Current Practices and Ethical Issues of Reproductive Genetics

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Topics for Discussion

- Eugenics
  - Definition & Objectives
- Contemporary practices
  - Eugenics & Reproductive genetics
- Ethical & Regulatory Issues
- New advances
  - Genomic editing
Definition of Eugenics

- Technique and policies that allow for the reproduction of people with the ‘desired’ attributes
- and reduce the reproduction of those with the ‘undesired attributes’

Thomas GM and Rothman BK. AMA J of Ethics, 2016. vol.18, 4:406-415
Objective of Eugenics

- Coercion of people’s reproductive choice
  - To ‘improve’ quality of the population
  - Prevention of suffering
  - Reduction of financial cost for whole society in caring for the disabled

King DS. Journ Medical Ethics. 1999:25:176-182.
Francis Galton

- Founder of the ‘Eugenics’ movement, coined the term 1883
- Eugenics literally means good birth
- He opposed to coercion, believing that if people were properly informed they would naturally make the “right” reproductive decision

In England during the late nineteenth century, intellectuals, especially Francis Galton, called for a variety of eugenic policies aimed at ensuring the health of the human species.


United States, Progressive movement embraced eugenic ideas, especially immigration restriction and sterilization.

Indiana enacted first eugenic sterilization law 1907

US Supreme Court upheld such laws in 1927.

State programs targeted institutionalized, mentally disabled women.


Beginning in the late 1930s, proponents rationalized involuntary sterilization as protecting vulnerable women from unwanted pregnancy.

By World War II, programs in the United States had sterilized approximately 60,000 persons.

After the horrific revelations concerning Nazi eugenics (German Hereditary Health Courts approved at least 400,000 sterilization operations in less than a decade), eugenic sterilization programs in the United States declined rapidly.

Simplistic eugenic thinking has faded, but **coerced sterilization** remains widespread, especially in China and India.

In many parts of the world, involuntary sterilization is still intermittently used against minority groups.
Background of further Development of Eugenics

- Growth of genetics
- Introduction of prenatal diagnosis and termination of pregnancy
- Enactment of Abortion Laws
- Acceptability of Screening in Medicine
- Medicalization of pregnancy
- Public exclusion & discrimination of disability
Development in Reproductive Genetics

- Prenatal testing
  - Non invasive prenatal testing
  - Prenatal diagnosis by
    - Chorionic villous sampling
    - Amniocentesis
- Preimplantation genetic diagnosis
- Future potentials
  - Genome editing
  - Mitochondrial transfer technology
Development in Reproductive Genetics

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Development in Reproductive Genetics

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Contemporary eugenics

- Historical eugenics refer to the atrocities operated on populations in history
- Contemporary eugenics operated on individuals at present

Ref. Thomas GM and Rothman BK. AMA J of Ethics, 2016. vol.18, 4:406-415
Contemporary Eugenics (Cont’d)

- Criticisms on prenatal screening and testing
  - Parental decisions has little choice
  - Autonomy compromised through routinization of reproductive technology
  - Negative portrayal of disabilities, with decrease in social support
Development in Reproductive Genetics

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- Preimplantation genetic diagnosis

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Preimplantation Genetic Diagnosis (PGD) and Eugenics

- Characteristics of PGD
  - poses less emotional pressure on the female
  - Increases the culture of ‘prevention’
  - The females’ right to choose is less
  - IVF clinic and doctors’ decision power increased instead of parental choice offered at genetic counselling clinics

Potential outcome of PGD

- Increased choosiness for the ‘Best’ genetic profile
- Elimination of
  - ‘Minor’ undesirable traits
  - ‘curable’ conditions
  - ‘late onset conditions
  - Even autosomal recessive carriers
Preimplantation Genetic Diagnosis (PGD) and Eugenics (cont’d)

- Labelled as Consumer Eugenics
- Characteristics
  - Disrupting the parent child relation as we know now
  - Parental choice is greatly increased
  - Further decrease in tolerance to disabilities
  - Possibility that elites in the society will become more genetically privileged
Genetic Services in Hong Kong

Government funded
Clinical Genetics &
Prenatal Diagnosis

University funded
Research & Service
Programmes

Private Sector
Hospitals &
NGO
Regulatory Development

- 2000 Human Reproductive Technology Ordinance (Cap. 561, Laws of Hong Kong)
- 2001 Council on HRT established
- 2002 Code of Practice
Organization Chart of the Council on Human Reproductive Technology

Council on Human Reproductive Council

- Secretariat
- Ethics Committee
- Inspection Committee
- Investigation Committee
- Working Group on Code of Practice
- Working Group on New Developments in Reproductive Technology
- Pre-implantation Genetic Diagnosis (PGD) with Tissue Typing Vetting Committee

Secretary

Assistant Secretary
Ethics Committee Guiding Principles

• Human life in all forms warrants respect and moral considerations
• Welfare of child of paramount importance
• Personal autonomy, individual liberty and human integrity be safeguarded
Ethics Committee Guiding Principles (cont’d)

• Recognition to basic community values (responsible parenthood, parental love, and the family)

• Use of resources based on principles of care, equality, justice and accountability, and a reasonable balance must be sought between individual and collective interests to protect vulnerable parties from harm or exploitation
Development in Reproductive Genetics

- Prenatal testing
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Genomic Editing

- DNA double stranded break (DSB) repair mechanics via
  - Non-homologous end joining
  - Homology directed repair

- Nuclease-based genome editing
  - Meganuclease
  - Zinc finger nuclease
  - TALEN (transcription activator-like effector nuclease)
  - CRISPR-Cas
Debate on CRISPR/Cas9-targeted Genome Editing

- **Chinese scientists** Huang et al 2015 worked on tripronuclear zygote
- **US scientists** called for ‘prudent pathway’, 2015 NIH not fund editing on human embryos
- **UK scientists** disagree
  - ‘research .... Is moral obligation’
  - Fertilisation & Embryology Authority approved research CRISPR on embryo
Position Statement ASHG

- Statement approved by American Society of Human Genetics Board March 2017

- Workgroup from
  - UK Association of Genetic Nurses and Counsellors,
  - Canadian Association of Genetic Counsellors,
  - International Genetic Epidemiology Society,
  - US National Society of Genetic Counselors.

Final statement also endorsed by
- American Society for Reproductive Medicine,
- Asia Pacific Society of Human Genetics,
- British Society for Genetic Medicine,
- Human Genetics Society of Australasia,
- Professional Society of Genetic Counselors in Asia, and
- Southern African Society for Human Genetics
Position Statement ASHG

• (1) At this time, given the nature and number of unanswered scientific, ethical, and policy questions, it is inappropriate to perform germline gene editing that culminates in human pregnancy.

• (2) Currently, there is no reason to prohibit in vitro germline genome editing on human embryos and gametes, with appropriate oversight and consent from donors, to facilitate research on the possible future clinical applications of gene editing. There should be no prohibition on making public funds available to support this research.
(3) Future clinical application of human germline genome editing should not proceed unless, at a minimum, there is
− (a) a compelling medical rationale,
− (b) an evidence base that supports its clinical use,
− (c) an ethical justification, and
− (d) a transparent public process to solicit and incorporate stakeholder input.
Conclusions

- Eugenics defined and utilized in different ways
- Lessons to be learnt from historical development of eugenics
- Contemporary eugenics is in practice
- Ethical & Regulatory issues of current practices discussed
- Advancing technologies
Thank you!