Concepts of Human Nature, Personhood and Natural–Normal in New Reproductive Technology Discourses in New Zealand

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Abstract: I examine how concepts of human nature, personhood and natural–normal are deployed in New Zealand in interviews with people with hemophilia and in public submissions on the subject of Human Assisted Reproductive Technologies (HART). "Genetically-determined" and "relational" personhood concepts are identified in discussions of the implications of HART for the living. Discussions of HART draw on or imply contextualized concepts of "natural–normal," alternately excluding or including science from human culture and nature, and pathologizing infertility and certain family forms. My analysis employs concepts of biosociality, care and genetic citizenship.

Keywords: personhood, biosociality, hemophilia, human assisted reproduction, New Zealand, gender

Résumé : J'examine la façon dont les concepts de nature humaine, de personne et de naturel-normal sont déployés en Nouvelle-Zélande dans des entrevues effectuées auprès de personnes hémophiles ainsi que dans des soumissions publiques abordant le thème des techniques de reproduction humaine assistée. Les questions relatives au fait d'être une personne « génétiquement déterminée » ou « relationnelle » sont relevées dans les discussions portant sur les conséquences de la reproduction assistée pour les êtres vivants. Ces discussions suggèrent des concepts contextualisés de ce qui est perçu comme « naturel-normal » ou s'en inspirent, excluant ou incluant tour à tour la science dans la définition de la culture et de la nature humaine, et pathologisant l'infertilité ainsi que certains modèles familiaux. Mon analyse fait usage des concepts de la biosociabilité, des soins et de la citoyenneté génétique.

Mots-clés : Personne, biosociabilité, hémophilie, reproduction humaine assistée, Nouvelle-Zélande, sexospécificité

> But, I'm sort of worried if we are preventing people from getting hemophilia. There [are] still the spontaneous people, and treatment for them is just going to be very hard because it won't be as available...and there won't be groups like there [are] now because not so many people will have it. [Nadine, a single woman carrier of severe hemophilia, who hoped to have children in the future without using new reproductive technologies, Interview 2006]

> From an early age I knew that I would not have a child with hemophilia. It didn't ever cross my mind that I would have a child with hemophilia. [Debbie, a married woman carrier of severe hemophilia who wished to have children by using new reproductive technologies, Interview 2006]

In this article, I compare and contrast how concepts of human nature, personhood and natural–normal are deployed in texts derived from two separate studies in New Zealand. One is a set of interviews with people with hemophilia carried out in 2005-06, in which both Nadine and Debbie participated. The other is an analysis of archived submissions from the "general public" to the Parliamentary Health Committee in 2003 on the subject of Human Assisted Reproductive Technologies (HART).

The two introductory snippets of conversation serve to indicate some of the diverse ways in which people with the same genetically inherited coagulation disorder respond to the possibilities afforded by new reproductive technologies, especially prenatal diagnosis (PND) and preimplantation genetic diagnosis (PGD).[1]

What Is Hemophilia?

Hemophilia is a blood coagulation disorder inherited on the X-chromosome. People with it bleed longer than others. Without adequate treatment hemophilia may be life-threatening or lead to severely damaged joints and bodily organs through repeated bleeds. In New Zealand,

state-funded treatment is available to all those diagnosed and most people with hemophilia respond well to treatment.[2]

Because women have two X chromosomes, women who carry the gene mutation for hemophilia are usually protected from bleeding problems by their non-affected X chromosome and are almost always protected from the most severe forms. However, about one third of all women who carry the mutation do suffer from some bleeding issues.[3] Men, having only one X chromosome, always have hemophilia if they have an affected gene. All of their daughters, but none of their sons, will be carriers. The children of women carriers have a 50% chance of inheriting the mutation.

Family members with hemophilia inherit the same mutation and therefore usually have the same level of severity. Although hemophilia is an inherited condition, in any one generation about 30% of hemophilia cases are new "spontaneous" mutations. These new mutations are subsequently inherited.

It was these "spontaneous" families who would receive a surprise diagnosis of hemophilia that were the subject of Nadine's concern. Nadine welcomed the ability to be able to prevent having children with hemophilia, although she thought that hemophilia was "not so serious nowadays" because of the availability of safe and effective treatment. However she was also worried about preventing hemophilia. This was partly because she believed (and so did her brother), that her brother was the person he was because of hemophilia. Nadine admired him. But it was also because she cared about future people with hemophilia. She foresaw that through using PND only "spontaneous" families would have hemophilia and they would not have the political support and care of a numerically strong and experienced hemophilia community. Therefore, Nadine hoped that at least some people who were aware of hemophilia in their family would have children with it.

In contrast, Debbie had been so scarred by her father's experience of hemophilia that she would not countenance bringing a boy with hemophilia into the world, despite her and her husband's desire for children and the availability of treatment. Her care was for her own future child.

Much to the relief of Debbie and her husband, hemophilia was listed in December 2005 as one of the serious disorders for which two state-funded cycles of PGD were permitted. This was legally possible because of the passing of the HART Act in 2004 which, among other things, set up the machinery to produce guidelines on the permissible grounds for the selection of embryos for PGD. Fortuitously, the two lines of research informing this paper, hemophilia and HART, were drawn together dramatically for me when I interviewed Debbie and her husband on the day the funding for PGD was announced.

Recognizing Personhood, Human Nature and Natural–Normal in the Texts

I am particularly interested in statements about when and how one becomes a person, or a non-person.[4] Carsten, writing about approaches to the study of the person, refers to the well-known distinction between "Western bounded and autonomous individuals, and non-Western 'relational' persons" (2004:28), which has been elaborated on most particularly by Strathern (e.g., 1992). Carsten points out that while stories relating to assisted reproduction can be interpreted in terms of genetic connection and individual rights indicative of an emphasis on the individual human being, they can also be interpreted as being about "how close ties are intrinsic to the social constitution of persons" (Carsten 2004:83). She suggests that a reason why the autonomous individual is so prominent in anthropological writings on the West is because of where we go looking. If we look instead in contexts where relatedness comes to the fore—and I suggest that encounters with certain medical technologies provide some examples—"some rather less bounded and more relational ideas about the person are revealed" (Carsten 2004:28).

