to 34.0 in Spain where consent for donation is vigorously sought after. A number of reasons exist for the low NZ donation rate, of which the public is not generally aware. First, only 1.5 - 3% of people who die in the western world do so in circumstances where they could be deceased organ donors. These people die in traumatic and unexpected circumstances, and must be certified brain-dead by two Intensive Care physicians, independent of each other, before donation can become a possibility. An Intensive Care specialist then offers the family of the deceased the option of organ donation for their loved one. A family may or may not agree, no matter what the intent of the deceased as listed on his or her driver's licence.

Second, deceased donation rates are increasingly low due to improvements in road safety, which include laws about wearing seat belts, improved car design, better road layouts, more frequent use of motor cycle helmets, speed control, and reduced road speed limits. Demand for tissue and organs outstrip supply, and the numbers of people on waiting lists for organ transplantation in NZ is growing. Supply is also relative to demand. Reiss lists reasons for increased demand: advances in transplant surgery, for instance, make it possible to transplant more organs than previously (e.g., lungs), and a greater range of conditions can now be treated by transplantation (www.biotechlear.org.nz/themes/bioethics/ethics_of_organ_donation Accessed 11/04/2010).

Somewhat understandably, the health focus of transplantation advocates in the business of saving lives tends toward increasing supply to meet demand and ensuring favourable outcomes after transplantation operations. Successful transplantation and "healthy" life is thus an end-point in this process. As one would expect, interview data corroborate media accounts of transplant recipients, who do indeed speak of their successful operations in terms of renewed life. In her personal story, Loates-de Roles (2009, p. 50), for example, describes organ transplantation as 'a life-changing experience.'

Participants in Author 1's research not only talked about renewed life, given a second chance to live again, and doing well for their donor families, they spoke of marking the occasion of their operation with 're-birthdays'. These are second birthdays to commemorate the day of their successful transplant, a phenomenon documented in the literature (see Sharp, 2006). At the time of interview, one research participant in this study commented that he was about to celebrate his 7th birthday.

The gratitude and thanks expressed by transplant recipients to their donors, donor families, to physicians and the medical profession for their new lives cannot be overestimated. Indeed, discussion about being able to say 'thank you' properly was a central component of the interview conversation in the foregoing study. In conjunction with this, transplant recipients also raised another topic in their interviews. Talk around this topic is largely invisible in mainstream bioethics discourse on organ donation and transplantation, not to mention subjugated in popular press representations of tissue exchange, especially that which focuses on discussion about new life, and accepting the newly transplanted organ as a part of the 'new me'. This talk includes discussion of how transplant recipients come to terms with their hybrid identities as embodied subjects incorporating organs from others, often unknown to them.

The related topic of bodily integrity and hybrid identity is often an emotional one for transplant recipients, closely tied, as it is, to being able to convey gratitude and reciprocity to anonymous donors and donor families of deceased donors. Health professionals and psychologists do not typically discuss the matter of incorporating aspects of other's identities in the course of

organ transfer with organ donors and recipients who prepare them for their operations. There is anecdotal evidence indicating that chaplains and social workers may discuss the subject in the NZ hospital setting, but no hard evidence to verify that this is systematic. In any case, this issue is certainly not a topic for discussion post-transplant. Consequently, the question of corporeal changes to the self and the experience of what Shildrick calls 'psychic alterity' (2008, p. 16) for organ recipients post-transplant is invariably left unspoken. Preliminary findings from the first author's research indicate that this subject produces different levels of anxiety for transplant recipients, often conveyed by intense emotion in the talk of interviewees about this issue. Although questions about hybrid identity are reported in studies about public attitudes to organ transplantation (e.g., see Sanner, 2001), there is currently no health care forum for discussing this matter comprehensively other than what research participants impart in their interviews with social researchers, and in conversation with family and friends.

