Huntington's Disease
Society of America

Psychological Consequences of a Negative Test Result

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June 9, 2012
27th Annual HDSA Conference
Las Vegas, NV

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Presenter Disclosures

Carol Manning, Ph.D.

The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:

No relationships to disclose
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Objectives

- Review Basics of Testing
- Discuss Why People Get Tested
- Discuss Common Responses
- Discuss Who is Affected
- Suggestions for Easier Adjustment

Basics of HD Testing

- Measures CAG repeats
  - – 40+ repeats = will develop HD, 50% risk for children
  - – 36-39 repeats = may develop HD
  - – 27-35 = indeterminate, No HD, small risk to kids
  - – <27 repeats, normal, no HD, no risk to kids

Basics of HD Testing

- Positive test results means got the HD gene
  - – Will get symptoms
  - – 50% risk to kids
- Negative test result
  - – Did not get the gene
  - – No risk to kids

Who Gets Tested?

- More women than men
- More married people than single people
- Must be 18 or older

Why Do People Get Tested?

- Family planning
- Marriage
- To Relieve Anxiety
- To Reduce Uncertainty

HDSA Testing Guidelines

- Initial telephone contact/pre-screening interview
- Three pre test, in-person sessions for genetic counseling, neurological evaluation and psychological evaluation
- Fourth session for disclosure of results
- Post test counseling

“Soon everyone is going to have an option like this. You make the decision to test, you have to live with the consequences.”

“

Nancy Wexler, PhD
President, HDF

“I’ve been thinking about this for years and I’m ready now. Can’t we just do it?”

Positive or Negative Results

- More preparation for positive results
- Short-term distress worse for positive results
- Long-term distress the same for positive and negative results
- Anxiety lower for both groups post-results

Common Responses to Negative Results

- Joy
- Relief
- Elation

Common Responses to Negative Results

- Survival guilt
- Why did I get lucky?
- How can I be happy when my siblings got the gene?
- I “want” to take care of everyone else
- It is my “job” to take care of everyone else

Common Responses to Negative Results

- I wasted so much time
- Regret for past decisions
  - Kids, education, career
- I need to do something important with my life now

Common Responses to Negative Results

- Are these really my results?
- What if the results are wrong?

Common Responses to Negative Results

- Initial period of elation followed by low period
- "The good news didn't change my life as much as I thought it would"
- Same old pressures
- What now?

Who is Affected? Spouses

- Same distress as person getting tested during the process
- After testing, partners have lower anxiety than when results are positive
- Different future
- Change in roles

Who is Affected? Children

- No longer at risk
- Won’t be HD caregivers to parent
- Did they know parent was at risk or getting tested?
- When to tell them?

Who is Affected? Extended Family

- Are they at risk?
- Do they have the gene?
- Did they know about the test?
- When to tell them?

Easier Adjustment

- Testing protocol with counseling
- Clear reasons for getting tested (for example family planning decisions)
- Have a test partner
- Have discussed outcomes
- Discuss feelings after testing

Easier Adjustment

- Not depressed at beginning of test process
- “Stable sense of self”

Easier Adjustment

- Realistic sense of what will change with the results
- Realistic understanding of "normal" feelings after a negative result
- Adjustment takes time
- Change takes time
- Seek support

Thank you for listening. Now let me hear what you have to say!