The medical technologies discussed in these interviews and submissions provide contexts for explorations of cultural concepts of personhood because their use problematizes taken-for-granted understandings of kinship, instigates debate about how personhood comes into being and poses urgent questions of interpersonal rights, claims and responsibilities. For example, in debating reproductive technologies, some submissions argue that new beings become fully human only through interactions with other persons and environments, while others assert that full personhood is present at the moment of conception and the embryo has all the rights of a legal person. My explorations in these contexts in New Zealand indicate that both relational and non-relational ideas of persons are prominent, and both may be drawn on to support arguments for or against the use of particular technologies.

I define statements about "human nature" as those which distinguish between humans, other species and inanimate objects, and comment on what are natural or unnatural attributes or desires. Frequently, these statements also concern personhood. One individual argued that the use of a sperm or egg donor reduced humans to animals (Submission 56). Another individual submission (35) asserted: "To reduce human beings to manipulated technological events is indeed playing at being

Frankenstein." Such statements delineate what is "not human" in the views of their authors.

Statements concerning natural–normal I recognize, quite literally, by the use of those and cognate terms in the texts as well as by the occurrence of their opposites, for example *unnatural* or *artificial*. Sometimes nature and the divine are conflated: "the natural laws of nature are the divine laws of creation" (Submission 57, Individual), an association also noted by MacDonald (1994) in the Canadian context.

Imagining the Hemophilia Community

The hemophilia community may be considered an "imagined genetic community," as discussed by Simpson (2000). However, despite the importance of family and genealogy to this condition, what is imagined is not a nation or ethnic group but a transnational community based on narratives of hemophilia as being no respecter of ethnicity, nation or class. As in Anderson's (1983) original conceptualization of "imagined community," print media and now the internet, video and digital media, as well as calendars and reports of frequent meetings at all levels, from local groups to world congresses, confirm this relatedness. Collective representations based in shared genes, blood, blood-borne viruses, suffering, caring and treatment issues are anchor-points in this imagining.

The concept of a life-confirming "biosociality" as Taussig et al. (2003) describe for the Little People of the United States, drawing on Rabinow's (1996) work also has a good deal to offer in conceptualizing hemophilia internationally. These authors explain that Rabinow "has used the term *biosociality* to describe the conscription into a new identity politics as people come to align themselves in terms of genetic narratives and practices" (Taussig et al. 2003:60). Sociality in the hemophilia community operates through the informal support of friends in local branches; via email and phone at the national level of the New Zealand Haemophilia Foundation (NZHF); through partnerships ("twinning") between national organizations from developed and less developed countries; and through the World Federation of Hemophilia. "The language of kinship" (Rapp et al. 2001:395), as well as other metaphors of relatedness, such as comparisons with the United Nations, abound, especially at the biennial World Congress.

In many respects, this network and organization conforms to Rabinow's descriptions of biosociality: medical specialists, laboratories, pharmaceutical companies, a range of other specialists, patients and their families with shared historical narratives and common traditions act and interact on behalf of this imagined community as well as in their own interests (Rabinow 1996:102). Relatedness here is not based just on recognition of a shared bodily condition—although this is a precondition—but on common experience, especially the experience of care. Living with a bleeding disorder and its complications, living with and dying from blood-borne infections (notably HIV and Hepatitis C), taking common cause against the corporate and state authorities that failed in their duty of care in preserving a safe blood supply, memorializing those who have died, and working tirelessly for safe and adequate treatment now and for the future in concert with others, characterize this community. As Nadine indicated, these are significant ties, sufficient to persuade her that there are reasons for the hemophilia community, and for herself, to be cautious in approaching HART as a means to prevent the conception or birth of babies with a hemophilia mutation. Her expression is of concern for continuing hemophilia-based biosociality.

In understanding her approach as informed by an ethic of care, I have been influenced by Herzfeld's (2001) discussion, which in turn draws on the work of other scholars, especially Das and Borneman. Herzfeld (2001:217) asks: "How can anthropology contribute to a rethinking of the social that will make it, not the space of regulation, punishment and blame, but rather that of relief, care and acceptance?" This question can be asked of the concept of biosociality too, but rather than setting up regulation in opposition to relief, as does Herzfeld, the social can be rethought as being a space of regulation and relief, punishment and care, blame and acceptance.

My reworking of biosociality is similar to the concept of "genetic citizenship" elaborated by Heath et al. (2004: 153). This group of scholars has been working over many years with organizations based around shared genetic conditions. For them, a space for an ethics of care has emerged from the diverse entailments and changes in techno-science and the public sphere. Among the repercussions is a breakdown of distance between lay and expert and creation of new spheres of regulation, choice and participation. "Genetic citizenship" alludes to these new contexts and to the concomitant changes running from the individual to the state and to large multinational companies or other organizations.

In this article, I prefer to use the reworked concept of biosociality with an emphasis on care to refer to relationships within the hemophilia community, whether within New Zealand or internationally. However, the concept of genetic citizenship becomes useful in thinking about the relationships between the hemophilia community and the nation. I believe that these theoretical developments which point to complexity and a recursive counterpoint between,

for example, regulation and relief, prompt a more satisfying ethnographic account.

Although I attempt a gendered analysis of the hemophilia interviews, in this community it is difficult to disentangle gender from hemophilia or indeed kinship status.[5] In my representations of a gender analysis I am mindful that "gender" is always complicated.

The HART Submissions

In addition to the detailed and varied data derived from our work with the hemophilia community, this paper is also built on submissions by self-selected members of the general public in relation to legislation on HART.

