Universiteit Maastricht

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PGD: A celebration of 20 years
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PGD: dynamics and ethics

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PGD: categorical objections?

1. Unjustified selection?
   - the status of the embryo
   - the 'disability rights' critique

2. Disproportionally burdensome?
   - feminist paternalism ('maternalism')
   - informed choice

Categorical objections? (cont.)

3. Totipotency of the blastomere?
   - valid scientific assumptions?
   - questionable moral assumptions

4. The slippery slope argument
   - designer babies?

Conclusion: PGD is morally justified

The medical model 1: PGD for HD

A. The simple case: a carrier of an *abnormal* HD allele applies for direct testing

Valid moral objections?

- 'suffering is part of life'

  → a duty to transmit HD?!

- 'the moral ambiguity of the quest for perfectionism'

  - perfectionism is not the point!

1A (cont.)

Valid objections to *medically assisted* reproduction in view of one of the parent's poor prognosis?

Standard to evaluate risks to the welfare of the child: reasonable welfare: avoid high risk of serious harm

Case 1 asymptomatic carrier

Case 2 symptomatic carrier/patient

1B: PGD/HD for other types of carriers?

- reduced penetrance alleles

- intermediate alleles

1C: PGD exclusion testing

Valid objections?

1. Unnecessary burdens for women?
2. Unnecessary loss of embryos?
3. Unnecessary costs?
4. Unnecessary risks for the child
   a. medical
   b. psychological

An overriding argument pro:
The applicant's right not to know his/her genetic status

1D: non-disclosure PGD

Problem: the feasibility/costs of protecting the applicant's right not to know

- informing the applicant hat (s)he proves *not* to be a carrier is an indirect breach of *other* clients' right not to know … →
- repeated IVF/PGD cycles for *non*-carriers?
- placebo/sham transfers to avoid inferals of the applicant about his/her carrier-status?

The medical model 2: hereditary cancers – the case of BRCA 1/2

Valid objections?

- incomplete penetrance of mutations in BRCA
  - but still very high!
- preventive options for carriers
  - but what about the effectiveness and burdens?

Consistency, please: if PD is allowed …

The medical model 3: PGD for mtDNA disorders

- scientific research
- risk-reducing PGD may be justified
- avoid high risk of serious harm: cutoff points
- an additional principle: minimize risk
- follow-up studies: genetic testing in children thus conceived?

Bredenoord et al., EJHG 2009

Beyond the medical model 1: PGD/HLA typing

Two preliminary issues:

1. Using a living child as a donor: morally justified?

2. Conceiving a child hoping to obtain a transplant: morally justified?

If so:

3. What about PGD/HLA typing?

PGD/HLA-testing: unjustified?

A *practical* problem: the low THBR

The *fundamental* issue: this case is *beyond* the medical model. Valid objections?

- the slippery slope argument: the 'designer' baby …
- the additional loss of 'healthy' preimplantation embryos

Conclusion: no convincing moral objections

- but clearly: PGD/HLA typing is not an easy solution

Further evolution of PGD/HLA-testing?

From type I to type II: isolating hESC from matched embryos in order to obtain HSC for therapy

Advantages:

- avoids some of the limitations of type 1
- avoids some of the pitfalls of type 1

Controversial: the production of embryos as a source of hESC (for 'instrumental use')

- proportionality
- subsidiarity

Beyond the medical model 2: sex selection for intermediate reasons

Case: a haemophiliac patient wants to have *sons* – and requests PGD/sex-selection

Questions/concerns:

1. 'It is beyond the medical model'

a. But what if female carriers could be affected: *stretching* the criteria ('high risk') used in the medical model?

b. If female carriers will (probably) not be affected: beyond simplistic dichotomies: medical, social, and *'mixed'* reasons for sex-selection

Sex selection for ‘mixed’ reasons (cont.)

(like before: proportionality)

2. Burdens for women: justified paternalism?
3. Risks of ART for the child (harm principle): a high risk of serious harm?
4. Embryo-loss: pre-conception/sperm selection as a possible alternative?
5. Costs (justice): collective financing?

Comprehensive PGS?

- The challenge to select the best embryo
- Comprehensive screening → the transparent embryo?
- Issues include:
  - Is informed consent possible?
  - Impossible trade-offs
  - We are all fellow-mutants …
  - The future child's right not to know