As a significant theme for participants in the organ donation research, the question of embodied psychic alterity bears on the management of a strict organisational imperative of anonymity around organ donation in NZ. As is the case in Australia and the United Kingdom, personal information about donor families and recipients cannot be disclosed, so the parties to the organ exchange process know very little about one another. Recipients do not know the name of their donor or contact details about the donor's family. They typically do not know their donor's age or gender, although sometimes such information is discovered 'accidentally'. Recipients are permitted to write anonymous thank you letters to donor families and anonymous donors and these are mediated through the hands of donor and recipient co-ordinators. In this research, recipients were clear about the need to respect donor families' rights to anonymity, especially as they were grieving, but they were also cognisant of the fact that their ability to act morally in relation to expressing gratitude and reciprocity was constrained by anonymity protocol. In their conversations, they explained this troubling aspect of their new identities as they came to terms with the incorporation of body parts gifted from another. Without undertaking primary sociological research on people's perceptions of organ transfer, we would not be aware of the significance of this aspect of the process for those involved.

From the perspective of these participants in organ donation and transplantation processes the exchange of body tissue not only saves and enhances lives, it is also 'relational and social' (Waldby, 2002, p. 240). That is, organ donation and transplantation not only has cultural and spiritual implications for different groups of people (see Lewis and Pickering, 2003), it can also instantiate profound changes to people's sense of self-identity.

When a transplant operation goes well and an organ recipient has successfully incorporated an organ (the time-period beyond risk of rejection is calculated at around three months), then the outcome, from clinical assessment standards, is considered to be good. In addition to clinical and physiological success, however, organ donation and transplantation also needs to be successful on a psychosocial level, as Shildrick (2008) says. Interviews from this study indicate that this aspect of the process is not taken into account when the focus is primarily medical.

Models of the body

Data from the organ donation study suggest that acceptance of rules around anonymity protocol depends on how people conceptualise embodiment and how they view their identities and the identities of others in relation to their own bodies. Linked to the theme of anonymity was the matter of how people constructed their identities post-transplant in relation to the incorporation of an "alien" body organ and to their donors and members of donor families.

In the interviews with donors and recipients, people referred to two main ways of understanding their bodies in the course of transplantation (sometimes simultaneously). The first

model conforms to a dominant paradigm of self-body understanding, aligned to a mechanistic Cartesian model that views mind and body as distinct and separate entities. Shildrick (2008, p. 16) notes that people who adopt such a model initially do very well clinically post-transplant. I encountered this perception numerous times in interviews with transplant recipients. The following quotation, from a lung transplant recipient is typical:

I am extremely grateful to my donor and I don't mean to trivialise it. [...] I know that not all cultures see it that way, but when you see the organ and if you didn't know what it was you'd probably think it was something in the supermarket. It's a piece of meat. Um, I don't mean to sound insensitive.

For this interviewee, her own lungs and the new organ she received were not imbued with 'personhood' or any special qualities.

Some interviewees did not accept this model of the body; rather, they rejected it. For some Māori participants in the connected study this alternative conception of embodiment was associated with culturally specific models of health, as well as spiritual understandings of the body and self in relation to others (see Note 2). As Lewis and Pickering (2003, p. 33) say, for Māori who do hold traditional cultural and spiritual views about burying the dead, not to inter a body whole, or to have its parts living on outside the body, could potentially tamper with ancestral heritage, which may breach customary rules and observances. Hence, the ethics of donative practices such as organ donation cannot be taken lightly in terms of thinking about embodied subjectivity in this context and may require discussion with whanau, if not within the larger collective. Elements of this view, although not entirely commensurate, are also significant for Pakeha who do not subscribe to any spiritual or religious belief system.

