Power Point Slide: Catherine Mills

Choice and consent in prenatal testing in Australia

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1

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Prenatal testing, freedom and biopolitics

- Prenatal testing is inseparable from biopolitical decisions about who comes into the world and who does not.
- Those decisions are often seen as based on individual freedom/autonomy, where freedom is understood in terms of individual or parental choice, and the main imperative is to reduce external interference in/coercion of that choice.
- My question is: what does the emphasis on individual choice *do*? What effects does the structuring of prenatal testing around individual choice have?
- I propose the notion of an "*apparatus of choice"* to argue that this emphasis:
  - reveals a complex nexus of affect, ethics and normalization at work in reproductive biopolitics;
  - often works to reinforce existing inequalities and patterns of discrimination.

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2

Prenatal testing in Australia

- Screening tests available: ultrasound, (in conjunction with maternal blood test for trisomy conditions); recently, cell-free fetal DNA testing (often called NIPT, NIPS); microarray testing; diagnostic tests such as amniocentesis and CVS.
- Well-established regime for ultrasound screening: 12wk and 18wk scans, available in both public hospitals (for some patients) and private ultrasound or radiography clinics.
- Public subsidies through Medicare for ultrasound tests, for all 18wk scans and many but not all 12wk scans. Not for other screening tests.
- National guidelines for ultrasound testing are provided by Australian Society of Ultrasound Medicine (ASUM), and Royal College of Obstetricians and Gynecologists
- These are guidelines only
- What clinics test for, what markers they use, can vary (eg. Nasal bone in DS testing)
- Ongoing accreditation requirements to ensure quality of service
- ASUM has issued document on normal range fetal measurements that is widely used.

3

Choice and consent

- How does the introduction of cell-free DNA testing (known as NIPT) relate to and affect ultrasound testing?
- Changing rationale for/practice of 1st trimester scan
- Also reveals contradictions in approach to choice and consent in non-invasive prenatal testing regimes.
- Ultrasound requires informed choice; NIPT requires informed consent.
- Would an explicit consent procedure for ultrasound diminish some of the effects of the apparatus of choice, or is it just a different manifestation of the same phenomenon?

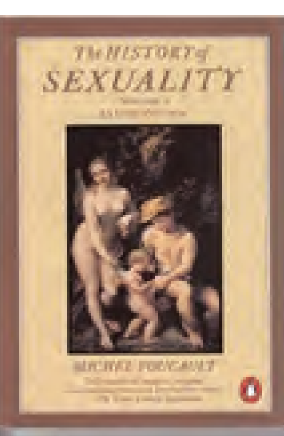
The study

- ARC DP with Niamh Stephenson(UNSW) and
  – Research assistance: Kim MacLeod (UTas) and Helen Ngo (Monash)
- Qualitative study of obstetric ultrasound (OU) in Australia
- Interviewees recruited from both private clinics and public hospital settings
- Semi-structured interviews as well as (9) observations of ultrasound scans
  – 26 women interviewed, following either 12 week nuchal translucency scan or 20 week fetal morphology scan
  – 27 professionals, including sonographers, obstetricians, genetic counsellors, disability advocates
- How ultrasound impacts on ideas of moral status of fetus, and decisions about selective termination (ST)
- Didn't set out to focus on choice, but quickly became evident that this was a major trope in almost all reflections on the experience of undergoing or using OU

5

Biopolitics and reproduction

- First, establish the *biopolitical* nature of the context of prenatal testing:
- Foucault on biopower: "the ancient right to *take* life or *let* live was replaced by a power to *foster* life or *disallow* it to the point of death" (*HS* 1, 136) .
  - 2 poles - discipline and biopolitics
  - tied together in deployment of sexuality
- "Sex was a means of access both to the life of the body and the life of the species" (1990, 146)
- "Socialization of procreative behavior" was one of the "four great strategic unities" that formed the mechanisms of a power focused on sex (103-4)
  - Political socialization through responsibilization
  - Medical socialization through pathologization



