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

Master’s Thesis

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Shawn Fayer

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Abstract

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

A thesis presented to the Graduate Program in Genetic Counseling
Graduate School of Arts and Sciences
Brandeis University
Waltham, Massachusetts

By Shawn Fayer

Lynch syndrome (LS), attenuated familial adenomatous polyposis (AFAP), and MUTYH-associated polyposis (MAP), are hereditary colorectal cancer syndromes with increased susceptibility for multiple cancers in adulthood. Genetic testing for these adult-onset colorectal cancer syndromes may be offered to the emerging adulthood demographic (ages 18-25), before the time of increased cancer risk and surveillance protocol initiation. Emerging adulthood is defined as a time of identity exploration through career planning, relationship forming, and family planning. To determine if genetic testing for a colorectal cancer syndrome during emerging adulthood is more detrimental to psychosocial functioning than testing later in life, we surveyed 241 participants through an online survey tool who had genetic testing for LS, AFAP, or MAP at different ages grouped as under 18, 18-25, 26-40, 41-60, and over 60. All respondents were recruited through the Hereditary Colon Cancer Foundation. Psychosocial functioning was assessed through quantitative and qualitative analysis of open-ended questions, which were focused into themes of 1) anxiety related to cancer risk, 2) family planning, 3) exploration, 4) career planning, and 5) forming and maintaining relationships. In the LS cohort, those who
underwent genetic testing during emerging adulthood reported significantly less anxiety directly after receiving genetic testing results and today, compared to those who had testing later in life. For AFAP, however, those who had genetic testing during emerging adulthood reported significantly greater anxiety today those who had testing between ages 41-60, but no other group. Themes that emerged from qualitative analysis related to increased anxiety were living at increased cancer risk, risk to family members, and uncertainty. Factors that decreased anxiety were preventative screening/surveillance, knowledge, and acceptance. The emerging adulthood group was also significantly less likely to have had children or to have had cancer, but more likely to consider alternative reproductive options. There were no other detectable differences in levels of psychosocial functioning between groups. Taken together, this evidence is suggestive that genetic testing during emerging adulthood for adult onset colorectal cancer syndromes is not more detrimental to psychosocial functioning than testing later in life.
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Introduction

Hereditary Colon Cancer Syndromes

Lynch syndrome, attenuated familial adenomatous polyposis (AFAP), and MUTYH-associated polyposis (MAP) are highly penetrant colorectal cancer (CRC) susceptibility syndromes with increased cancer risk confined to adulthood (Lynch et al. 2009, Necklason et al. 2008, Simpson et al. 2003). Lynch syndrome is characterized by autosomal dominant inheritance and an 80% lifetime risk for CRC, as well as increased risk of endometrial cancer, other gastrointestinal tract cancers, urinary tract cancers, ovarian cancer, and central nervous system cancers (Lynch et al. 2009). AFAP is another autosomal dominant, highly penetrant CRC susceptibility syndrome where individuals present with between 10-99 adenomatous polyps in the large intestine after age 30, and have a 70% lifetime risk of developing CRC (Neklason et al. 2008). Comparatively, Familial Adenomatous Polyposis (FAP), which is caused by the same gene as AFAP, is the most penetrant of the hereditary colon cancer syndromes, and if left untreated, patients with FAP will develop hundreds of colorectal adenomas and CRC almost 100% of the time (Giardiello et al. 2002). MAP follows a similar course as AFAP, but is autosomal recessive and requires an individual to have pathogenic mutations in both copies of the MUTYH gene (Al-Tassan et al. 2002, Simpson et al. 2003).

Genetics and Genetic Testing

Major discoveries in genetics of hereditary colon cancer syndromes occurred in the early 1990s. The first such discovery occurred through research on FAP and the mapping of the
causative locus to 5q21 (Kinzler et al. 1991). Shortly after, a causative locus for Lynch syndrome was mapped to 2p16-p15 (Peltomaki et al. 1993). These studies were the first lines of molecular evidence that susceptibility to CRC could be inherited.

Genetic testing for Lynch syndrome has been available since 1993 when Fischel et al. cloned the human MutS homolog-2 (MSH2) gene, a DNA mismatch repair gene and identified pathogenic variants in MSH2 in two Lynch syndrome families (Fischel et al. 1993). Mutations in the bacterial MutS and S. cerevisiae MSH genes cause similar genomic and microsatellite instability (MSI) as that seen as a hallmark in Lynch syndrome tumors (Thibodeau et al. 1993). In years following the discoveries by Fischel et al., 4 more Lynch syndrome associated genes, MLH1, PMS2, MSH6, and EPCAM were discovered and are now routinely tested for causation of Lynch syndrome in individuals with tumors that display MSI or with indicative family history (Leach et al. 1993, Liu et al. 1996, Niessen et al. 2009).

Genetic testing for FAP, and thus AFAP, has been available since 1996 when a clinical test for mutations in the adenomatous polyposis coli (APC) gene became available (Petersen, 1996). The link between the MUTYH gene and cancer susceptibility was made in 2002 when Al-Tassan et al. identified biallelic MUTYH mutations in siblings with polyposis and no mutations in the APC gene (Al-Tassan et al. 2002).