As discussed elsewhere (Haddow, 2005; Shaw, 2010; Shildrick, 2008), this model fits a phenomenological description of the body-subject. This self inhabits a body that is inextricably linked, "inseparable from and exists only in relation to other bodies inhabiting a world" (Shildrick, 2008, p. 14). Because phenomenology holds that the self changes as the body changes, subjectivity and embodiment exist in a dynamic relationship with other selves and the material environment. We can thus see how this understanding of the body might be significant for people who lose a body organ, at the onset of bodily breakdown or disease, thus threatening their sense of self as continuous and whole. While some people objectify the diseased organ as "waste": a defunct, failed, or replaceable body part, as in the quotation above, others talked about mourning the loss of that organ as a part of the self they need respectfully to let go. Even when described as diseased, transplant recipients do not necessarily dispose of their old organ. The ODNZ website, for example, cites a story (posted on 31 May 2010, accessed 4/10/10) about a heart transplant recipient who: "keeps his old heart in a bag in his room. The Christchurch teenager hasn't decided what to do with the defective organ since it was removed from his chest last year and replaced with a donor heart." Likewise, a *Weekend Herald* (April 10, 2010: B4) story describes the emotion one heart recipient felt as she collected her old heart from the hospital, took it home, and "slept next to it in the sitting room tangi-style". Treating her old heart like 'whakapapa', this woman recalls how she "then took it to the cemetery, wrapped it in a family cloak and buried it on top of her mum."

For some people, the incorporation of body parts rather than their loss reconstitutes embodied identity in moral and spiritual ways. In Lock's (2002) research, organ recipients were reported as experiencing feelings of intense identification for their unknown donor, thus confirming McKenny's (1999, p. 355) observation that the transplanted organ retains traces of the 'otherness' of its donor long after recipients have adjusted to the physiological and immunological effects of organ transfer.

The following account below from a Pakeha woman, who talks about her family's interactions with a recipient after donating her deceased son's organs, captures these phenomenologi-

cal aspects of organ transfer. This account conveys her understanding of cultural issues for Māori around sharing her son's body parts and life. In addition, the quotation offers a perspective as to why anonymity protocol may need to be re-examined in NZ.

One of [the recipients] was Māori, and for the year after [my son's] death, every now and then there would be a telephone call. With the first one nothing was said at all, and the second one, nothing much was said. And then, after about a year, this man explained to us that we mightn't want to know him, because he was an old Māori bloke, but he had received one of [my son's] kidneys. And we assured him that it made no difference to us that he was an old Māori bloke. But what transpired from that was, when [X] had [a significant] birthday he invited us, and he invited the family of the other recipient and the surgeons, and we all met on the Marae together to celebrate his birthday. [...] So that was pretty amazing, and it wasn't until then, really, that I began to understand the whole issue about organ donation and so on, as far as Māori are concerned. The interesting thing was when [X] finally died he had left a phone message to say, 'would it be all right for ... [sobs] ... [my son's] kidneys to stay with him?'

The above quotation makes sense in light of perceptions of tissue donation as a gift relationship rather than a uni-directional form of exchange, as well as linking the importance people place on both the social and biological dimensions of human life. A comment from a Pakeha anonymous altruistic donor confirms this view:

It's funny but I still feel like I've got two kidneys. It's just the other one is in someone else's body and that is part of the reason why I have asked the transplant coordinator to let me know if the recipient actually does pass away, because that's part of me. And also, I feel that if I die tomorrow in an accident, well there's actually still part of me alive. I know that sounds really weird, but I do feel like I still do have two kidneys. Obviously I'm not going to get the other one back, nor do I want it back, but I still do feel that I've got two, just one of them is in someone else's body.

Quotations such as these demonstrate how organ transfer not only enhances life for those threatened by the failure of specific body parts; for a number of participants in this research project tissue transfer also conveys meanings about subjectivity, identity and intercorporeality. Dominant bioethical discussions of organ donation and transplantation that focus specifically on questions of supply and demand will not be able to uncover this kind of information, but a sociological investigation informed by phenomenology would be concerned to make sense of what organ transfer means for people not only physiologically, but also on a symbolic, social and metaphysical level. The value of such data lies in its practical use to inform debate and reflection on how best to meet the needs of prospective organ donors and recipients.