6

Transforming reproduction

- Technologization
- Commercialization
- Normalization
    - Ultrasound as pre-eminent normalizing technology
        - necessarily operates within a context of the medical management of risk and uncertainty on the one hand, and the political management of population wellbeing on the other
        - However, norms that underpin ultrasound practice do not in themselves require the eradication of the abnormal. Rather, the eradication of the abnormal points to their location and operation within moral and affective economies of the normal
- The "desire for the normal" (Kittay) is channelled through choice, revealing nexus of affect, ethics and normalisation

7

PNT and Choice

- This is consistent with bioethical/biomedical emphasis on the standard of ***informed choice*** as required to undertake prenatal screening
- Yet clinicians (obstetricians, sonographers, genetic counsellors) expressed the concern that women were *insufficiently informed* about having the ultrasound test, its purpose etc
- Worried that women did not appreciate that ultrasound screening is a medical examination; that is has potential consequences; that it may require them to make difficult decisions
- At the same time, they also strongly valued *non-directiveness* when an anomaly is found, so that the decision to terminate is understood as an expression of woman's autonomy
- In particular, there was a strong emphasis that it was a woman's decision whether or not to terminate a pregnancy following indications of fetal anomaly (though with the caveat that not all requests for termination are necessarily supported)

8

The apparatus of choice

- How might this emphasis on choice be understood and its effects analysed?
- There is a strong concern in feminist bioethical literature that choices made are not genuine choices – (eg, because women are insufficiently informed), or that it is mere fantasy that genuine choices can be made in this context (Kittay, Paul)
- This is not my approach; rather, I ask, what does the emphasis on choice do? Can we understand the effects of the operation of choice?
- Propose the notion of an 'apparatus of choice'?
- What is an 'apparatus'?
  - Relatively cohesive and coherent conglomerate of material and discursive elements that shape but do not determine behaviour in a given context
  - Operates differently in different contexts, but some consistent characteristics

9

Elements of the apparatus of choice

- Foucault highlights the three axes of subjectivity, knowledge and normativity as ways of tracing an 'apparatus' and its effects
- In the apparatus of choice:
  - **Subjectivity:** presupposes subject capable not only of making choices, but of making *rationally justifiable* choices
  - **Knowledge:** emphasis on being 'informed', where this primarily means in terms of medical view of an anomoly; but also state of knowledge re anomolies etc; uncertainty generated by technology itself
  - **Normativity**: choices are understood as needing to be 'free', ie, unimpeded by others. Liberal notions of negative freedom, autonomy as independence etc. Stongly individualistic focus.

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10

Clinicians as service providers

- Allows clinicians to adopt position of moral neutrality, and also forces them to, even if they would like to provide more engaged care.
- Emphasis on non-directive information provision, both prior to and after PNT.
- However, prior to ultrasound, the standard of informed choice and implied consent rather than express consent means that no-one takes responsibility for providing information or ensuring that women are sufficiently informed.

> “This is simply about providing information that allows women to make their own choices” – Ben, Obstetrician

> “People have individual choice and might not make the same decisions as me. And I think, if they can rationalise that and, you know, it, they put together a sensible argument, then I’m here to, to help them through the difficult time. But, yeah, I mean there would be circumstances where I know the hospital would say, “No, that’s not reasonable.”” - Ben, Obstetrician

11

Clinicians as service providers

- After testing, (non-directive and neutral) roles as clinical agents can be more or less strictly held, but either way, moral responsibility for any decision is projected onto women.
- Clinicians are reluctant or unable to publicly reflect on the moral ambiguity of their roles (even if they want to).
- The apparatus of choice allows clinicians to avoid the moral ambiguity of their practices and project responsibility solely onto women.
- Some clinicians are very reflective about this.

> “Have we become more sophisticated in our counselling? No doubt. Are women more aware of their choices? Yeah, almost certainly. You know, are most better, women better off? I’m not sure.” Ken – Sonographer

> “So I don’t think we do give women lots of choice. I think we give them lots of information and we sometimes bamboozle them, and then we say, “It’s all your choice.” And, in a way, we’re kind of handing over professional responsibility.“ – Deanna, genetic counsellor

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12

Women as moral actors

- In the apparatus of choice, women are cast as responsible moral agents capable of informed decision-making and who bear primary culpability for their actions

OR

- Fundamentally ir-responsible, incapable of informed decision-making but nevertheless culpable for this (perceived) moral failure
  - For example, women who are insufficiently informed about or respectful of the medical aspects of ultrasound (as opposed to the social) are seen as irresponsible and morally culpable for this failure.
  - Women who do not read English, or who do not have easy internet access, also fall into this category.

