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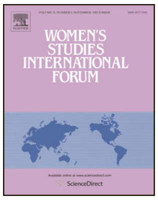

Fetal genetic difference and a cosmopolitan vernacular of the right to choose

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ABSTRACT

We engage with feminist and critical disability studies and cosmopolitan ethics to search for a cosmopolitan vernacular of the “right to choose” among people faced with the predicaments surrounding fetal genetic difference. Our argument is grounded in reflections on a decade of ethnographic fieldwork on everyday decision-making in these circumstances in Aotearoa/New Zealand. We argue that the ethical notion of “obligations to strangers” rather than the dialectic of “right to choose”/“right to life” has a greater capacity to recognize a shared horizon of meaning between publicly polarized positions on reproductive choice among various activist groups. These groups include the Abortion Law Reform Association New Zealand, Saving Downs, Parent to Parent and the New Zealand Organisation for Rare Disorders. We also debate the merits of a more superficial (cosmopolitan) engagement with others in discussions of these highly politicized topics versus the deeper engagement more commonly associated with feminist research projects such as this.

Introduction

The issues of belonging, recognition and difference, which link the contributing articles to this special section, are tightly intertwined in the ethical dilemmas in responding to fetal genetic difference. In this politicized terrain, a variety of medical, disability and feminist discourses collide. In doing so, a sense of belonging emerges for members of various communities of interest, frequently coalescing around shared imaginings of “normal” life defined through the active exclusion of “othered” types of lives such as motherhood, or life with a genetic impairment, and sometimes both. This article explores the character of such arguments as mounted by various interest groups in New Zealand, all of which are concerned with ante-natal testing and the appropriate moral reaction to (possible) genetic disorders. Rather than exploring these arguments in relation to subject positions such as ‘women’, ‘parents’, ‘NRT’ or ‘babies’, we instead focus on duties towards human ‘strangers’ and how the latter might be reached, included and assisted—whether those ‘strangers’ are the yet-to-be-born or potential parents or the community at large.

Specifically, we suggest that cosmopolitan moral theory offers several advantages for feminists interested in exploring this ethical dilemma so often expressed in the US-centric terms of “right to life” versus “right to choose”. This is particularly so given the plethora of existing feminist analyses of rights and choice and the long-term feminist concerns about adequate conceptions of moral justice on a global scale (Duran, 2008; Reilly, 2011; Tong, 2001). Rather than these existing analyses, we argue that Appiah's (2006) account of a cosmopolitan ethics - in which citizens honour obligations to other strangers but retain stronger local loyalties to those identified as their own - offers a socially inclusive line of reasoning for the debate and controversy relating to the uses of genetic testing technologies. This is an approach that remains attentive to the challenges and affordances of such technologies for women, while also thinking inclusively about the situation of citizens with impairment and disability – more so, in our opinion, than existing feminist analyses.

In addition to Appiah's work, we also engage with Rapport's notion of cosmopolitan politesse (Rapport, 2012) as a conceptual framework with which to better resist the framing of these issues within a repetitively oppositional battle of contested moral rights. To explore this second application of cosmopolitan theories to our project, we will use the analytic of critical reflection on the difficulties that we have encountered in public speaking with feminist audiences about conservative (“right to life”) views on the topic of testing. We set out to argue that for a matter such as this, in which the interests of so many diversely situated women are so pivotally and passionately entwined, the unremarked and taken for granted androgyny implicit within the two cosmopolitan theories with which our work engages, offers unintentionally valuable political benefits. As such, our contribution to gendering cosmopolitanism is to argue for the utility of a genderqueer reading of this androgyny – in the sense of a queer androgyny's capacity to value the rejection of dualistic thinking – at least within this particular moral dilemma.

The empirical research that underpins this reflective essay has been undertaken over the preceding two decades and combines the

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independent research agendas of two sets of workers in a shared project group.[i] The resulting project, funded by the Marsden Fund of the Royal Society of New Zealand and named "Troubling Choice", linked retrospective analysis of jointly-accumulated data to newly targeted sites of ethnographic enquiry with various families and groups with experience of genetic differences (Fitzgerald, Legge, & Park, 2015; Park, Fitzgerald, & Legge, 2015); it also linked this data to public and social media discourse analysis of selective reproductive technologies (Wardell, Fitzgerald, Legge, & Clift, 2014).

Background arguments on the ethics of prenatal testing

We begin, for clarity and background, with some discussion of the moral quandaries of prenatal testing. These typically emerge for a parent or parents following the receipt of test results produced through the reproductive technologies known via a variety of terms such as amniocentesis, chorionic villus sampling, serum screening, prenatal testing, and nuchal fold testing. Gammeltoft and Wahlberg (2014) have coined the term "selective reproductive technologies" for this array of medical technologies. The name expresses the ambiguity surrounding prenatal testing in practice: screening for genetic difference during pregnancy offers very little in terms of "treatment" for the fetus or forthcoming child other than pregnancy termination. The exceptions to this would be the rare heritable metabolic disorders and some developmental anomalies. In Aotearoa New Zealand it is this difficult area around the government-funded provision of what are termed "therapeutic abortions" or "TOPs" (termination of pregnancies) that frequently forms the nub of public controversy.

