Ethical Concerns of Predictive Testing for Minors

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Current Views

- There are generally no benefits to genetic carrier testing of minors, except when adolescents are contemplating marriage or having children in the near future.
- Risks of such testing include stigmatization, discrimination, and parental misunderstanding of the meaning of the test results.

Current Views

- Most commentators contend that the primary determinant of whether a child should undergo genetic testing is the best interests of the child.
- In the absence of a clear medical benefit to the child, these commentators opine that avoidance of potential testing-associated harms and the preservation of the minor's future autonomy should be the overriding considerations.

Current Views

- Accordingly, these commentators maintain that children generally should not undergo genetic testing for late-onset disorders in the absence of a medical benefit and should not undergo genetic carrier testing for recessive disorders.

Current Views

- Ambiguity exists for:
  - Childhood onset diseases where preventative or therapeutic measures are not available
  - Timing of testing for childhood-onset diseases
  - Age limit
    - Adolescents 15-18 yrs of age might be capable of making testing decisions instead of 18+

More Controversial?

- Predictive testing for minors may be more controversial than carrier testing in minors
- Not all guidelines distinguish between childhood-onset and adulthood-onset diseases
  - Greater need for clear recommendations
- Juvenile HD may complicate the ethical/clinical issues; however, in the presence of symptoms testing is recommended.

Goals of Genetic Testing

- Promote the well-being of the individual
- Family network of decision making
- Interest and ability to participate in decision making for his or her self

Goals of Counseling

- Parents and child understand:
  - Potential risk and benefits of the test
  - Decision-making capabilities of the child
  - Best interests of the child

- Only 20% of adults at risk for HD seek predictive testing

Impact of Risk/Benefit on Decision to Test

- Primary justification is medical benefit to child
- Substantial psychosocial benefit
- Testing of late-onset diseases should be deferred
- Risk ≠ Benefit
- Testing should be avoided when the risks outweigh the benefits

Family Involvement in Testing

- Education and counseling demonstrates competency
- Obtain permission of parents, assent of child, or consent of adolescent to test
- Provider obligated to provide in the best interest of the child
- Requests for results by an adolescent is given priority over parents’ request

Benefits/Harms to Testing Minors

- Medical Issues
  - Treatment/Prevention of disease
  - Surveillance for prognosis
  - Avoidance of harmful procedures
  - Clarification and refinement of prognosis

Benefits/Harms to Testing Minors

- Psychosocial issues
  - Reduction of uncertainty or anxiety
  - Alteration of self-image
  - Impact on family relationships
  - Impact on life planning

Benefits/Harms to Testing Minors

- Reproductive issues (in the future)
  - Prenatal diagnosis
  - Adoption
  - IVF/PGD
  - Donor egg or sperm

Promoting Family and Children Interests

- Parental authority
  - Roots of parental authority
  - Limits of parental authority
  - Legal trend to recognize authority of minors

- Decision-making capacity of children
  - Legal vs. moral/ethical

Promoting Family and Children Interests

- Provider’s role in testing minors
  - Assessing requests for tests
  - Assessing requests for communication of results
  - Disclosure vs. Nondisclosure

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