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## Exploring Motivational Factors to Pursue Genetic Counseling and Testing in Adolescent and Young Adult Cancer Patients

Megan Morand

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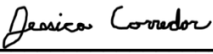
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Exploring Motivational Factors to Pursue Genetic Counseling and Testing in Adolescent and  
Young Adult Cancer Patients

by

*Megan Pope Morand, BS*


APPROVED:



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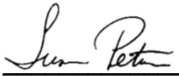
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Exploring Motivational Factors to Pursue Genetic Counseling and Testing in Adolescent and  
Young Adult Cancer Patients

A

Thesis

Presented to the Faculty of

The University of Texas

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for the Degree of

Master of Science

by

Megan Pope Morand, BS

Houston, TX

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# EXPLORING MOTIVATIONAL FACTORS TO PURSUE GENETIC COUNSELING AND TESTING IN ADOLESCENT AND YOUNG ADULT CANCER PATIENTS

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Adolescent and young adult (AYA) cancer patients face a unique set of challenges when navigating cancer treatment and survivorship. For many patient populations, motivational factors to pursue genetic counseling/testing have been described, but these motivational factors in AYA cancer patients have yet to be explored. The goal of this study was to describe AYA cancer patients' decision-making process, including motivational factors and barriers as it relates to genetic counseling/testing. We conducted a qualitative study consisting of semi-structured interviews with 30 individuals from the AYA Program at MD Anderson Cancer Center who attended or were referred to a genetic counseling appointment. Data analysis showed that motivational factors for patients who attended and/or were referred but did not attend a genetic counseling appointment include learning about genetic counseling, family, gaining information, affordability, and easing worry. For those who were referred but did not attend their genetic counseling appointment, the following barriers emerged as themes: scheduling or other priorities, worry, and cost. The majority of those who did not attend their appointment expressed that genetic counseling was something they would pursue eventually. Our data indicated that AYAs have similar motivational factors of other patient populations, but their younger age of diagnosis alters the lens of how these factors affect patient decision making. Additionally, while there are barriers limiting access to genetic counseling/testing, they do not decrease the interest in genetic testing/counseling for most patients.

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## INTRODUCTION

Each year approximately 70,000 individuals between the ages of 15-39 are diagnosed with cancer [1]. This makes up approximately 6% of all cancers diagnosed a year. Additionally, cancer is the leading cause of non-accidental death for this age group [1]. Patients in this age group are known as adolescents and young adults or AYAs. This patient population faces unique challenges in their cancer journey, including secondary cancer diagnoses, infertility, susceptibility to depression and anxiety, education and work transitions, financial concerns, and even access to genetic counseling and testing [2]. Some pediatric and/or adult cancer centers have multi-disciplinary programs specifically created to manage the comprehensive cancer care of these individuals [3].

Due to younger ages of diagnosis, many AYA patients meet criteria for germline genetic testing for hereditary cancer syndromes [4-7]. Hereditary cancer is when an individual has a pathogenic/likely pathogenic (P/LP) germline variant in a gene that leads to an increased risk for cancer. This accounts for approximately 5-10% of cancers in all patients [8], and studies have found similar rates in pediatric cancers [9]. Cancer patients or their unaffected family members may be offered genetic testing to determine if they have a hereditary cancer syndrome.

Some studies have looked at factors for why patients may pursue genetic counseling services. A patient's knowledge of genetic counseling services and/or genetic testing has shown to play a factor in patients' uptake of these services [10]. In populations other than AYA, studies have found that women with a family history of breast and/or ovarian cancer are motivated to pursue genetic counseling and testing because they have a desire to aid cancer research, obtain information for children or other family members, and protect their own health through screening and prevention [11]. Additionally, potentially negative consequences, such as concerns about life insurance and confidentiality, were not as important in their decision-making process to pursue genetic counseling/testing compared to the perceived benefits