Genetic testing for Lynch syndrome, attenuated FAP, and MAP is offered after age 18, since there is no clinical benefit or alteration in medical management to testing before that age (Benson et al. 2000, Winawer et al. 2003, Syngal et al. 2015). Given that medical management does not begin until age 20 to 25 for these syndromes, it may be reasoned that most people with Lynch syndrome, attenuated FAP, and MAP are asymptomatic at the time of testing if they are tested before age 25. The effects of testing for these adult-onset cancer susceptibility syndromes on psychosocial functioning between the ages of 18 and 25 have not been extensively studied.
Emerging Adulthood

The term emerging adulthood was coined by Arnett and is defined as the developmental period between the ages of 18-25 inclusive (Arnett, 2000). Arnett argues that this is a distinct, subjective and demographic developmental period that can be differentiated from adolescence and early adulthood. A major theme of emerging adulthood is identity exploration through examination of possibilities of themes such as love, work and worldview. As such, this is a time period defined by change where young people tend to define themselves and undergo major life events, such as choosing a career, getting married, and family planning. A genetic diagnosis of a hereditary colorectal cancer syndrome presents the emerging adult with a new set of challenges during this time of substantial change.

In order to explore the effects of a cancer diagnosis on the psychosocial functioning in the emerging adult, Millar et al. surveyed 63 patients who were diagnosed with cancer during emerging adulthood. Millar et al. assessed how adequately the patient’s needs were met during treatment, as well as psychological functioning through the Depression, Anxiety and Stress Scales (DASS-21). They found that in a group of patients more than one year since their last treatment, the most commonly unmet needs pertained to emotional and psychological issues related to survivorship and life direction. Additionally, a positive correlation was found between the number of unmet needs and increased levels of anxiety and stress (Millar et al. 2010). These results show that at least a portion of cancer survivors who were diagnosed during emerging adulthood have unmet needs related to the psychosocial functioning of the emerging adulthood demographic, and as a result have increased levels of stress and anxiety.
Psychosocial Implications of Hereditary Colon Cancer

The psychosocial effects of a hereditary colorectal cancer syndrome diagnosis in general have been studied by multiple groups since the implementation of clinical and genetic testing. Bleiker et al. introduced the concept of psycho-onco-genetics, or the meeting of the fields of psychology, oncology, and genetics in the context of Lynch syndrome. They revealed that up to 30% of individuals who seek genetic testing for Lynch syndrome show clinical levels of distress, defined by anxiety and depression (Bleiker et al. 2013). Additionally, Bleiker et al. review that perception of risk across many studies was shown to depend heavily on family history and not on the specific risk that was discussed in a genetic counseling session (add references*). Further, the concept of self within society is changed for mutation positive individuals in that many people report feeling different from others and a stigma related to their diagnosis (add reference*). It does appear that specific risk groups would benefit from psychological evaluation at or around the time of genetic counseling. Such groups include, those with cancer history in parents during childhood, people who are the first in their family to be diagnosed with Lynch syndrome, those with a previous history of depression, and those with a lack of social support (Bleiker et al. 2013).

The study of psycho-onco-genetics in Lynch syndrome, includes a representation of those patients who have had multiple cancers or a strong family history of associated cancers. To delve further into the psychosocial implications of a Lynch syndrome diagnosis, Petersen et al. conducted a qualitative study which surveyed 12 participants with Lynch syndrome who had not yet developed a cancer on how they function knowing they are at risk of cancer. This more specific patient population allowed for a separation of implications of the genetic diagnosis and implications from an associated cancer diagnosis and treatment. Family context, interpretation
and transformation, approach to risk, and balancing life at risk were the main themes that emerged in managing life at risk in this population. There was significant variability in this management depending on the interplay of these themes. Some people felt that this was just another bump in the road, while others were more negatively affected and were in the process of trying to pick themselves up from what they felt was a devastating diagnosis. The authors, however, point to the need to expand this work in subgroups of unaffected carriers to help better identify the needs of all affected individuals, which is surely a very heterogeneous group (Petersen et al. 2014).

Research has also focused on the psychosocial distress associated with genetic testing for hereditary colorectal cancer syndromes. Vernon et al. first assessed this correlation utilizing the Center for Epidemiologic Studies Depression (CES-D) Scale to assess the prevalence of symptoms of depression and the State-Trait Anxiety Inventory (STAI) to assess anxiety levels in 200 individuals who were undergoing genetic testing for Lynch syndrome. 24% of subjects showed signs of depression related to the genetic testing process and anxiety levels were highest in younger patients and those who had limited access to social supports (Vernon et al. 1997).

In a follow-up study, Gritz et al. surveyed patients undergoing genetic testing for Lynch syndrome prior to genetic testing and 2 weeks, 6 months, and 12 months following disclosure of test results. This study also utilized the CES-D Scale and STAI and found that the highest levels of anxiety and distress were in patients who tested positive for Lynch syndrome, but had yet to develop cancer. These patients were also most likely to show long term anxiety and distress. Additionally, those patients with a higher baseline mood disturbance were more likely to report long term distress from a positive genetic test (Gritz et al. 2005).
Finally, research conducted on attitudes toward and uptake of genetic testing for hereditary colorectal cancer syndromes shows that personal experiences and family history greatly influence uptake. Codori et al. found that there is a higher likelihood of an individual to undergo genetic testing for Lynch syndrome if they have a higher personal risk perception and have more frequent cancer thoughts (Codori et al. 1999). This suggests that young individuals who seek genetic testing for a hereditary colorectal cancer syndrome may have a higher baseline risk perception for developing cancer than those who do not test.