Rapid changes and advancements to biomedicine and surgical procedures mean that people often find themselves in predicaments where they have to act quickly about their health care and the health of others, and in situations where they often lack sufficient time to deliberate the pros and cons of their decisions. The choices people make as they find themselves at the forefront of techno-science and biomedicine arguably position them as 'moral pioneers', as Rapp (2000, p. 306) has said of women confronted with decision-making choices around pre-natal screening. People in such circumstances must enact 'situational responsibility' – to borrow a phrase from Scully et al. (2010) – when making novel ethical decisions, not just for themselves, but also for others to take into account. Against a dominant bioethics' perspective that views those directly involved in health care interventions as too close to see the issues underpinning their situations objectively, we believe such experiential accounts provide ethical resources for enhanced bioethical deliberation. The following sections, which draw on accounts of women's experiential encounters of prenatal screening technologies, highlight this point.

The public voice in bioethical debate

A useful starting point in considering the question of public engagement with bioethics – the extent to which this may already occur, as well as what might constitute an ideal relationship

– is to inquire into the public's expectations of bioethics. Work has been undertaken to gauge public opinion and debate on topics of specific bioethical interest, but there is little research to indicate what the public might want and expect from bioethics and bioethicists.

This kind of sociological work forms part of a qualitative social science study by Author 2 toward a PhD in Sociology on how pregnant women come to terms with ethical dilemmas raised by prenatal screening. This research focused on how the increasingly routine practice of prenatal screening (and in particular, the expanding use of ultrasound scanning such as nuchal translucency scanning or NTS) is constructed as a choice in contemporary public health discourse in NZ.

As a key aim of qualitative interviews is to uncover subjective accounts of particular phenomena, the primary purpose of the empirical component of this research is to explore prenatal screening as a 'lived experience', from the perspective of those to whom this technology is applied. In qualitative research, the value of such accounts is to give voice to hidden dimensions of human experience, which may otherwise be excluded from analysis. Although the approach taken in this particular study recognises the importance of documenting empirical accounts for critically oriented sociological research, it is not phenomenological research per se. However, through exploring lay experiences of, and attitudes towards, bioethical processes (e.g., protocols of informed consent and patient information) the research positions the phenomenon of bioethics – its form, operation and impacts – as a topic of critical sociological enquiry and can be seen to fit within the broader frame of the sociology of bioethics.

In seeking to foreground the lived experience of prenatal screening, the issue of informed consent was a key focus for the project overall. Accordingly, the 20 in-depth interviews for the study explored the extent to which pregnant women experience their decision-making as informed and autonomous, and their view on what constitutes a meaningful consent.

Interviews were conducted in late 2005 and early 2006 and were guided by a series of open-ended questions, which were used to prompt participants in describing and evaluating their experiences of prenatal screening, and to recall these events on their own terms. With participants' permission interviews were recorded and transcribed, then analysed for emergent themes.

In short, findings from the research indicate that the framing of prenatal screening, as both a matter of individual 'choice' and as the right choice, problematises pregnant women's decision-making and raises important questions about the ethics of the current approach to prenatal screening in NZ. A key finding of the study is participants' evident ambivalence around the experience of screening, and chiefly around the extent to which such choices felt "compelled" in certain directions, both through the practices of individual clinicians, and more broadly within the climate of contemporary pregnancy care. This ambivalence suggested the need for urgent ethical attention to the issue of informed consent in the context of current prenatal screening practice in New Zealand. In this research, participants were also asked their opinions about the purpose and value of bioethics in society, and whether or not prenatal screening should be a matter for public debate. The purpose of this auxiliary line of questioning was to gain a preliminary sense of what expectations those 'at the receiving end' of this rapidly evolving technology might have in terms of bioethics processes, and in particular, their views of the significance of public involvement in this area.