The story of HART legislation and the public submissions in New Zealand is long and complex. In the report of the Royal Commission on Genetic Modification (1991) was a view that certain areas in relation to HART should be amenable to legislation. A report focusing on assisted human reproduction was completed in 1994 and was followed by the introduction of two separate Bills, a Member's Bill and a Government Bill, on the issue into Parliament in 1996 and 1998. Both these Bills drew on the earlier reports as well as on subsequent events including the experience of legislation and the technologies themselves in other countries, notably Britain. They differed in several respects, especially in how HART should be regulated, but also shared a good deal of common ground. Although public submissions were called for on these Bills, little progress was made until 2003, when Cabinet decided that a Supplementary Order Paper should be drawn up which could give a clear direction on several points of difference between the Bills. A new call for public submissions was made. All these submissions were treated by the Parliamentary Health Committee as if they were on the 1996 Bill. Oral submissions were also heard. However, the body of text for our analysis comprised only the written submissions.

Although anyone could make submissions, only 79 individuals or groups did so. One of the submissions was private. Thirty-two submissions were made by individuals or what appeared to be small family groups. One of these individuals was a member of an email pro-surrogacy network, one was a donor-conceived person and a third was the son of a woman with Huntington's disease. Others did not reveal personal links to the issue. The other submissions were made by organizations. These included academic experts, named religious groups, ethics committees, the Law Society, the Human Rights and Health and Disability Commissioners, an environmental group, anti-abortion organizations, an abortion reform organization, disability groups, providers and users of fertility services and various groups promoting women's issues and family policy. There were no written submissions from self-identified ethnic groups. Maori had been consulted orally by the Parliamentary Health Committee which itself had Maori members.

In January and February 2006, two graduate summer scholars in Anthropology (University of Auckland), Laura McLauchlan and Elizabeth Frengley, and I, took a discourse analytic approach to the 78 public written submissions (Park et al. 2008). In this process, we were and continue to be guided by Sarah Franklin's (1999) analysis of the British Parliamentary Debates on a similar Bill and by the successive detailed analyses of these debates by Michael Mulkay (for example, 1996).[6]

Updating Hemophilia

With colleagues, I have been doing fieldwork with people with hemophilia in New Zealand since 1994, examining a wide range of issues that impinge on their lives: the everyday experiences of living with hemophilia for men and women, blood-borne infections, gender issues, reproductive decision-making and bio-political sociality, to name a few. Midway through 2005, Deon York, a young man with severe hemophilia and a Masters degree in Anthropology, and I commenced a second up-date study of "living with hemophilia in Aotearoa New Zealand" focusing on new technologies and treatments (Park and York 2008). Three of the focal issues in this update are pertinent to this paper: carrier testing, prenatal testing including PGD and gene therapy. Carrier testing involves a DNA test of those girls or women who are the daughters of women carriers or else suspected spontaneous carriers. If the family mutation has not already been identified, blood samples also need to be requested from several family members to pinpoint the mutation. I have included gene therapy here partly because, although not a reproductive technology, people often imagine that one of its uses may be as part of reproductive technology. Gene therapy is not available at present, but is likely to involve the introduction of normal copies of the affected DNA sequences, most likely via a viral vector.

We formally interviewed 37 people who responded to our invitations to participate and interacted with many more through the community activities in which we participated.[7] This recent study is a little larger than our first update study five years earlier, but much smaller than the initial study where, through a questionnaire, nearly 200 people participated and we interviewed 80 (Park et al. 1995). It is estimated that there are around 600 people in New Zealand with hemophilia.

Differences between the Two Sets of Texts

The documents from the two studies, hemophilia and HART, contrast rhetorically. The HART submissions try to persuade legislators of the rightness of their views, to alert them to less obvious implications and to adduce what the citizen or group sees as relevant evidence. They contrast with the hemophilia interviews where people often do not have decided views but tend to ruminate, like Nadine, with lots of "buts" and "howevers," and are not always sure of how they would act in any given set of circumstances. Nonetheless, some, like Debbie, did express strong views.

The documents also contrast in terms of prescriptiveness. Within the hemophilia community, some people would never use PND or PGD; some would not use it for hemophilia, but might for something "more serious"; others intended to use it; and many others would consider it, or would have considered it, were it available during their child-bearing years. But while the whole range of views for and against new reproductive technologies existed within the hemophilia community when individuals considered what they would do personally, we have yet to meet a person with hemophilia who expressed the view that these new technologies should not be available. Even people who were quite vehement about not using them themselves thought that they should be available to others. Here is a major contrast with the views expressed by some of the general public in the HART Bill submissions. Many of them were opposed to reproductive technologies being available at all.

Concepts of Persons

New reproductive technologies are a touchy subject within the hemophilia community as well as outside it. Two sisters who carried severe hemophilia were interviewed for an article in a weekend national newspaper not long before our update study began. The two women were lobbying for the approval and funding of PGD because, based on their father's dreadful experience of severe hemophilia and associated problems, they were adamant that they would never bring a boy with hemophilia into the world. This article caused considerable comment and was spontaneously mentioned in several of our interviews and informal conversations by people who had boys with severe hemophilia. Typically, they expressed sadness and sympathy toward the sisters who had shared their late father's suffering, but these parents of boys with hemophilia wanted to reach out to them to say that hemophilia is not like that now in the 21st century. They told us that a boy born now can live a full life, with some pain and suffering certainly, and regular need for treatment with replacement clotting factor, but nothing bad enough to make that life not worth living. Although not stated outright, but intimated with "you knows" and facial expressions, some parents implied that in their enthusiastic support for PGD, the sisters, or the reporter, had unwittingly denigrated the value of lives currently being enjoyed by people with severe hemophilia. Although the sisters took pains to say that this was *their* experience and *their* view, the publicity and their impassioned pleas for PGD were taken to reflect on lives being lived and, perhaps, the decisions that other parents have made.