This body of literature shows that individuals with a colorectal cancer syndrome show clinical levels of psychological distress (Bleiker et al. 2013). Younger patients and those who have not yet developed cancer are most susceptible to long-term psychological distress and anxiety (Vernon et al. 1997, Gritz et al. 2005). There, however, has not yet been a study conducted on the psychosocial implications of a genetic diagnosis of a hereditary colorectal cancer syndrome diagnosis during emerging adulthood, specific to the needs and functioning of this age group. Our aim is to fill this gap in the literature and assess psychosocial functioning in areas of family planning, career planning, exploration, and forming relationships.
Methods

Study Design

This is a cross-sectional phenomenological survey study that was achieved through an anonymous online survey created using Qualtrics software. The data generated from the survey is both quantitative and qualitative in nature. Because there is no existing information on the psychosocial functioning and outcomes for individuals who had genetic testing for a hereditary colorectal cancer syndrome during emerging adulthood, gathering quantitative and qualitative data provided us with the most information on the psychosocial needs and functioning of the demographic. Data was collected online to allow for easy access to the survey and to maximize the number of respondents. Demographic information was collected from each participant to help us determine if the study will be generalizable to the Lynch syndrome, AFAP, and MAP populations as a whole. This study was reviewed and approved by the Brandeis University Institutional Review Board.

Sample and Recruitment

Upon approval by the Brandeis IRB, participants were recruited through the Hereditary Colon Cancer Foundation [hcctakesguts.org]. Participants were recruited to an information page for the study on hcctakesgut.org, both through email and social media platforms. A link to the study was also included in the March Hereditary Colon Cancer Foundation newsletter. An advertisement and link to the information page was posted to the Hereditary Colon Cancer
Foundation Facebook and Twitter feeds, as well as, closed Facebook support groups. Subjects were also encouraged to ask their family members who have had genetic testing to also take the survey, emphasizing the value of responses from family members with negative genetic testing results.

**Data Collection Procedure**

An anonymous online survey created through Qualtrics was used for data collection. This survey opened on March 9, 2016 and closed on March 21, 2016. The survey asked questions regarding demographic information, genetic testing outcomes for Lynch syndrome, AFAP, and MAP (positive, negative, or variant of uncertain significance), information regarding the subjects’ personal and family history of cancer and polyps, anxiety levels before and after genetic testing, family planning decisions, career planning and exploration, relationship forming, and open ended questions on advice for future patients and medical professionals. Other open ended questions asked subjects to share factors that contributed to their perceived changes in anxiety, reflect on how genetic testing influenced their family planning, reflect on how genetic testing influenced their career planning and ability to explore, and reflect on how genetic testing influenced their ability to form and maintain relationships with romantic partners and friends. As a token of our appreciation, subjects were asked if they would like to enter a drawing for one of three $50 Amazon.com gift certificates at the end of the survey, which was conducted through a separate, unlinked Qualtrics survey.

**Data Analysis**

Quantitative data was analyzed using SPSS, a statistical application supported by Brandeis University. This data was first evaluated using frequencies and descriptive statistics.
Bivariate and multivariate statistical analyses were performed to determine relationships between the independent and dependent variables.

Responses to the open-ended questions were manually analyzed by the author using an inductive approach to identify themes using Atlas.ti software. The data from the open-ended survey questions was analyzed to determine themes that describe levels of psychosocial functioning after genetic testing.
Results

Survey respondents

241 surveys were completed and grouped by syndrome (159 LS, 67 AFAP, and 15 MAP) and 45 partial surveys were submitted (23 LS, 18 AFAP, and 4 MAP). Of the 241 completed surveys, 32 had had genetic testing during emerging adulthood (18 for LS, 13 for AFAP, and 1 for MAP). Of the 159 respondents with LS surveyed, 91% were female and 60% had at least completed an undergraduate university degree. For those with AFAP, 83% were female and 50% had completed at least an undergraduate degree. Finally, of the respondents with MAP, 82% were female and 82% had completed at least an undergraduate university degree (Table 1).

Table 1.

<table>
<thead>
<tr>
<th></th>
<th>LS</th>
<th>AFAP</th>
<th>MAP</th>
<th>total</th>
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<tr>
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<td>182</td>
<td>85</td>
<td>19</td>
<td>286</td>
</tr>
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<td>159</td>
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<td>18</td>
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</table>

Demographics

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<th>AFAP</th>
<th>MAP</th>
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</tr>
</thead>
<tbody>
<tr>
<td>female</td>
<td>91%</td>
<td>83%</td>
<td>82%</td>
<td>88%</td>
</tr>
<tr>
<td>male</td>
<td>9%</td>
<td>17%</td>
<td>18%</td>
<td>12%</td>
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<tr>
<td>undergraduate deg</td>
<td>60%</td>
<td>50%</td>
<td>82%</td>
<td>59%</td>
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</table>

Age at testing

<table>
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<th>AFAP</th>
<th>MAP</th>
<th>total</th>
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</thead>
<tbody>
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<td>6</td>
<td>0</td>
<td>6</td>
</tr>
<tr>
<td>18-25</td>
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<td>13</td>
<td>1</td>
<td>32</td>
</tr>
<tr>
<td>26-40</td>
<td>64</td>
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<td>104</td>
</tr>
<tr>
<td>60+</td>
<td>11</td>
<td>2</td>
<td>0</td>
<td>13</td>
</tr>
</tbody>
</table>
Anxiety