Participants' accounts reflected a broad view that public consultation is an important requirement for ethical practice in prenatal screening, with all but two participants indicating that they regarded prenatal screening as a matter for public ethical debate, and not as a solely private concern. Public involvement in decisions around the use and development of screening technologies in this area appeared to be viewed as an important ethical safeguard, and responses to these questions often emphasised the importance of diverse representation in ethical processes, which included the views of 'ordinary people'. The following remark exemplifies this view:

[...] I think there needs to be input from people across, right across, you know, society. Not just the doctors and the medical people and the researchers, but also from the public because I think there is quite a big sort of ethical thing here. I should also say I'm not religious in any way...so this is not from a sort of firmly entrenched religious perspective or anything, it's just you know sort of a feeling that I have that there needs to be a lot of consultation, we have to be really careful where we go with it.

For another participant in the study, it was very important that accounts of women's experience should, at a minimum, be included in this debate (particularly about developments in high-tech prenatal care), or more ideally constitute the starting point for broader public deliberation. As she put it:

Well, I think research like yours helps, you know, it helps. One, you're working with subjects, you're working with people who have the experience of tests like this, so it helps people move from their experience, from their raw experience to another kind of level, and kind of process their experience. And that's important because otherwise it's just an experience. And for it to move from that experience to kind of critically thinking about "well, what did that experience mean?" [...] And I think research helps feed the dialogue and the debate, yeah? So, one person's question has the ripple effect of getting more people to ask questions.

Similarly, another respondent remarked; 'it's only those that have walked the road that really know the ins and outs and have faced the issues.'

Within the context of this research on prenatal screening, comments made by participants about the value of public engagement in ethics debates hint at what may be a broader reluctance among pregnant women in general to privately and exclusively bear ethical responsibility for the dilemmas raised by foetal screening practices. So, while liberal notions of prenatal screening as a choice emphasise individual rights and freedoms, pregnant women themselves, while valuing such rights, also conceive of the issue as a matter of broader public interest. For example, while a majority of participants held a 'pro-choice' view of abortion many appeared to find the issue of targeted prenatal screening for specific conditions such as Down syndrome ethically troublesome, viewing it as a practice requiring a broader social mandate. For example, one participant commented:

Well, that's a question for everybody, about whether we're trying to eliminate some conditions from our society, whether we're trying to stop them costing us so much money, that would be another way of looking at it, or whether we're just trying to give people the option as to how they want to live their lives.

Study participants also emphasised how important it was for bioethics to operate as a kind of "buffer" between ordinary people and the realm of techno-scientific developments. They expressed concern that somebody filled this role in a formalised capacity, although questions about the ideal credentials of those persons, such as membership of ethics committees, tended to elicit rather generic suggestions. One respondent, for instance, remarked, "ideally I think you'd need to have a really well chosen sort of committee, I suppose, or a panel, made up of a good cross-section of people." The representation of a diversity of viewpoints was also a clear concern for these respondents. This included considerable support for the representation of people affected by conditions currently targeted by prenatal screening on such committees, and not simply those vying for the elimination of deleterious conditions and traits. Study participants emphasised the importance of lay views here, especially if bioethicists on ethics committees are going to instil confidence in the public.

While clearly signalling an expectation of public consultation in the development of screening policy, participants were ambivalent about the value of ethical 'debate' per se on this issue, suggesting that reliance on this approach alone would be unlikely to represent an adequate diversity of concerns. As one respondent remarked, "the trouble with public debate is you get the loud strong voices, and the quiet ones, the people that don't have the skill to speak publicly, are not always heard." The likelihood of public consultation to produce simplistic conclusions, and thus fail to reflect the complexity of what is actually at stake in prenatal screening deci-

sions, is also reflected in the following quotation:

I think sometimes when things become opened up to public debate the questions just get turned into a very simple yes/no, and they can miss the major point. It will get high-jacked by one group or another, it can cause rifts in society and perhaps you won't end up with results that are any better than sort of a softer approach.