This is a consideration that looms large. In all three phases of our study, women[8] carrying hemophilia have said to us, "what does it mean for [my son with hemophilia or my brother] if I abort a fetus with hemophilia or have PGD to avoid a boy with hemophilia?" Franklin's (1999) study showed that this line of thought was influential in the British Parliamentary Debates, and the New Zealand legislation makes provision for it in section 4(b) of the HART Act (2004): "the human health, safety, and dignity of present and future generations should be preserved and promoted." Similar concerns have been widely reported internationally, for example, Rapp et al. (2001) for the U.S. and Ivry (2006) for Japan.

This is the question that leads us most directly to understandings of human nature and personhood that are expressed in the interviews and submissions: what does it mean to living people with a genetically inherited condition if an embryo or fetus with it is selected against?

People in the hemophilia community who asked this question were invariably women carriers or their husbands, and they did so rhetorically. Even when pressed, they would sometimes sidestep an answer. People who asked it usually had gone ahead with their pregnancy or had no intention of having a prenatal test, a termination or PGD. But on a few occasions, our participants told us what they thought others meant by it and a few participants, when pressed, told us what they meant. The question meant that deciding not to have a boy with hemophilia questioned the value of the lives of those with hemophilia in the past, present and future. Within the community, people were well aware of this line of thinking. Some of them believed that reproductive decisions did have implications for others, but nonetheless maintained that "what is right for the family is right." Others dismissed the whole notion that reproductive decisions aimed at preventing the inheritance of genetic conditions devalued living persons with that condition. These different viewpoints appeared to entail different concepts of personhood.

Hartouni states, "who or what is called a person is, among other things, a highly contingent historical formation; it is both the site and the course of ongoing cultural contests and always under construction as a self-evident fact of nature" (Kaufman and Morgan 2005:321). This was indeed the case in this instance. I could discern two lines of thought about how human personhood comes about within the hemophilia community that underlay decisions not to test or abort because of the implications for other children or adults or the community. The differences of expression are subtle but underlying them are diametrically opposed conceptualizations of the process of becoming a person.

One conceptualization I have labelled the "genetically-determined person" to indicate the cultural idea that identity or personhood is conferred by genetics. For hemophilia, for example, if you select against a fetus or embryo that is carrying a slightly scrambled bit of genetic code on that part of the X-chromosome that governs the proteins involved in the clotting cascade, then you are denigrating the value of a living person with the same bit of scrambling. The embryo is *just the same as* a living person because of that shared mutation. Within the HART submissions, this reasoning underlay the mainly Christian-identified ones that maintained the notion that human life and personhood begins at "conception" or when the egg is "fertilized." While this was sometimes stated as a self-evident truth—"it is a new human being, thus assuming all human rights, it has forty six chromosomes" (Submission 56, Individual)—or discursively implied, for example, using terms like "murder" or "kill" to refer to the disposal of embryos, others used varieties of the genetically-determined person concept as evidence. They argued, in more detail than Submission 56, that all the genetic material that would, as they saw it, govern the individual's life is present at conception and therefore the embryo has personhood.

Six submissions used this argument. Three were made by individuals, two by Catholic groups and one by an anti-abortion group. This was also a particularly strong argument in the British debates, and was labelled by Franklin (1999:145) as "developmental essentialism." This line of thought, as Franklin explains, is based on the assumption that the embryo has *within itself* the potential for development.

A similar underlying argument of genetically-determined personhood was found within disability rights discourses in the HART submissions. For example, Submission 74, from the Disabled Persons Assembly, maintained that the prevention of disability is offensive to those with a disability, and compared this to the offence caused to women when female births are prevented. The phrase "curing us out of existence," used to argue against HART, suggests that the identity of the "us" is determined by genetics.

The contrasting conceptualization I call the "relational person." This argument within the hemophilia community agrees that living with hemophilia is tough, but not as tough now, with good treatment, as it used to be. The following is a composite argument compiled from phrases derived from several conversations and interviews: "My son or brother is the fine person he is because of his struggles with hemophilia. Indeed, the challenge of living with hemophilia can be the making of a better person. Through his hemophilia, he has met some wonderful people and has enriched other people's lives and we have met those people too." Therefore to select against a mutation causing hemophilia is to devalue the people in the hemophilia community who are who they are, not just because they have a small genetic similarity, but because they have learned to deal with it in companionship with others.

This is a relational argument that constructs personhood as the product of an on-going relationship between genetic endowment and experience–environment including meaningful human relationships. Nadine's perspective used this concept but also elaborated on it using a concept of biosocial care. Women carriers and their husbands commonly used this concept of becoming human when explaining their views on HART.

There were few references in the HART submissions to the relational person concept, although one from the son of a woman with Huntington's disease did touch on it, writing about the value of adversity to the development of a sense of responsibility (Submission 36). The nearest most submissions came to it was an acknowledgment that an embryo was not safe if it was outside "the sanctuary of the mother" (Submissions 18, Christian Heritage Party; Submission 68, Family Life International), which is a tacit acknowledgement that a particular environmental interaction is required for the safe development of an embryo, but which simultaneously constructs women as safe "containers."[9] Franklin, too, noted that reference to the relational character of the embryo was very rare in the British debates. She cites just two speakers who referred to the necessity of maternal-embryo interactions or parental and societal interactions for an embryo to develop into a human being (1999:150-151).

In contrast to these authors and interviewees who believed that using reproductive technology had implications for people already born, other people thought such views were "nonsense" or "ridiculous." Like Debbie, they might be adamant that these decisions related only

to the family circumstances of those making the decision at that time, especially whether a particular family or individual could cope with caring for a(nother) child with hemophilia, and whether they were accepting of the possibility of having a child with hemophilia. These decisions were closely related to the parents' perceptions of the seriousness of hemophilia. This was frequently encapsulated in the hemophilia community by "what's right for the family is what's right."