Anxiety related to cancer risk was reported on a Likert scale from 1 to 5 (1 meaning no anxiety at all, and 5 meaning extreme anxiety). Participants were asked to reflect on anxiety levels related to personal cancer risk before genetic testing, immediately after receiving genetic testing results, and today. Overall, anxiety increased after receiving genetic testing results and is reportedly decreased today for all three groups (Fig 1). Factors commonly reported as increasing risk after test result from open-end question analysis are high cancer risk (n=79), risk to family/children (n=37), and uncertainty about future (n=20). Conversely, factors that are most commonly reported as reducing anxiety to levels reported today are preventative screenings/surgeries (n=72), knowledge (n=14), acceptance (n=7), time (n=4), and support groups (n=7). In order to further break-down factors that modify reported anxiety levels, we analyzed anxiety levels reported by age group at diagnosis, personal history of cancer, family history of cancer, having had children, and education level. Statistical analysis was conducted for the LS and AFAP groups separately and since the MAP group had too few respondents, it was excluded from statistical analysis.
Age at time of genetic testing was the most significant factor in modifying self-reported anxiety. Reported anxiety was analyzed through a two-tailed t-test, with a significance cutoff at p=0.05. In the LS group, those who were tested between ages 18-25 (n=16) reported significantly less anxiety related to cancer risk relative to those who were diagnosed at age 26 or older (n=146), both directly after testing (18-25 average 3.38, 26+ average 3.92; p value=0.049) and today (18-25 average 2.44, 26+ average 3.20; p value=0.032) (Fig. 2A). This difference was also significant when comparing anxiety of those diagnosed between 18-25 (n=16) and those diagnosed between 26-40 (n=64) after (18-25 average 3.38, 26-40 average 4.13; p value=0.0076) and today (18-25 average 2.44, 26-40 average 3.41; p value=0.0096) (Fig. 2B), but only anxiety today for those diagnosed between 41-60 (n=76) (18-25 average 2.44, 41-60 average 3.11; p value=0.0087) (Fig 2C).
For the AFAP cohort, however, differences in anxiety levels were not statistically significant except when comparing reported anxiety level today for those diagnosed between 18-25 (n=12) and those diagnosed between 41-60 (n=12). Those diagnosed between 18-25 reported increased anxiety today compared with those diagnosed between 41-60 (18-25 average 3.33, 41-60 average 2.25; p value=0.016) (Fig 2D).

Figure 2.

For both the LS and AFAP cohorts, personal cancer history (LS before p=0.32, AFAP before p=0.53; LS after p=0.43, AFAP after p=0.31; LS today p=0.20, AFAP today p=0.79), family history of cancer (LS before p=0.57, AFAP before p=0.40; LS after p=0.93,AFAP after p=0.29; LS today p=0.24,AFAP today p=0.87), having had children (LS before p=0.30, AFAP before p=0.75; LS after p=0.64, AFAP after p=0.35; LS today p=0.23, AFAP today p=0.64), an being the first person in the family to have genetic testing (LS before p=0.20, AFAP before p=0.19; LS after p=0.37, AFAP after p=0.87; LS today p=0.21, AFAP today p=0.94) were not
associated with any significant difference in reported anxiety related to cancer risk before genetic testing, immediately after receiving genetic testing results, or today.

**Family Planning**

The effect of LS or AFAP diagnosis on family planning was measured by whether a respondent had had children, whether diagnosis influenced the decision to have or not have children, whether diagnosis influenced when a respondent had children, and whether respondents considered *in vitro* fertilization (IVF) with preimplantation genetic diagnosis (PGD). Further, respondents were asked to reflect through open-ended questions on how their genetic testing experience influenced their family planning decisions. Most commonly, those who reported that LS or AFAP testing did not influence their family planning decisions, had already had children prior to their diagnosis (n=99). Notably, 11 respondents report that they would not have had children had they known their status for LS or AFAP prior to having children.

Younger age at genetic testing was associated with a greater likelihood in reporting that testing experience influenced family planning decisions in the LS group. There was no significant difference when comparing both influence on decision to have children and influence on the decision of when to have children when comparing those tested between ages 18-25 and those tested between 26-40. When compared with those tested between ages 41-60, those tested between 18-25 were significantly more likely have report that testing influenced their decision to have or not have children (18-25 (n=16): 25% yes; 41-60 (n=69): 1.5% yes, p value=0.0040), when to have children (18-25 (n=14): 36% yes, 41-60 (n=66) 1.5% yes, p value=0.00045), and whether they considered PGD (18-25 (n=14): 21% yes, 41-60 (n=63): 0% yes, p value=0.0050). Respondents who had testing between ages 18-25 were also less likely to have children compared to those who had testing at age 26 or older (p value=0.0069) (Fig. 3)
For the AFAP group, significant differences in family planning were limited to consideration of PGD when comparing those who were tested between 18-25 and those after age 26. The 18-25 group was significantly more likely to consider PGD (18-25 (n=10), 50% yes; 26+ (n=31), 16% yes; p value=0.045).

Figure 3.

**Career Planning**

Participants were asked to rate their agreement that their experience with genetic testing limits their ability to move on a Likert scale from 1-5 (1 meaning strongly disagree and 5 meaning strongly agree) and asked if their diagnosis influenced their career choice. The cohorts who had genetic testing in emerging adulthood for both LS and AFAP did not report significantly different perception of their diagnosis limiting their ability to move or influence on their career choices, except when compared with the 41-60 year old LS group. Those diagnosed between 41-60 were more likely to report that diagnosis limits their ability to move (18-25
Factors most commonly reported as limiting one’s career choices and ability to explore are needing a job with good insurance (n=16) and the need to live close to doctors (n=16). For example respondent LS54 wrote:

“I must have a job with good insurance, good time off/disability, and need to be close to family in case I need help when or if I get sick. In addition, finding good doctors for my treatment team is a challenge at times. I have been lucky, but hear of others having difficulties.”