"I always get the sense that I'm kind of on my own to make the final, the final choice" – Maria, 12 wks pregnant, considering amniocentesis

13

Women as moral agents: further aspects

- Control of information: lack of consent process means women are made responsible for their own condition of being informed or uninformed
- Control of her body: ideal woman having ultrasound is thin, but not too thin; her bladder is full, but not too full; her baby is active, but not too active
- Control of emotions: ideal woman having ultrasound is concerned but not anxious, engaged but not demanding

"The super-anxious ones are difficult..." Beatriz, Sonographer

".. when woman comes in here with her girlfriend, that's a nightmare. They talk about all their shopping expeditions and their friends, and their social ... And I think, "What are you doing here?" Beatriz, Sonographer

14

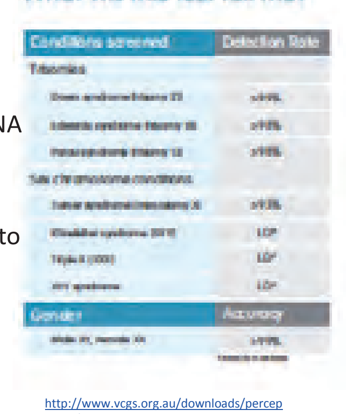
Fetus as boundary object

- The apparatus of choice makes the fetus something about which one makes choices
- These choices are ones about the differential valuation of life and possible lives
- It also makes the normative status of fetus – its inclusion in moral community and normative life –dependent on technology
- Intersects with medical normalization
  - Disability and norms
- Not only choices made, but choices made available (Nancy Press)
  - social structures within which choices can be made at all
  - The apparatus of choice tends to obscure this aspect of the material conditions of choice

15

Ultrasound and Cell-Free DNA test (NIPT)

- Available at various clinics in Australia since about 200?
- Samples generally sent overseas, but Victorian Clinical Genetic Services recently developed Australian test, called percept
  - http://www.vcgs.org.au/perceptNIPT/



http://www.vcgs.org.au/downloads/perceptNIPT/CT-W-138v3_web.pdf, p1.

- High rate of accuracy, but not diagnostic; amnio or CVS still required for diagnosis
- 12wk ultrasound still recommended (in conjunction with cfDNA test)
- Costs around $500; this is **not** subsidized by the govt, nor is there currently any discussion of incorporating cfDNA tests into the publicly subsidized prenatal screening regime.
- As it only requires a blood test, there is no risk to the pregnancy.
- Other tests: Harmony, Panorama (microdeletions; tests for Angelman, Cri du Chat, DiGeorge, Prader-Willi Syndromes)

16

Choice and consent in non-invasive screening

- cfDNA tests such as percept require explicit patient consent; the standards of informed consent are (supposed to be) applied
- Ultrasound is also a form of non-invasive screening
- It does not require a consent form to be signed; the standards of informed choice are taken to be sufficient.
- There is no principled justification for this difference; the contradiction is an historical artefact of the ad hoc introduction of ultrasound (and now cfDNA testing)
- Would a coherent system undo the requirement for consent in cfDNA, or introduce it for ultrasound?
- While there are problems with consent procedures, the introduction of consent for ultrasound may ameliorate some of the negative effects of the apparatus of choice in regards to ultrasound – eg, making women responsible for being informed, addressing clinical concern with lack of knowledge, and associated lack of preparation for high risk results

17

Conclusions

- The apparatus of choice casts women as the principlan – indeed, only – moral agent who bears responsibility for PNTdecisions.
- The clinical introduction of cell-free DNA testing in Australia, puts pressure on the emphasis on informed choice for non-invasive screening, since it requires explicit consent.
- Though consent is only a formalization of choice, a shift toward a coherent consent system across non-invasive screening techniques may alleviate some of the negative effects of the apparatus of choice.
- More research is required on whether a consent system would be feasible or desirable.

Thank you!

18