This phrase is a key statement of situational ethics and a strategy for accommodating diverse views in this biosocial community, where some members are opposed to abortion, for example, but do not wish to deny others the possibility of it. This position is paralleled by some of the HART submissions, for example, one from a mother with Huntington's disease, in support of PGD who said she was "not fighting for a genetically modified baby, just a healthy one" (Submission 7, Fertility New Zealand). Her submission represents those who saw these technologies as a means of avoiding pain and suffering for future babies, with no implications for those already born, including herself, but with enormous implications for affected families. They refused the genetic determinism which says that an embryo or fetus is just like a living human person and instead focused on the needs of future babies and families to support their arguments for the availability of PGD.

Perhaps not surprisingly, because it is an umbrella group for organizations like the HFNZ, the Bill submission which is closest to the perspectives of people with hemophilia came from the New Zealand Organisation of Rare Disorders (Submission 64). This drew attention to possible benefits and downfalls of reproductive technologies (genetic screening for example), recognized that rights of disabled people needed protection but advocated that where the technology exists to identify painful and deteriorating diseases at such an early stage, it should be able to be used. The argument in this submission emphasized the concept of quality of life for the child, recognized what I have called the genetically determined person (but distanced itself from it) and emphasized the relational person perspective.

Gendered Talk about Persons

Not everyone in the hemophilia community was used to discussing the issues around HART, although interestingly, discussions about gene therapy were much less circumscribed. Women spoke more readily about these issues, a point discussed in our earlier publications where we noted that it was men's bleeding and women's reproductive capacities that were stressed, even though men passed on hemophilia as much as women and quite a number of women also had bleeding problems (Park 2000, 2005). Reproductive choices are not generally regarded as men's issues in New Zealand and are therefore not usually the topic of masculine conversation. When Deon, as interviewer, and Neil, a man in his 50s with severe hemophilia, had a conversation about amniocentesis and CVS, they remarked on the gendered nature of such talk in this community:

> Deon: This issue, though I mean, it's something that, it's not your usual topic of conversation [they both laugh], but have you talked about it much with other people?
> Neil: Umm, only with people involved with hemophilia, and I think only women, that I'm aware of, in fact, yeah.
> D: So you don't think it is really an issue that men with hemophilia would discuss?
> N: I have never heard it discussed among men with hemophilia, either of those procedures.
> D: And why do you think something like that hasn't been discussed, considering its implications for hemophilia?
> N: Well, it, um...[pause]...I think that's very relevant to a remark that we heard recently and that is that, you know, it's not solely the woman's role to determine, you know, the future of a child and yet in a number of circumstances, those two tests that we talked about, it seems to me have been, sort of largely, largely an area of "Women's Issues" and, apart from the topic, you know, not being as interesting as rugby, and that fact that, you know, it's into the women's issues sort of sector, maybe that's why you don't get half a dozen people, men with hemophilia, sitting around talking about chorionic villi sampling [laughter ensues from both sides]
> D: And while watching rugby, it wouldn't really work would it! [Interview 2006]

The humour in this exchange comes from Neil's self-ridicule as an acknowledged rugby fanatic as well as from the idea that this is a ludicrous topic of conversation among men. It was significant that when Neil had discussed it, he described women as his conversational partners and this seemed to be the case for the others too. For example, Euan, another middle-aged man with hemophilia, said that one of his women friends in the hemophilia community had talked with him about amniocentesis, and he and his young adult daughter have had considerable discussion about the merits of prenatal tests and PGD. Ben, an older teenager with hemophilia, planned to talk with women—his mother and sister—about these issues when the time came.

Discussions about reproductive choices are largely left to women carriers and their husbands and partners. As Andy (mid-20s with severe hemophilia) said, "see we haven't discussed it much simply because she is not the

carrier and we know what the odds are with our children." Prenatal testing is not usually a big issue for men with hemophilia and their partners because they already know that any daughters will be carriers. Carrier women and their partners have many more choices to make and more hangs on those choices. However, the perspectives and experiences of men and boys with hemophilia are important to a full appreciation of the repercussions of these choices, especially as women and their partners include as a very important part of their decision-making what they consider might be the implications of their choices for men with hemophilia who are their focus of care. In our update study, then, we addressed questions about reproductive choices to men with hemophilia, and found that this, though sometimes difficult, was rewarding and revealing.

The nine men with hemophilia in the update study did not interpret prenatal testing or PGD by women in the community as having implications for the value of their own lives. One used the term "ridiculous" to describe this assumption. Two of the men had not had, or would not have, biological children, at least partly because of hemophilia, but this did not mean they devalued their own lives. A couple of the men said that they did not think that hemophilia was serious enough for abortions to be considered but all of them thought that having the various technologies available for the hemophilia community was a good thing: "the more options the better" was a common opinion. Some were quite enthusiastic, particularly about PGD. Marty, for example, a younger man, thought PGD was more desirable "because you don't really see a face," whereas he was opposed to abortion for hemophilia. One young man did remark that if prenatal testing were available to his mother, and she had used it and had a termination, then he would not be here now, but he still favoured the availability of HART. The others talking about the topic did not link it to themselves. Unlike several of their sisters or mothers, they explained that they did not think it reflected on them in any way. Instead, they focused on avoiding pain and suffering for the grandchildren and on saving their daughters from the impact of caring for a child with hemophilia: "I know that it would dictate so much of their life for 20 years and beyond," said one man, referring to his daughters.

While I have discussed caring here in terms of gender, gender in the hemophilia community is also implicated in whether one is "a person with hemophilia" or "a carrier" or a spouse or partner. It is also inseparable from kinship. Thus the analysis could also be carried out in terms of "having hemophilia" or "being a father." Men with hemophilia are largely making decisions on the basis of caring for their daughters and future grandchildren, while women—the "daughters" and "carriers"—are caring about their fathers, brothers and sons and to a more limited extent, their daughters. Men married to women carriers tend to express similar views as their wives, in contrast to men with hemophilia. As Herzfeld (2001) has pointed out, discussions of caring have moved beyond fixed notions of gender.