This suggestion of a need for a 'softer approach' to consultation on prenatal screening as one which recognises the complexity of prenatal screening decisions, reiterates the value of documenting accounts of lived experience as part of the brief of bioethics enquiry. As Kerr and Cunningham-Burley note, investigating lay ambivalence about emerging health technologies offers an "as yet undeveloped critical resource for contemporary bioethics debates" (2000, p. 293). Positioning lay experiential accounts within the clinical and bioethical domains in terms of an 'ethical resource' might usefully aid the development of health policy, which is more meaningfully responsive to the diversity of experiences and attitudes among those with most at stake in such debates.

Another significant topic raised by participants in the study related to attitudes regarding the involvement of scientific and medical experts in bodies such as ethics committees, and here participant responses revealed considerable variation. While some participants clearly indicated a fundamental degree of trust in bio-scientific projects and emphasised a leadership role for medical experts within bioethics, others expressed concern that the interests of such experts may dominate the bioethical agenda and exclude lay perspectives. These views deserve voicing because they highlight the kinds of ideological tensions and value clashes that bioethics must address within the contemporary moral landscape. To illustrate, one respondent was a mother of a child with Down syndrome, undetected by current prenatal screening techniques, but clear that she would have proceeded with the pregnancy in any case. She made the following comment about medical expertise:

I'd like to know what their goals are; because success to them might be to delete the condition [Down Syndrome]. I mean, I have heard professionals; they have actually come up to me and said, "you know, that it would be one of the best things in the world if they could find something that would stop the chromosome from splitting into three..." It's crazy. I wonder where these people are coming from.

These remarks by a clinician suggest the current pervasiveness of a 'geneticised' model of health (Lippman, 1991) within contemporary medicine and raise a number of ethical questions about the 'downstream' consequences of prenatal screening as a cultural norm that has direct, real life significance for every woman facing prenatal screening decisions. Where a condition is perceived as 'avoidable', to whom is responsibility attributed for the birth of an affected child? When such children are born, what are clinicians' roles in offsetting the genetic 'story' of that individual baby with parents' expectations that their child should be valued equally to other children? Such tensions between 'clinical' and 'lay' evaluations of the value and appropriate use of screening were a recurrent motif in participants' accounts within the research more broadly. This shows a need for closer attention by bioethicists to whether existing ethical processes are sufficiently responsive to a diversity of understandings of notions such as 'health' and 'disability', and to broader social values and concerns.

Examination of the history of public engagement with medicine and bioethics in New Zealand highlights the evolving nature of concepts such as "experts" and the "lay public". The aftermath of the Cartwright Inquiry represented a time of heightened public concern over such issues, the ethical conduct of health professionals, and informed consent for patients undergoing medical treatment. The establishment of the Health and Disability Commissioner in 1994, and the Code of Health and Disability Services Consumers' Rights in 1996 constituted a vast ideological turning point in terms of the relationship between biomedical and lay communities in New Zealand. Such changes arose from public reaction to specific and publicly identifiable

cases, and within the particular historicity of this moment, what the public wanted and needed in terms of a “bioethical response” was quite clear.

Although events such as this have laid out the role of bioethics in terms of professional regulation in the New Zealand context, the level of public trust in medical and scientific research remains on shaky ground. Several events post-Cartwright have tested public trust in the medical profession and medical research practice. The Gisborne Cervical Screening Inquiry is one such example, as is the debacle over the retention of organs at Green Lane Hospital in Auckland in 2001 (see Cole and McCabe, 2002; Jones, 2002). Similar events elsewhere, at Alder Hey Hospital in the United Kingdom and at the Institute of Forensic Medicine in Sydney in 2001, have likewise shattered public confidence in the medical professional undertaking research. Bioethicists and policy-makers have long debated the importance of consent in these contexts, but notions about what informed consent should entail have gathered renewed urgency with the development of genetics databases and research, specifically with regard to public participation and involvement in this area. Within New Zealand, the somewhat controversial indefinite storage of newborn blood samples at the National Testing Centre in Auckland is a case in point.