As previously mentioned, the development in the early 1970s of selective reproductive technologies has produced some important critical feminist ethical analyses. At the same time, such testing also has become so routinized for those with access to high technology biomedicine that many users consider it to be "just another blood test" or "the first Facebook photo". (This is of course unless the outcome is an unanticipated *or* un-wished-for positive result.) The potential for global creep in the transnational uptake of these technologies as best practice in prenatal care is one of several issues of concern for women as clients and as feminist analysts; it also explains our interest in finding a similarly transnational (or in our case) "cosmopolitan" ethical response to the varied challenges and opportunities that such technologies represent. In promoting the value of a cosmopolitan ethics we will also explain the reasons for our rejection of alternative claims to explanation of moral reasoning in situations of prenatal testing by principlist bioethics and feminist ethics.

The first study of these technologies by sociologist Barbara Katz Rothman (1986), in the US, argued that the technologies induced a change in women's experiences of their pregnancies as a result of this fetal surveillance. She described the acquired lack of confidence in such sensations as "the tentative pregnancy". Anthropologist Rayna Rapp (2000), in another US study, coined the term "moral pioneers" to describe women grappling with what she saw as an unsupported and lonely ethical decision-making process around pregnancy termination or continuation. As the testing procedures have proliferated, other writers have noted their contribution to the further medicalization of pregnancies (Lupton, 2012), and their impact on the varied manifestations of disability communities around the world (Asch, 2001; Asch & Wasserman, 2005). Cross-cultural ethnographic studies (Gammeltoft, 2014; Hashiloni-Dolev & Weiner, 2008; Sleeboom-Faulkner, 2010) have focused on the considerable impact of socio-political context on moral reasoning at the individual level, importantly suggesting that a moral pluralism may prevail over the interpretation of the "good" in testing. Collectively, this work creates the sense that cultural knowledge, social conditions and recent history provide different contexts from which a variety of "goods" can be promoted. These are not comparable to each other outside of the context in which they were elaborated. Ethnographic studies have also revealed the challenges and joys of parenting a child with significant genetic difference (Landsman, 2009) and the manner in which the urgency for a diagnosis of difference is now co-constructed in the clinical performance by both health professionals, and family members (Latimer, 2007). More recently, the topic has been explored ethnographically at the wider societal level in a variety of peripheral contexts through a biopower analytic (see Fitzgerald et al. (2015) for Aotearoa New Zealand; Meskus (2012) for Finland; Gottfredsdóttir and Árnason (2011) for Iceland). It is notable that in these latter studies principlist[ii] bioethics (Beauchamp & Childress, 1979) has emerged for each of the involved states as the preferred governmental and biomedical expert-led discourse for the regulation of prenatal testing. The cultural and geographical distance between these three locales illustrates the globalizing potential of this influential ethical discourse, which is created through the theory's powerful impact on the field of bioethics. This works in conjunction with the accepted status of bioethics as handmaiden to biomedicine and means that as biomedicine increases its global reach, the ethical discourse of principlism follows. The extraordinary uptake of Beauchamp and Childress's text in medical schools around the globe attests to this. Despite this, in each locale a different discursive resistance to principlism has emerged among users of the services. These discourses have included virtue ethics, citizens' rights ethics and an ethics of care in Aotearoa New Zealand (to be discussed below); personalized ethics mediated via social media and peer discussion in Finland; and a zone of exclusion in Iceland in which the state withdrew from the provision of testing services, leaving the testing to a private laboratory.[iii] Together, these studies emphasize that despite the globalizing potential of principlism and its theoretical attempts to speak to a universal "good" in prenatal testing technologies, its presence is simultaneously accompanied by a proliferation of different, empirically derived, and highly localized theories as to where the "good" in such testing lies.

As researchers with long experience in the study of moral reasoning in issues of human reproduction, we are thus reluctant to endorse principlism as an inclusive and global ethical framework for understanding people's decision-making about reproductive dilemmas. The remainder of this essay will explain why we have turned instead to a cosmopolitan ethics to demonstrate how an alternative theorizing of a common ethical framework for testing need not obliterate these locally inflected conversations of the "good". As Appiah notes, "not all values have a single measure" (Appiah, 2006:166).

Appiah's cosmopolitan ethics

We will first explore the advantages offered by a cosmopolitan ethics framework in understanding the variously situated dilemmas in moral reasoning posed by prenatal testing around the globe. Appiah's (2006) work, and the principlism of Beauchamp and Childress (1979), which we are rejecting, are similarly based on Kantian notions of a shared humanity and a universal common good. The benefits of working with Appiah's perspective, we consider, is the open-endedness of his approach to reaching universal values that do not rely on an arbitrary ranking of one particular group's values as the preferred approach for all humankind. For example, although he notes that cosmopolitans agree that cultural values overlap sufficiently for us to "begin a

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[i] PIs for the Troubling Choice Group were Ruth Fitzgerald, Julie Park, and Michael Legge. This was a Marsden funded research grant to the value of $NZ 735,000 and ran for three years from February 2011.

[ii] The principle-based approach argues for the notions of beneficence, non-maleficence, autonomy and justice as the universal principles for the ethical regulation of biomedicine. It was first proposed in 1979 by Beauchamp and Childress in their work *The Principles of Biomedical Ethics*. It draws on Kantian notions of the universal recognition of shared humanity to promote these "oughts" or principles as appropriate to ethical best practice in clinical medicine.

[iii] During the time of the Icelandic study, no babies with Down syndrome were born.

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