Another consideration mentioned by the men with hemophilia was reducing the burden that hemophilia places on the health service and on New Zealand taxpayers. This broader anxiety concerned a lot of people within the community, men and women, as hemophilia is one of the most costly medical conditions to treat. This is an instance where the concept of genetic citizenship is useful. As members of the nation and beneficiaries of a state-funded hemophilia treatment program, for which they have lobbied long and hard, many people in the hemophilia community in New Zealand are concerned at the health dollars that their treatment uses and the opportunity costs that their treatment represents for others. One mother, a nurse, said that she often thought about how many knee operations could be done with the dollars spent on her son's treatment products. These considerations often lead to self-regulation of daily activities to minimize the demands on treatment products as well as to considerations about limiting the numbers of children with hemophilia.

Thus although the men drew on an ethic of care, as did Nadine, they came to opposite conclusions from her about the use of prenatal and preimplantation testing because the focal points of their caring were different. These men with hemophilia completely ignored genetically determined concepts of personhood. Although they might be classified by some as "disabled" they entirely avoided the disability rights discourse (and also disagreed with the argument). Frequently, they acknowledged a relational person concept when talking about how their lives with hemophilia had shaped them as persons, often, they thought, for the better, but they did not use this argument in relation to HART. Instead they concentrated on caring for future babies in families, for the health care needs of other members of the nation and the financial burden fellow citizens carried for hemophilia treatment, to argue for the availability of HART for people with hemophilia.

What Is Natural–Normal?

People with hemophilia have become used to genetic technologies: they are already beneficiaries. In the mid 1990s, in response to the devastation caused to people with hemo-

philia by HIV/AIDS and hepatitis in the blood supply, a few drug companies began producing a synthetic clotting factor replacement product using polymerase chain reaction techniques. These genetically engineered products have reduced the risk of viruses to close to zero and are used by previously untreated persons and many others who have switched to them from plasma-derived products. Just as regular treatment, which involves venous access, is normalized within their lives, so too is genetic technology. The product just sits there in the fridge alongside the milk and the juice. It is what allows children to be healthy and to grow up without too many limiting restrictions on their lives: in their words, to grow up "normally."

Several people spontaneously raised this background of familiarity with genetically engineered (GE) products that gave them or their children the prospect of a near-normal life when they responded to our questions about technologies that involve manipulation or selection of genes. These include gene therapy as a treatment for hemophilia and assisted reproductive techniques using genetic selection, such as PGD. They explained that without hemophilia they would be opposed to GE because of what they had seen on TV or read in the paper about the dangers of genetic modification of crops, cross-species genetic transplantation and so on. But dealing with hemophilia meant that they had to do serious research, not have knee-jerk reactions. This had led to their being more open-minded. They would consider all options that would help make their child's life healthier and happier and have him or her more protected from bleeds. While those participants who discussed this were very cautious about any GE crops, they were prepared to consider GE for medical purposes, including for hemophilia, if there were careful ethical scrutiny and long-term successful trials. This is a group of people whose lives are safer and more normal because of genetic engineering. They are a world away from the submissions against the HART Bill which described people born through these techniques as a "new type of person" or "second class citizen," who would represent a "threat to the integrity of the human race" (Submissions from three individuals, Family Life International and GE Aware).

Normal within the hemophilia community means that children will have a life expectancy no different from other New Zealanders, that they will be able to have consistent schooling without long periods of time off to recover from bleeds, that pain will be minimized (although not entirely avoided), that their joints will not be arthritic, that they will be able to have tertiary education, get a good job, have a family, live to see their grandchildren and have interesting leisure activities, and that they will enjoy being able to contribute to society. They will still have to have treatment. At present, this is from two to three times a week to once a day. They will not be able to play a full range of sports (including rugby, a deprivation which is very difficult for many New Zealand boys), they will have to be careful about how they do everyday activities (for example, taking a lid off a jar, not tripping over a stick), they will have a somewhat restricted range of employment choices, and they will need to plan and be well-organized when it comes to activities like going camping or travelling (the clotting factor, needles and all the rest of it have to come too) or having routine medical and dental procedures. Women with hemophilia-related bleeding problems often need medical help to manage menstruation and extra care during childbirth for them and their babies.

Most people now imagine that gene therapy will be more like an effective and longer lasting clotting factor replacement treatment, perhaps needed only every few months, rather than a once and for all "fix." If available and safe, it too will be normal within their lives and make their lives more normal.

How something is natural or normal is defined by the contrast with what is unnatural or abnormal as many scholars have pointed out (Douglas 1966; Foucault 1977; Said 1978). The contrasts people made were sometimes expected and sometimes surprising. For example, some of the HART submissions drew on Christian- or God-related assertions that procreation is a natural and therefore a divine process, for example, "the natural laws of nature are the divine laws of creation" (Submission 57) and therefore that it should not be tampered with. Others used science as proof of what they took to be the scientific fact that the human person began at fertilization and, therefore, because of that immediate personhood, no HART should be permitted. But astonishingly, in view of the realities of modern, industrial dairy-farming where the whole life of the cow is regulated by techno-science, one person who thought HART was unnatural, suggested that instead "more holistic or organic methods" like those used in dairy herds should be used with humans (Submission 6, Individual)! Unfortunately, he did not explain this further. Recourse to nature and the natural was also used to support aspects of the Bill. For example, arguments in support of PGD and other treatment and research involving embryos up to 14 days old stated that because the development of the primitive streak did not occur until around 14 days, before this time the embryo could be manipulated.[10]

The relation of science to human nature was another area of interest. Some argued that it was part of human

nature to be curious and to experiment, so science is really just an aspect of human nature. Further, a few submissions noted that it was in the nature of science to progress, so that new technologies were a natural outcome of science. In the sense that it is part of human nature to construct and inhabit culture, of which science is a part, science is therefore naturally human rather than in opposition to nature. As Franklin (1999:146) points out in reference to similar statements by British parliamentarians, the inexorable progress of science parallels and supports the inexorable development of the genetically determined person. In yet other submissions, science is imagined as alien to human culture and represented as outside human control: a force in its own right. The use of science (and science fiction) in these documents is a topic that deserves its own analysis (see Strathern 1992; Mulkay 1996; Franklin 1999).