**Relationships**

Respondents were asked open-ended questions about how their genetic testing experience influenced their ability to form and maintain romantic relationships and relationships with friends. The most common theme related to romantic relationships was that their diagnosis put a strain on romantic relationships (n=47). Some examples of this theme include:

“I was in a relationship when I received my diagnosis. The relationship became strained and fell apart a few months later. We had been together for two years and he had been with me through my mother’s cancer and I partially attribute things not working out to my diagnosis” –Respondent LS122

“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 LS131

“[A LS diagnosis] makes a casual date get super serious fast. I was dating a wonderful man who couldn't handle the prep for the surgery and had to leave. I understand. It was sad but I understood.” -Respondent LS143

“Yes [AFAP diagnosis has influenced my romantic relationships]. I feel bad that I may not live as long as a normal woman would. I feel like he deserves somebody who will live a long time and a woman who can bare his child. He wants children so bad and I can't give that to him. I feel like I need to be alone so when I die early nobody will feel too badly about it.”-Respondent AFAP34
With regards to forming and maintaining relationships with friends, 12 respondents reported that friendships were strengthened. Respondent AFAP17 wrote:

“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.”

An additional 12 respondents, however, wrote that they lost friends. The most common theme associated with influence on relationships with friends was the feeling that others did not understand the risk associated with LS or AFAP (n=28). For example:

“It is extremely isolating, so while it hasn't change my relationships with friends, I do find it difficult to share this piece of my life with most people.” –Respondent LS8

“Friends only want to hear we WIN! they really don't to hear anything but that so you tell everything is great which makes them feel ok but does nothing but reminds you of the shit hole you really live in...” –Respondent LS30

Advice

Respondents were also asked open-ended questions about their advice for individuals considering genetic testing for LS or AFAP during emerging adulthood, as well as, how medical professionals could have better served their needs. Common themes for advice to individuals considering testing were to get testing (n=61) and to know what testing would mean for them prior (n=15). For example:

“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 LS8

“Get tested before making any major decisions, it might change your outlook” – Respondent LS19
Another common advice relate theme was to live your life (n=41). Notably, none of the 241 total respondents advised against genetic testing.

42 of the total respondents reported that their needs were served by the medical community. Of those who expressed advice for medical professionals, common themes for that arose were to learn more about LS or AFAP (n=53), provide more information (n=14), and provide more follow up after giving results (n=12). For example:

“I really wish someone, my genetic counselor or family doctor, would have followed up with me after my diagnosis. I floundered for quite a few months post diagnosis. I felt very overwhelmed.” –Respondent LS10

“Post testing support would be helpful, e.g. Don't just give test results and say good bye, but help set up a testing/surveillance protocol so that getting established with doctors and other medical professionals isn't so overwhelming. This type of ground work is very time consuming, and when a doctor doesn't know or care to know about Lynch Syndrome, the process of finding another professional starts all over again…” –Respondent LS
Discussion

We surveyed 286 participants who had genetic testing for LS, AFAP, or MAP to gain an understanding of the psychosocial implications of testing during emerging adulthood as compared to other age groups. Psychosocial functioning was assessed through quantitative and open-end, qualitative questions that were focused into themes of 1) anxiety related to cancer risk, 2) family planning, 3) exploration, 4) career planning, and 5) forming and maintaining relationships.

Anxiety

A growing body of literature has been defining the psychosocial implications of a hereditary colorectal cancer syndrome diagnosis in general, with a majority of the research done within the LS community. The term psycho-onco-genetics was coined by Bleiker et al. and they have reported that 6-30% of individuals with LS exhibit clinical levels of distress, defined by anxiety and depression (Bleiker et al. 2013). These findings however, were not confirmed in two separate longitudinal studies employing the State-Trait Anxiety Inventory, where individuals that tested positive for LS showed no difference in psychosocial functioning or anxiety than those who tested negative for LS (Aktan Collan et al. 2013, Esplen et al. 2015). A follow-up review further classifies the psychosocial implications of a LS diagnosis as an increase of anxiety and depression after receiving genetic testing results, but normalizing 6-12 months after diagnosis (Galiatsatos et al. 2015).
Our findings in the LS cohort that those who had genetic testing during emerging adulthood reported lower levels of anxiety relative to those who had testing later in life are contrary to our hypothesis that genetic testing for a hereditary colorectal cancer syndrome during emerging adulthood would decrease levels psychosocial functioning relative to those tested later in life, especially since surveillance and preventative measures are not typically offered until after age 25 (Syngal et al. 2015). The resiliency of the emerging adulthood demographic with respect to cancer and cancer risk, however, has been documented in the past. Gearhardt et al. surveyed individuals during emerging adulthood who had survived childhood cancer and found that there was no detectable differences in social outcomes between childhood cancer survivors and control peers (Gearhardt et al. 2003). In a follow-up study the same group assessed educational and occupational outcomes in the same cohort and found that childhood cancer survivors had similar long term goals and educational attainment of the control population (Gearhardt et al. 2007). This level of resiliency likely factors into our finding of lower reported anxiety in the emerging adulthood LS cohort.

Further, the group that reported the most anxiety related to cancer risk after receiving test results and today is the LS group who had testing between ages 26-40. The only difference detected through our survey between this group and the group tested during emerging adulthood is that the 26-40 group was significantly more likely to have had children (p value=0.036). This suggests that having had children is a significant factor that may increase levels of anxiety and distress for an individual who has undergone testing for LS. Further evidence within this cohort that having had children increases anxiety and distress for those tested for LS is that of the 76 respondents that shared they had already had children before testing, 7 reported that they would not have had biological children had they know their genetic status before family planning.
Several respondents described the phenomenon of increased distress related to having children prior to genetic testing:

“[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 LS20

“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 LS5

“Had I known I had Lynch syndrome before having children, I WOULD NOT HAVE HAD ANY.” – LS19

“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 colorectal cancer 2 months shy of my 1 [year] anniversary [of my] 1st cancer. I blame myself for his cancer.” – Respondent LS149

Similar themes arose in the AFAP cohort with regards to anxiety, but there was no significant difference in anxiety levels between groups, except that those who had genetic testing in emerging adulthood report more anxiety today versus those who have had testing at age 41 and older. This phenomenon may be due to the fact that colectomy is typically recommended in approximately 2/3 of individuals with AFAP that are 40 and older (Burt et al. 2013). Individuals over 40 with AFAP may have already undergone colectomy, reducing their cancer risk, and thus reducing cancer related anxiety.

