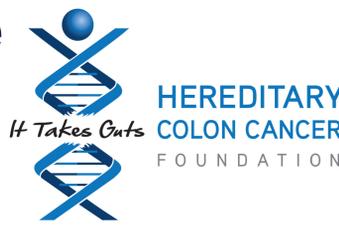




The Psychosocial Implications of a Hereditary Colorectal Cancer Syndrome Diagnosis During Emerging Adulthood



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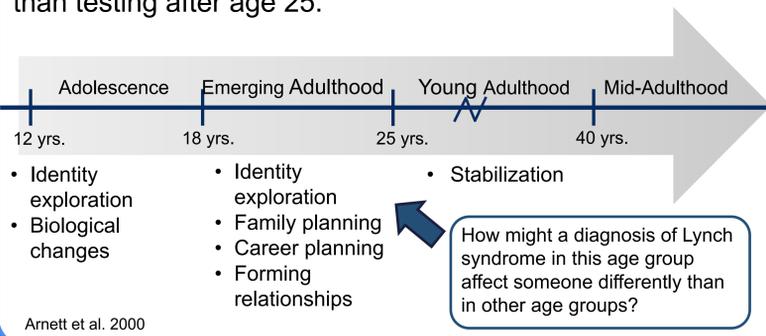
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Background

- Genetic testing for Lynch syndrome (LS) is typically not offered for anyone under the age of 18. Further, screening and surveillance measures are often not initiated until an individual with LS is 25.
- The period between ages 18-25 is termed emerging adulthood and is characterized by identity exploration through family planning, career planning, forming relationships, and geographic movement. Emerging adulthood is a time of great change in one's perceived identity that is typically stabilized later in life.
- We ask: how might a diagnosis of LS during emerging adulthood affect someone's psychosocial functioning compared with those who are diagnosed in other age groups.

Hypothesis:

Genetic testing for Lynch Syndrome during emerging adulthood is more detrimental to psychosocial functioning than testing after age 25.



Methods

Recruitment: Hereditary Colon Cancer Foundation (hctakesguts.org)

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Online survey for anyone who had genetic testing for LS (Qualtrics)

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Quantitative and qualitative analysis

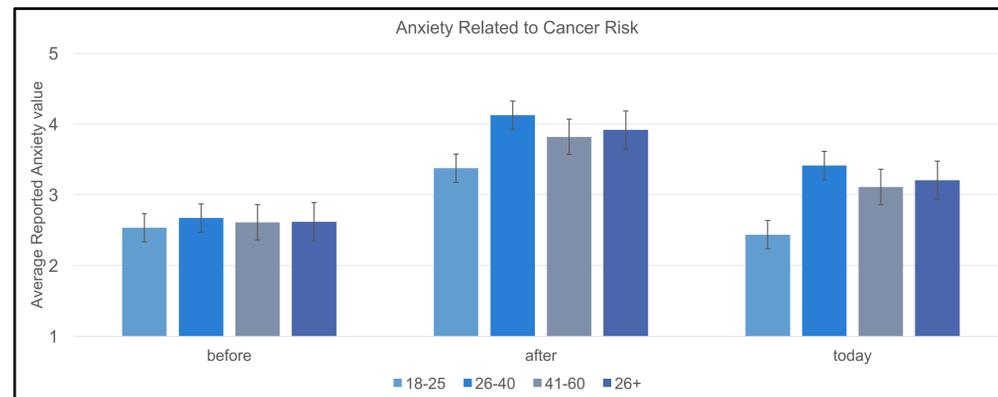
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Themes assigned to describe differences between groups tested between 18-25, 26-40, 41-60, and 61+

Demographics

LS Cohort Demographics				
Total Respondents	174			
% Female	91%			
% Male	9%			
At Least Undergraduate Degree	60%			
Age at Genetic Testing	Number	% with Personal Cancer History	% that have Children	% that are First in Family to Test
Under 18	0	--	--	--
18-25	18	16%	44%	12%
26-40	64	42%	77%	36%
41-60	81	67%	79%	51%
61+	11	100%	100%	45%

Reported Anxiety by Age at Genetic Testing



Major Themes and Selected Quotations

Increased Anxiety	Decreased Anxiety
Cancer Risk (n=52)	Preventative Screenings/Surgeries (n=58)
Risk to Family Members (n=23)	Knowledge/Acceptance (n=15)
Uncertainty (n=18)	Support Groups (n=5)

- "[Increased anxiety because of] the constant worry about developing another cancer and the worry my son will get lynch syndrome. I would like to get him tested now and not have to wait till he is 18" –Respondent #20 (26-40)
- "Oh yes indeed. LS was passed down to me and now my children. Since my son passed away at the age of 27, he was diagnosed stage iv colon cancer 2 months shy of my 1 [year] anniversary [of my] 1st cancer. I blame myself for his cancer." –Respondent #149 (41-60)

Effect on Family Planning	No Effect on Family Planning
Pursuing PGD (n=13)	Already had Children (n=76)
Had Children Sooner (n=12)	Infertility Due to Treatments (n=12)

- "I had my child before my Lynch diagnosis -- I never would have had children had I known before. Don't have children unless you can afford PGD." –Respondent #5 (26-40)

Major Themes and Selected Quotations

Limitations to Career Planning	Strengthen Romantic Relationships
Need a Career with Good Health Insurance (n=14)	Strained (n=32)
Need to Live Close to Doctors (n=16)	Strengthened (n=3)
Strain on Friendships	Strengthen Friendships
People don't Understand Risks (n=22)	Strengthened (n=8)
Lost Friends (n=12)	

- "Forming long, lasting relationships seems pretty futile sometimes. Additionally, once you get to the stage of dating/ relationship that it comes up that you have Lynch syndrome, a lot of partners feel that's a heavy burden to take on. I've met several guys who weren't willing to even try and left me purely because of the risks associated with Lynch syndrome and my cancer diagnosis." –Respondent #131 (26-40)
- "I feel it has made me a better friend to others. I was a young person when diagnosed and was finding my way in the world. Although I've always been a mature person I feel my experiences have helped define me. I never make assumptions about someone as there are so many people battling "invisible" conditions. I have many people in my life who suffer mental illnesses especially depression. I feel that my experiences have enabled me to become a person people confide in and like to talk to about the struggles of life." –Respondent #17 (18-25)

Advice to Others Considering Testing
Get testing (n=52)
Know What Results Would Mean to You Prior to Testing (n=14)
Live Your Life (n=34)

- "Do it. Get the test. If it comes back positive, first, don't panic. Take a few days to mentally recover. I have analogized it to having a poisonous snake in the yard. All other things being equal, I would prefer to not have a poisonous snake in my yard. But if there one, I sure would like to know about it." –Respondent #41 (41-60)
- "Have a very clear idea [before] testing of what you think it will mean for you, your spouse/family, etc. if you receive a positive [or] a negative result. Nothing can really prepare you for the real moment, but having some sort of plan in place for "what to do if..." can be helpful." –Respondent #8 (26-40)

Discussion and Conclusions

- Genetic testing for LS during emerging adulthood is not more detrimental to psychosocial functioning than testing later in life.
- Evidence is suggestive that testing between ages 18 and 25 leads to less psychosocial harm than testing after age 25.
- No participants suggested to not have genetic testing during emerging adulthood.
- Emerging adults:
 - exhibit greater resiliency after diagnosis,
 - have a higher likelihood of having more choices in family planning,
 - feel less limited by LS geographically/in careers