In the HART documents, a pathologizing discourse of infertility is discernable: "we feel deeply for those unfortunate couples that are unable to conceive, or unable to carry a child" (Submission 68, Family Life International). Such expressions of care and concern were deployed by those who nonetheless were opposed to HART but who did not wish to appear heartless. Those who wished to provide and support such services stressed the naturalness of *couples* wanting to have a *family*, thereby normalizing heterosexuality, the nuclear family and having children. This despite the statistics from fertility clinics indicating that about half the clients are single or lesbian women, who, from the point of view of those opposing HART, would not be seen as "normal" couples nor as forming "proper" families (MacCormick et al. N.d.). These arguments work on the assumption that it is part of human nature to want to have children and to have these children in a heterosexual relationship: a widespread cultural belief and one that underlies much academic work on kinship (Borneman 1996). Some submissions anticipated that this would be a likely argument and requested consideration for "non-traditional" families in relation to HART. The prospect of such families having access to HART was, of course, one of the reasons why some groups and persons, especially Christian-identified ones, were opposed to the whole process: it was part of the unnaturalness that these artificial technologies would promote. Furthermore, a few argued, using a "slippery-slope" metaphor, that this would lead to the breakdown of society as we knew it.

Where almost everyone agreed, however, was in relation to the unnaturalness and distastefulness of commodification of sperm, eggs, embryos and wombs. The reasonable expenses of a surrogate, some argued (seven submissions from fertility organizations, ethics committees, an academic and an individual), should be recompensed, but only two individual submissions (Submission 46; Submission 67, a member of a pro-surrogacy network) argued for a fee for service, similar to that paid to the fertility specialist. All were careful to differentiate any such fees from payment for a baby.

Some of the HART submissions wished to alert the legislators to the fact that normalization of these techniques would bring pressure to bear on women—making women responsible for having normal babies, and therefore likely to suffer blame and guilt if they did not (Submission 2, Individual). This is also a sensitive area within the hemophilia community, with women being forced to make choices in a context where the very existence of various tests and procedures has made not testing also a choice (Park and Strookappe 1996).

Within this community it is well understood that approximately one in three boys with hemophilia are born to families where there is no known history of it. Because of this, as we were told many times, no matter how carefully people with hemophilia manage their reproduction to avoid passing on hemophilia, there will always be these "spontaneous" people. These people were the focus of Nadine's concern. Because it is at present inconceivable that there could be prenatal population screening for such a rare condition (1:5000 male births) as hemophilia, the condition is not likely to disappear.

While there appeared to be no blame attached to known carriers having one or two children with hemophilia, families rarely went beyond that. Their own personal resources for caring and providing, as well as their awareness of how much hemophilia costs the health service, were some of the reasons for limiting family size—an aspect of genetic citizenship, as noted above.

Some reasons for not testing and "taking your chances" with a pregnancy which might result in a child with hemophilia were based on a critique of the concept of "normality." Several people, including men with hemophilia, women carriers and their partners, argued that it was good for the community at large to have a range of people in it, including people with hemophilia. For example, a few people in our initial study said that their hemophilia helped their friends realize that it was possible to be an "OK Kiwi bloke" without playing rugby. More recently, others mentioned the destructiveness of the idea of the perfect baby, pointing out that there were many ways other than having an inherited genetic disorder that babies can differ from the ideal of perfection. The spectre of "designer babies" was there in this anxiety, incorporating concerns about terribly controlling parents who constrain the natural development of their children. Also

mentioned was the idea that it is normal for human beings to have some things wrong with us and we need to learn to accept that. Concerns about eugenics, where the boundaries of "serious" disorders lie and who decides them, were frequently mentioned. As the opening quotation suggests, even severe hemophilia may be seen as "serious" or "not so serious."

Despite the frequently mentioned guideline based on "what's right for the family," not everyone was comfortable with this. One young man commented, "but OK, at what point do we (i.e., society) say 'No' to the choices that individuals want to make?" Worries about commercialism or unregulated use of selection also led to disquiet. Such concerns were also detectable in many of the HART submissions, both those for and against the use of such technologies. These fears all relate to caring for future human persons and for an ethical society where "human rights and dignity," as so many of the HART submissions reiterated, are respected.

Conclusion

New reproductive technologies are an arena in which anthropological as well as socially important questions can be explored. Even in one small nation there is considerable complexity in the ways in which personhood and what is normal are conceptualized. The contrast between the strength of the relational person concept within the hemophilia community and its relative absence in the submissions to the Parliamentary Health Committee on the New Zealand HART Bill and in the British parliamentary debates lends support to Carsten's (2004:28) suggestion that the anthropological prominence of the autonomous Western individual may derive from "undue emphasis on judicial, philosophical, and religious sources." The emphasis in these law-making contexts on the autonomous, genetically determined person gives further support to her proposition.

Men with hemophilia entirely ignored the genetically determined person concept in discussing the meaning of HART for the hemophilia community. Although they acknowledged the relational person argument in other contexts, they refused the idea that prevention of the yet-to-be-born with hemophilia had anything to say about the value of people with hemophilia who were already born. Instead, a future-oriented ethic of biosocial care and genetic citizenship underlay their relative enthusiasm for HART. This care encompassed their own multi-generational families and the hemophilia community, as the concept of biosociality would suggest, but extended well beyond that to the health system and to their fellow citizens, in line with understandings of self-regulating genetic citizenship where people with a debilitating and costly preventable condition feel a sense of responsibility to the nation and limit the number of affected children born. In contrast, when Nadine, a carrier woman and sister of a young man with hemophilia, invoked the ethic of care she had in mind the future hemophilia community but she used it to argue for the exercise of caution in the use of HART.