Surprisingly, differences in anxiety levels over time were not associated with personal history of cancer, family history of cancer, having had children, or being the first in the family to have genetic testing in either the LS or AFAP cohorts. Open-ended response analysis of factors that respondents report as influencing their change in anxiety levels suggested that having had children may be associated with increased levels of anxiety. The theme of risk to family was identified in 35 respondents, but through analysis of reported anxiety levels, there was no
significant difference between those who had children and those who had not before testing (LS p=0.30; AFAP p=0.75), immediately after receiving test results (LS p=0.64; AFAP p=0.35), or today (LS p=0.23; AFAP p=0.64).

**Career Planning**

There were no significant differences in perceived limitations to career planning across age groups in both the LS and AFAP cohorts, except that those diagnosed between 41-60 were more likely to report that their diagnosis limits their ability to move than those tested in emerging adulthood (p value=0.010). For individuals who reported feeling limited in the ability to move, the most common theme was the need to be close to their medical team (n=16). Overall, the most common factor influencing career options was the need for a high quality health insurance plan (n=16). Given that individuals in the United States may now remain on their parent’s health insurance plans until age 26, this may factor into the reduced level of feeling restricted in career options and exploration in the emerging adulthood cohort.

**Relationships**

Ability to form and maintain relationships with friends and romantic partners in both the LS and AFAP groups across all age groups was reportedly not affected by most respondents. We were unable to quantify the amount of respondents who felt the diagnosis did not affect relationships due to the fact that some respondents replied with “not applicable”, and others skipped the question. However, the theme of strain on romantic relationships was reported by 47 respondents in open-ended responses, but was commonly related to post-surgical/treatment consequences, and not due to genetic testing results alone. For example:

“I believe that having a colostomy at 38 ([due] to Lynch) hinder[ed] my ability to maintain any relationship .... maybe that's my fault but I don't believe it did anything to help.....lots of female friends but nothing ever went anywhere no matter what I tried” – LS30
“I had to move forward with the removal of the female organs. I couldn't keep this ticking time bomb inside me any longer. It has made it tough to share that I cannot have more children and am not sure what lies ahead health wise.” –Respondent LS143

The implications of genetic testing and implications of preventative surgery and cancer treatment are difficult to separate. Since prophylactic surgeries are not recommended in emerging adulthood, however, this evidence is suggestive that testing at a younger age results in less strain on romantic relationships.

**Advice**

Participants were asked to share advice for individuals who may be considering genetic testing for LS, AFAP, or MAP during emerging adulthood. Themes of open-ended responses were to get testing, to live your life regardless of test result, and to know what testing would mean for you before having it done. This advice is exemplified by the open response by respondent number 41, a woman who tested positive for LS after age 60:

“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

Respondent number 8, a woman who tested positive between ages 26-40, reflected on the theme of knowing what the result would mean before testing:

“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

Importantly, of the 241 completed surveys, no respondent gave advice to not have testing. This, coupled with our findings of decreased reported levels of anxiety in the emerging
adulthood LS cohort, is suggestive that testing at age 18 versus at a later age is less harmful to an individual’s psychosocial functioning. Given the resiliency of the emerging adulthood demographic in psychosocial functioning relative to cancer diagnosis and cancer risk, our results are consistent with evidence that favors earlier genetic testing for LS and AFAP, even if it is done years before an increase in cancer risk.

Overall, evidence is suggestive for higher levels of psychosocial functioning in the LS group who had genetic testing during emerging adulthood relative to those who had testing later in life. Reported anxiety levels were significantly lower both immediately after receiving genetic testing results and today, relative to those who had genetic testing at age 26 or older. As expected, respondents in the group who had testing during emerging adulthood were less likely to have had children than those who had genetic testing later in life. Those tested during emerging adulthood were also more likely to report that their genetic testing result influenced their decision to have or not have children, when to have children, and to have considered IVF with PGD. This suggests that the sense of having more options for family planning results in lower levels of anxiety and greater psychosocial functioning. This is consistent with the common theme of cancer risk to family members as a factor that modified increased anxiety levels (n=35), since those who have children have an additional generation of family members at risk. This phenomenon of increased anxiety due to risk to children has been previously reported in the communication of cancer risk to relatives (Van Oostrom et al. 2006) and unmet needs in communicating risk to family members (Sharff et al. 2011).

**Future Directions**

Given the exploratory nature of this research, much of the measures of psychosocial functioning were based on coding of open-ended, qualitative questions to assign common themes
and allow for respondents to more openly share their experiences. Given our findings on anxiety levels, other measures of psychosocial functioning such as the validated Depression, Anxiety and Stress Scales (DASS-21) (Henry and Crawford 2005) could be utilized with these groups in future research to assess general measures of anxiety and depression across age group
Conclusions

Genetic testing for LS or AFAP during emerging adulthood is not more detrimental to psychosocial functioning than testing later in life. Those who had genetic testing for LS during emerging adulthood reported less anxiety than those who had testing later in life. In the AFAP group there was no significant difference in anxiety between groups except for one subgroup which may be an artifact of reduced post-surgery cancer risks. Additionally, those who have genetic testing in emerging adulthood are more likely to have more family planning time and options and are more likely to consider alternative reproductive options, such as IVF with PGD. These results suggest that genetic testing in emerging adulthood may be recommended over waiting until the initiation of cancer screening after age 25.
February 11, 2016

Shawn Fayer
Genetic Counseling Student
Brandeis University

Gayun Chan-Smutko
Thesis Faculty Advisor
Brandeis University

The Hereditary Colon Cancer Foundation hereby agrees to assist Shawn Fayer in recruiting suitable individuals within Lynch syndrome, AFAP, and MAP families for his Master’s thesis project. We understand that the goal is to recruit as many family members as possible, both with positive and negative genetic testing for participation in an online survey. The goal of the survey will be to assess the psychosocial implications of genetic testing for hereditary colorectal cancer syndromes in emerging adulthood.

