



Genetic Ties and The Right to Know

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De Melo-Martin

Right protects important interests

- Need to prove there is a vital interest at stake, if we claim there is a right to know information about one's biological parents
- Possible candidates:
 - Medical interests
 - Identity formation / self-knowledge
 - Strong family bonds
- Agrees that these are all vital interests, but denies that a 'right to know' is necessary



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- Claim – health interests justify a ‘right to know’
- Two kinds of possible harms
 - Lack of access to relevant medical information
 - Incorrect belief that social parent’s medical history is pertinent

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- Relevance of medical history to wellbeing is overstated
 - Many diseases are hard to avoid
 - Most people do not change their behavior in light of information about their predisposition to disease
 - Personalized medicine will make family history irrelevant
 - People often don't receive accurate medical family history information
 - No strong evidence suggesting that people without accurate family history information are harmed
- Thoughts?



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- Harm of incorrect inferences (Incorrect belief that social parent's medical history is pertinent)
- This can be addressed by mandatory disclosure of donor status → no need to reveal identity



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- Harm to identity formation / self knowledge
 - Evidence that most donor-conceived individuals have little problem adjusting
 - Our identities can be constructed in many ways, genetic relatedness is just one
 - Some people might be harmed, but is this enough to generate a right?
 - Harm seems contingent
- Thoughts?

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- Harm to family bonds
 - Most of the problems arise due to secrecy
 - Family members feeling they have to keep a secret
 - Accidental revelation of donor status
 - Can disclose donor status without right to access identifying information
 - We normally grant parents broad discretion about decisions that effect the welfare of children
- Thoughts?

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- That lack of information might result in a harm / impede an interest does not create a right
 - Examples?
- Thoughts?



Ravitsky

- People have a right to
 - Determine how important genetic ties are to their identity
 - Whether /how to respond to information about their medical history
- Secrecy about donor identity and donor status deny donor-conceived individuals the ability to value this information as they see fit
- Genetic information does have special value

Ravitsky

- Harming and wronging are not the same
 - Eg. Law school bans people names Reuven Brandt
- We do not assess wrongdoing on the basis of portion of people harmed
 - Even if *most* are not harmed by donor anonymity, this does not mean it's not problematic
- Even if people *can* develop a strong sense of identity through non-genetic means, they still ought to have the opportunity if they want it
 - Cultural importance
 - Religious importance
 - Causal history (and personal traits)
- State should protect the rights of donor-conceived people!
 - Genetic information is special, and so special case for rights

Ravitsky

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Ravitsky

- To what extent is Ravitsky right that genetic information is special?
- Does 'procreative obligations' on the part of parents (and possibly gamete donors) complicate De Melo-Martin's claim that we don't have right to all information that might advance our interests?
- Usually we think that people have a considerable right to privacy regarding their medical and procreative decisions. Is there a conflict between these privacy rights and a prohibition on donor anonymity?