Nadine's argument is particularly interesting, especially in light of Borneman's critique of certain social theory which places "the reproduction of persons as the central logic of social organization. In other words, [Borneman] says, in this view people develop relationships, not in order to care for each other, but in order to reproduce" (Herzfeld 2001:224). Nadine's perspective collapses this distinction. She argues that people who know that they carry hemophilia should continue to consider having children who might have hemophilia *in order to* care for one another, and especially for those who do not know that they are carrying it. She can come to this view because of her emphasis on care as an integral component of biosociality and also because her experience is that "hemophilia is not so serious nowadays." People with it can live near-normal lives because of the quality of medical care and the technological developments, including GE, which have improved and are expected to continue to improve treatment. While some members of the hemophilia community express fears about the high costs of treatment and who will pay for this treatment in the future, this was not a consideration for Nadine at this point.

The contrastive and situational conceptualization of normal is very evident in both the HART and hemophilia contexts, with some major differences notable between them. The most significant is the normalization of GE in the lives of people with hemophilia and therefore their relatively sanguine—but not overly optimistic—approach to gene therapy and PGD. The concept of normal itself and its hegemonic power are critiqued both by people with hemophilia and those making submissions to the HART Bills. Arguments in favour of respect for, or at least acceptance of, human physical and social variation appear in support of a range of specific arguments about reproductive technologies and varied decisions about using them.

Recourse to arguments invoking normal and natural was made repeatedly in the HART submissions both to support and to deny the use of HART. In the process, infertility and new family forms were pathologized. For example, it was argued that couples can fulfil the normal reproductive script by the use of HART, and also, that the use of HART is unnatural, giving rise to improper

human relationships and to a different class of person. Science too was constructed as part of normal human culture—a natural development of human intellect—as well as a development which threatened the normal, threatened human nature and was outside human control.

The addition of care to the concept of biosociality has assisted me to produce an analysis that I believe (and hope) is more complete and respectful of the very divergent views represented in the submissions and interviews and more consonant with the ways in which many people with hemophilia express their ethical dilemmas. Genetic citizenship and biosociality used in tandem refine and define both concepts and, in turn, clarify some of the dimensions of care for individuals, the biosocial community and the nation. They allow a greater understanding of the contrasting perspectives of people differently situated in the hemophilia community or in the debates about legislation on HART.

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Notes

1 Prenatal testing involves a DNA test using a sample taken through chorionic villus sampling (CVS), at around 11 weeks gestation. CVS involves removing fine "hairs" from the placenta. The hairs are cultured, then the DNA is compared for the hemophilia gene marker. Amniocentesis, which involves the extraction of fluid from the amniotic cavity surrounding the fetus, may also be used, but this test cannot be undertaken until 12-14 weeks. Both tests have a risk of spontaneous miscarriage of between 0.5 and 1%. PGD involves DNA analysis of single cells of in vitro fertilized embryos, and the implantation into the womb of only those embryos that are not males with hemophilia.

2 The two most common forms of hemophilia affect the production of protein factors VIII or IX, which are important components of the normal process of blood clotting that prevents prolonged bleeding. Production of these proteins is controlled by two genes and the type and location of the mutation on the gene influences its expression in terms of severity as well as in other ways. People with severe hemophilia have less than 1% of normal clotting factor, and may bleed internally even without receiving a knock or strain. People with mild hemophilia have 5-25% of normal factor and will usually bleed only in response to trauma. Despite advances in treatment, 10-20% of people treated develop antibodies to the treatment product. Effective treatment is still possible but is much more complex.

3 Processes that occur in cell division may limit the amount of protection that women receive from their unaffected X chromosome. The level of severity for affected women is less predictable because of the potential role played by their other X chromosome.

4 Statements about personhood I define as statements about human beings as social agents.

5 For example, so few women (one in the entire population during the time of the study) had severe bleeding problems that it is not possible to compare the statements of men with severe hemophilia with those from women with the same level of severity. Nor is it possible to do a comparison of being a carrier only based on gender alone because all male carriers also have hemophilia. The term "carrier" is used almost exclusively for women carriers in the hemophilia community. The exceptions are when people remind themselves that men also carry the gene into the next generation (see Park 2005). Because many of the public submissions to the Parliamentary Health Committee were made by groups, organizations and couples it was not possible to analyse them in terms of gender.

6 A reviewer drew my attention to a paper by Maggie Macdonald (1994) in which she carried out a somewhat analogous exercise, analyzing key metaphors in briefs to the Canadian Royal Commission on New Reproductive Technologies. There are some evident parallels, for example in the invocation of "nature," but also some differences in our mode of analysis. The New Zealand Royal Commission on Genetic Modification reported in 1991 and I have not, to date, studied the submissions to it.

7 These activities included regional and national meetings, attending conferences with Hemophilia Foundation members, participating in weekend camps for various age and gender groups and a range of informal social occasions as well as some home visits.

8 Women carriers and their husbands tended to voice these concerns. This is an instance where the mode of caring may be gendered but also, simultaneously, may be related to both carrier status and kinship roles.

9 As pointed out by a reviewer, the submissions that depict women as safe containers are in contrast to portrayals of women in medicalized childbirth, where women, their wombs and their capacity to safely deliver babies, as noted in much feminist scholarship, are systematically depicted as dangerous to the baby's survival (Davis-Floyd 2003; Wendland 2007). However, from the point of view of anti-abor-

tion, anti-HART groups, the womb is infinitely safer than the lab or operating theatre for the embryo or fetus.

10 The primitive streak is an early embryonic stage which serves to organize later development. It is sometimes taken to be a key step toward the formation of a potential human being.

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