Once the project has IRB approval we will assist Shawn in recruiting by sending email notices to members of the Hereditary Colon Cancer Foundation and associated support groups. Additionally we will post an information on the Hereditary Colon Cancer Foundation website, www.hcctakesguts.org.

Sincerely,

Travis Bray
Executive Director
Appendix B: Recruitment e-mail to Hereditary Colon Cancer Foundation Members

SUBJECT: Have you had genetic testing for Lynch syndrome, Attenuated FAP (AFAP), or MUTYH-Associated Polyposis (MAP)?
My name is Shawn Fayer, and I am a graduate student in the Brandeis University Genetic Counseling Program. I am writing to request your participation in an anonymous survey as part of my thesis research titled, “The Psychosocial Implications of a Hereditary Colorectal Cancer Syndrome Diagnosis in Emerging Adulthood”.

The purpose of this study is to gather information on the effects of genetic testing for Lynch syndrome, Attenuated Familial Adenomatous Polyposis (AFAP), and MUTYH-Associated Polyposis (MAP) between the ages of 18 and 25. Anyone over the age of 18 who has had genetic testing for any of these syndromes is encouraged to take the survey, even if your testing was negative. We also ask that you encourage your family members who have had genetic testing to take the survey. The results of this survey will help educate medical professionals who care for individuals with these conditions. The results will also help others who are considering genetic testing for Lynch syndrome, AFAP and MAP.

This survey will ask questions about how testing has influenced your decisions. These decisions include job choices, planning a family and forming relationships. It will also ask your opinions on how doctors and genetic counselors could better serve patients who are considering genetic testing for these syndromes. We will also ask you to give advice to people who are considering genetic testing.

Here are some important things to know about this study:

- The survey is open to anybody above the age of 18 who has had genetic testing for Lynch syndrome, Attenuated FAP, or MUTYH-Associated Polyposis.
- The survey will take approximately 15 minutes to complete.
- The survey is anonymous and participation is voluntary.
- You can skip question(s) you are not comfortable answering and may exit the survey any time.
- All participants who complete the survey may enter a drawing for one of three $50 gift cards to Amazon.com. Your survey responses will not be connected to your contact information.
- The survey will be available until mid-March 2016.

This study was reviewed and approved by the Brandeis University Institutional Review Board. If you have any questions about this research project, please contact Shawn Fayer at sfayer@brandeis.edu, or the Brandeis University faculty sponsor, Gayun Chan-Smutko, at gchansmutko@brandeis.edu.

“Click Here to Take the Survey” (will hyperlink to “STUDY PAGE” on hcctakesguts.org)
Thank you in advance for your time and participation.

Sincerely,

Shawn Fayer, M.Sc.
MS candidate, Brandeis University
Genetic Counseling Program
Appendix C: Study Page Language

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

Why is this study being conducted?

The research team is collecting information on the effects of genetic testing for Lynch syndrome, Attenuated Familial Adenomatous Polyposis (AFAP), and MUTYH-Associated Polyposis (MAP). The results of this survey will help educate medical professionals who care for individuals with these conditions. The results will also help others who are considering genetic testing for Lynch syndrome, AFAP and MAP.

Who can participate?

You are being asked to participate in this study because you are a member of HCCF. Other criteria for participating are:

- You must be over 18 years-old.
- You had genetic testing for Lynch, AFAP or MAP.

Do I have to test positive in order to participate?

No, you can participate if your test was negative or you had an uncertain result (variant of uncertain significance).

You can encourage your family members or friends who had genetic testing to participate! Your answers are kept confidential and cannot be linked to your family member’s or friend’s answers. Just share this link (add link) with your family members or friends.

Who is running this study?

This study is being sent out by the Hereditary Colon Cancer Foundation to HCCF members. This study is being conducted by Shawn Fayer a graduate student in the Brandeis University Genetic Counseling Program as part of his thesis research project. This study was reviewed and approved by the Brandeis University Institutional Review Board. If you have questions about your rights as a research subject please contact the Brandeis Institutional Review Board at irb@brandeis.edu or 781-736-8133.

Are there any risks if I participate?

Your responses to this online survey will be anonymous. Although we anticipate that the risks will be minimal, some people may experience distress when answering questions about how their genetic test has affected them. Participation in this survey is voluntary. You may skip any question you are not comfortable answering, and you may exit the survey at any time.

Are there any benefits if I participate?

Some people may benefit from knowing that they are helping improve the care of future patients who are considering genetic testing for Lynch syndrome, AFAP, or MAP.

Who do I contact with questions about this study?
If you have questions about this study please contact Shawn Fayer, at sfayer@brandeis.edu, or the Brandeis University faculty sponsor, Gayun Chan-Smutko at gchansmutko@brandeis.edu.

**How do I participate?**

By clicking “Next”, you acknowledge that you have read the information above and you consent to participate in this survey. Please only complete this survey once.