Regardless of criticism, the pragmatics of how best to involve lay people in such debates seems difficult to resolve. This is partly due to obstacles to public participation such as access to information and resources, as well as variation in degrees of public interest and motivation. Research around the new genetics magnifies these concerns. Although many people may readily express a sense of concern for the “ethical wellbeing” of society regarding the new genetics (e.g., concerns about eugenics, preservation of human dignity, the notion of diversity, and respect for individual privacy), a sense nonetheless persists that ethics and ethical governance is something that occurs at a remove from mainstream society in this domain.

Ebbs and flows in opportunities for public involvement in bioethics: The New Zealand experience

The extent to which imperatives around consent and consultation have increasingly become part of the landscape of healthcare provision in New Zealand should arguably leave us reassured of the enduring positive legacy of the Cartwright Report (1988). Certainly public health literature and government health reports produced in the last decade or so convey a reassuringly consultative ethos, often citing processes of consultation undertaken as evidence of ethical integrity and ‘robustness’. Furthermore, the recent undertaking of a public consultation project on “pre-birth testing” by Toi Te Taio/Bioethics Council of New Zealand does provide some evidence for an emerging concern to build public trust in bioethical governance and to attempt to engage the public in debates about the appropriate use of biotechnology. The Council’s “Who Gets Born?” project, undertaken in 2007, was unique in New Zealand in framing public engagement in bioethics in terms of deliberation; that is, as a dialogical process open to everyone, rather than a more traditional approach involving consultation with specific groups. The project focussed primarily on the use of preimplantation genetic diagnosis (PGD) and involved 18 ‘deliberative’ public events (including hui and fono) and the use of a web-based forum for registered participants to lodge and discuss their perspectives on the issue.

Reported to have generated a following of over 60 regular contributors, and the accumulation of over 120,000 words of online commentary by participants (Steadman, 2008), the project drew considerable local and international interest, with the Bioethics Council subsequently awarded ‘Project of the Year’ in 2008 at the international Association for Public Participation Core Values Awards in Scotland. While not without an element of controversy, the high profile achieved by this example of an initiative towards increasing public engagement does seem to indicate a readiness, in both bioethical/professional and lay domains, to at least make a start in tackling the

obstacles to meaningful public engagement in bioethical debate discussed earlier.

However, subsequent changes in the landscape of bioethics governance in New Zealand would seem to leave a question mark over the extent to which we can take for granted institutional endorsement of ideals of consent, consultation and informed decision-making. In March 2009, the recently elected National-led government perfunctorily disestablished Toi te Taiao, the Bioethics Council of New Zealand. In the press release indirectly announcing the dissolution of the Bioethics Council, Minister for the Environment Nick Smith commented that the work of the Council was “somewhat duplicated” by other agencies and that the Government preferred to ‘invest in frontline services that really matter for New Zealanders not expensive slogans.’ Such remarks would seem to suggest a view that the public have little interest in involvement in decisions around biotechnologies, and that such processes are not something that ‘really matter’ to ordinary people. This evident shift away from previous attempts to democratise public policy around health technologies would seem to set New Zealand apart from a broad international trend towards greater rather than fewer opportunities for public involvement in bioscience debates, in recognition of growing public mistrust in science. The apparent haste to dismantle such avenues for engagement here seems puzzlingly retrograde.

A stated aim of the Bioethics Council was to enhance public trust in the regulation of emerging health technologies. In the absence of a body working to fulfil this brief, and a user-friendly way for ordinary people to keep abreast of new developments in biotechnology, exactly how current or future governments now plan to determine ‘what really matters for New Zealanders’ with an interest in such issues remains to be seen.