- Next (link to beginning of survey on Qualtrics)

- I do not want to participate.
Appendix D: Survey Instrument

Demographics:

1. Are you 18 years of age or older?
   a. Yes
   b. No (end survey)

2. How old are you?
   a. 18-25
   b. 26-40
   c. 41-60
   d. Above 60

3. What is your gender?
   a. Male
   b. Female
   c. Prefer not to answer

4. In which country do you live?_____________

5. What is your highest level of education?
   a. Some High School
   b. Completed High school or GED
   c. Some College/University
   d. Completed College/University
   e. Some Graduate studies
   f. Completed Graduate studies

6. Have you had genetic testing for a hereditary colon cancer syndrome?
   a. Yes
   b. No (end survey)

7. How old were you when you had genetic testing for a hereditary colon cancer syndrome?
   a. Before 18
   b. 18-25
   c. 26-40
   d. 41-60
   e. Above 60

8. Have you ever had genetic testing for [AFAP, MAP, or Lynch Syndrome]?
   a. Yes
   b. No
9. **(If “Yes” to question 8.)** What was the result of that test?
   a. Positive (you have AFAP)
   b. Negative (you do not have AFAP)
   c. Uncertain result (variant of uncertain significance, VUS)

**Personal and Family History:**

10. Who was the first person in your family to have genetic testing for (syndrome from question 8)?
   a. I am the first person in my family.
   b. My mother/father was the first person.
   c. My brother/sister was the first person.
   d. Another relative was the first person. Please specify______

11. Have you been diagnosed with colon polyps?
   a. Yes
   b. No

12. **(If “Yes” to question 15) What was your age at first polyp diagnosis?_____**

13. **(If “Yes” to question 15) How many polyps have you had?_____**

14. Have you personally been diagnosed with cancer?
   a. Yes
   b. No (proceed to next section)

15. **(If “Yes” to question 18) How old were you at your first cancer diagnosis? ______**

16. **(If “Yes” to question 18) What type of cancer were you diagnosed with?____**

17. Were you diagnosed with a second cancer?
   a. Yes
   b. No

18. **(If “Yes” to question 21) how old were you at your second cancer diagnosis? ______**

19. **(If “Yes” to question 21) what type of cancer were you diagnosed with?____**

20. Were you diagnosed with a third cancer?
   a. Yes
   b. No

21. How many brothers and sisters do you have? ____

22. How many of your brothers and sisters have had cancer?_____
23. How many of your brothers and sisters have had polyps?

24. Has your mother ever had cancer?
   a. Yes
   b. No

25. To your knowledge has your mother ever had polyps?
   a. Yes
   b. No

26. Has your father ever had cancer?
   a. Yes
   b. No

27. To your knowledge has your father ever had polyps?
   a. Yes
   b. No

28. Have any of the above mentioned family members passed away from cancer?
   a. Yes
   b. No

29. In the space provided please list any other relatives that have had cancer (examples: grandmother, grandfather, aunts, or uncles)

30. In the space provided please list any other relatives that have had polyps (examples: grandmother, grandfather, aunts, or uncles)

31. Have any of these additional relatives passed away from cancer?
   a. Yes
   b. No

Anxiety:

32. Please rate your anxiety level before and after genetic testing for a hereditary colorectal cancer syndrome in the table below:

<table>
<thead>
<tr>
<th>Anxiety related to cancer risk</th>
<th>None</th>
<th>A little bit</th>
<th>Moderate</th>
<th>Quite a bit</th>
<th>Extreme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Before testing</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Immediately After testing</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Today</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
33. In the space below, please describe what factor(s), if any, can you attribute to your change in anxiety levels?

**Family Planning:**

34. Do you have biological children?
   a. Yes
   b. No

35. Did your diagnosis of ("positive" for question 9) influence your decision to have or not have children?
   a. Yes
   b. No

36. Do you feel that the diagnosis of a hereditary colorectal cancer syndrome has affected/will affect your decision on when to have children?
   a. Yes
   b. No

37. Have you considered using a fertility clinic to ensure that you do not pass ("positive" for question 9) on to your children? In other words, using assisted reproduction techniques such as in vitro fertilization (IVF) with preimplantation genetic diagnosis (PGD)?
   a. Yes
   b. No

38. If you would like to tell us more about how your diagnosis has affected your decisions to have or not have children, please use this space below:

**Career Planning/ Exploration:**

39. Please rate your agreement: My diagnosis limits my ability to move away for school or a job.

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Somewhat disagree</th>
<th>Somewhat agree</th>
<th>Strongly agree</th>
</tr>
</thead>
</table>

40. Do you feel that your diagnosis has an influence on your career choice?
   a. Yes
   b. No

41. If you would like, please tell us more about how your diagnosis has influenced your job or career decisions in the space below:
**Relationships:**

42. What is your relationship status?
   a. Single
   b. Married
   c. Common law
   d. Domestic partner
   e. Separated
   f. Divorced
   g. Widow/Widower

43. If you would like, please briefly explain how your diagnosis has influenced your ability to form/maintain relationships with romantic partners.

44. If you would like, please briefly explain how your diagnosis of a hereditary colorectal cancer syndrome has influenced your ability to form/maintain relationships with friends.

**General:**

45. What advice would you give someone who was considering testing for a hereditary colorectal cancer syndrome between the ages of (answer to question #7)?

46. How could medical professionals (physicians, genetic counselors, surgeons) better have served your needs as an (answer to question #7) year old with this diagnosis?
References


23. Millar, B., Patterson, P., & Desille, N. (2010). Emerging adulthood and cancer: how unmet needs vary with time-since-treatment. Palliative and Supportive Care, 8(02), 151-158.