Our earlier discussion presents evidence that lay people do value the opportunity to contribute to bioethics debates, and may indeed regard assurance of mechanisms for public involvement in such debates to be a requirement of ethical practice. It is, however, far from clear who in New Zealand now assumes institutional responsibility for providing the buffer between consumers and the juggernaut of emerging biotechnologies of health.

Such apparent shifts away from a consultative approach to bioethics in New Zealand further underscore the importance of documenting accounts of lived experience of the impact of emerging health technologies to be made available as a bioethical resource, and suggest the value of ongoing social scientific critique and commentary in this area. How else might ethical protocols be tailored to fit the expectations of lay people as the presumed beneficiaries of these technologies? A key contribution of lay perspectives to bioethical debate is in the attention such accounts draw to the existence of a diversity of views and perspectives which are often absent in scientific accounts of technological progress and endeavours such as genetic screening. As Scully et al. (2006, p.764) argue, ‘bioethics itself needs to become more knowledgeable about the concerns, values and forms of reasoning that lay people bring to their ethical deliberations’, and a commitment to paying attention to disparities between official and unofficial stories of practices such as prenatal screening is one way to ensure that this is done. Given the vicissitudes of public engagement as an ideal for bioethics (at least within New Zealand), it seems clear that social scientists have an important role to play in documenting these disparate stories as they are expressed in experiential accounts, and in turn in championing the value of these accounts.

Concluding remarks

In this article, we argue the value of phenomenological research for bioethical debate to give a fuller picture of peoples’ moral experience when they encounter innovative biomedical technologies. We also highlight the on-going importance of reflexivity in the work that bioethicists do when constructing issues of ethical urgency and concern, and suggest that the critical distance of sociology makes it more attentive to this issue in ways that mainstream philosophy and medical

ethics is not. We suggest that if bioethics is to maintain legitimacy in the public eye then bioethics' experts need to acknowledge the value of lay perspectives in understanding contemporary moral life, which is where researchers such as sociologists can contribute. This need is particularly pressing in the current context because the public has an increasingly active engagement with innovative technologies, positioning them - not bioethicists - at the forefront of techno-science and biomedicine as 'moral pioneers'. In sum, the value of our research is to enhance understanding about the ethical meanings people attribute to their perspectives on embodiment, identity, health and wellbeing and to suggest implications for policy and practice. As we have pointed out and as Scully et al. (2010, p. 29) note, the degree to which policy makers can best use lay accounts in regulation and philosophers such accounts in formulating theoretical models to more accurately reflect peoples' social realities, experiences and aspirations as yet 'remain to be settled.'

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Notes

- 1 Jurgen Habermas is of particular note here. His recent book, *The Future of Human Nature* (2003), for instance, deals specifically with bioethics and liberal eugenics.
- 2 The researcher interviewing Māori participants for this study is Dr. Robert Webb (AUT University).
- 3 The larger study received funding from a Royal Society Marsden Fast-Start Grant (07-VUW-028 SOC). Ethical approval for the study corresponds to different phases of the project: (2-2007-SACS), (MEC/08/03/027), and (VUW HEC 16628/4/06/09).
- 4 Thank you to Katrine Kranstad and Sonja Bohn who transcribed the interviews for this study.
- 5 NTS is a form of ultrasound scanning undertaken in the first trimester of pregnancy to measure the depth of fluid (the fluid appearing as a translucent area on ultrasound) at the back of the neck of the fetus. An increased amount of fluid may indicate the presence of Down syndrome, or another condition.
- 6 This study has ethical approval: (CEN/05/08/056).
- 7 This is a recently developed diagnostic genetic test involving the removal and testing of embryonic cells prior to implantation of the embryo in the uterus. This technique can only be used within the context of pregnancies created through the use of in vitro fertilisation (IVF).
- 8 The Bioethics Council's subsequent recommendations to overrule a prohibition on the use of PGD for sex selection for social reasons ran counter to the majority view of participants who took place in the deliberative consultation.

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