gained from these services [11]. Another study focused on the motivations of patients undergoing predictive testing for hereditary non-polyposis colorectal cancer. They found that early detection of cancer, learning children's risk, and reduction of uncertainty were the factors that most influenced patients' motivation to pursue testing [12]. These studies looked at unaffected patients who had a family history that was suggestive of a hereditary cancer syndrome. When similar studies were done with survivors of colorectal cancer, they were found to pursue testing for similar reasons to those only with a family history of cancer, including determining if children were at risk and if any additional screening was needed; however, a significant amount of these patients also underwent testing because it was offered and/or recommended by a health care provider [13]. Finally, worry has been described to play a role in patients' decision making for women pursuing testing for hereditary breast and ovarian cancer [14]. In one study, higher worry about cancer was associated with positive attitudes about the benefits of genetic testing, whereas high perceived cancer risk appears to be associated with skepticism of and concern with negative emotional consequences of genetic testing [14].

While the motivation to pursue genetic counseling/testing for hereditary cancer syndromes has been described for many sub-sets of cancer patients, it has not yet been described in the AYA patient population. Hart et al. (2020) found that one of the challenges of care in the AYA cancer setting is the overwhelming amount of decisions that patients must make, and that many rely on health care providers to make these decisions [15]. Although this study illustrated a challenge of care with AYAs and how they make medical decisions, it is still unclear what drives patients in this age range to pursue or not pursue genetic counseling/testing.

In order to address the gap in knowledge on motivations for AYAs to pursue genetic counseling and/or testing, we conducted a qualitative study with patients from the Adolescent and Young Adult (AYA) Program at MD Anderson Cancer Center. This program serves patients ages 15-39 who are in active treatment or survivorship. This comprehensive clinic meets the needs of this patient population by offering services to address challenges unique to AYAs,

including fertility, school and career goals, and quality of life issues. A genetic counselor reviews records of all patients referred to the AYA program and recommends or does not recommend a referral to genetic counseling for each patient. By interviewing patients from this clinic, were able to describe the AYA cancer patients' decision-making process, including motivational factors and barriers as it relates to genetic counseling/testing. This will ultimately lead to better understanding of the considerations and motivational factors among this population, will inform health care providers' clinical practice and increase opportunities to provide appropriate counseling and care for this unique population.

## **METHODS**

This study was approved by institutional review boards at the University of Texas MD Anderson Cancer Center (2020-0241) and the University of Texas Health Science Center at Houston (HSC-MS-20-0533).

### *Participants*

For this study, eligible participants were identified from the clinical list of patients attending the AYA program at MD Anderson Cancer Center who were recommended to be referred for further genetic counseling. Patients were eligible for the study if they were 18-39 years old at the time of recruitment, seen in the MD Anderson outpatient AYA clinic after July 12, 2018, had a recommendation for referral to genetic counseling, were able to speak and read English, and were able to provide informed consent. Patients who completed their genetic counseling appointment, as well as those who did not meet with a genetic counselor but were recommended to, were also included in the study.

### *Study Design*

Patients were purposefully sampled to include a variety of ages within the AYA group, and both patients who met and did not meet with a genetic counselor were sampled. Qualifying

patients were sent a study invitation through their electronic medical record, followed by a phone call from the study personnel. After receiving informed consent, participants completed semi-structured interviews over Zoom audio calls conducted by primary author (M.M.). Interviews began with gathering background information about the participants cancer journey, family and general understanding of hereditary cancer and genetic counseling. Another group of questions was based on the Health Belief Model (HBM). The HBM is a conceptual framework developed in the 1950s to predict health behaviors [16]. Since then, it has been used in other qualitative studies looking to predict health behaviors [17-19]. The last group of questions focused on motivational factors that had been identified in other patient populations. The full interview script can be seen in **Appendix A**. The interview script was reviewed by an AYA cancer survivor prior to beginning interviews. Interviews ceased after saturation of themes were met. A total of 30 interviews were completed. Interviews were audio recorded and transcribed prior to data analysis.

### *Analysis*

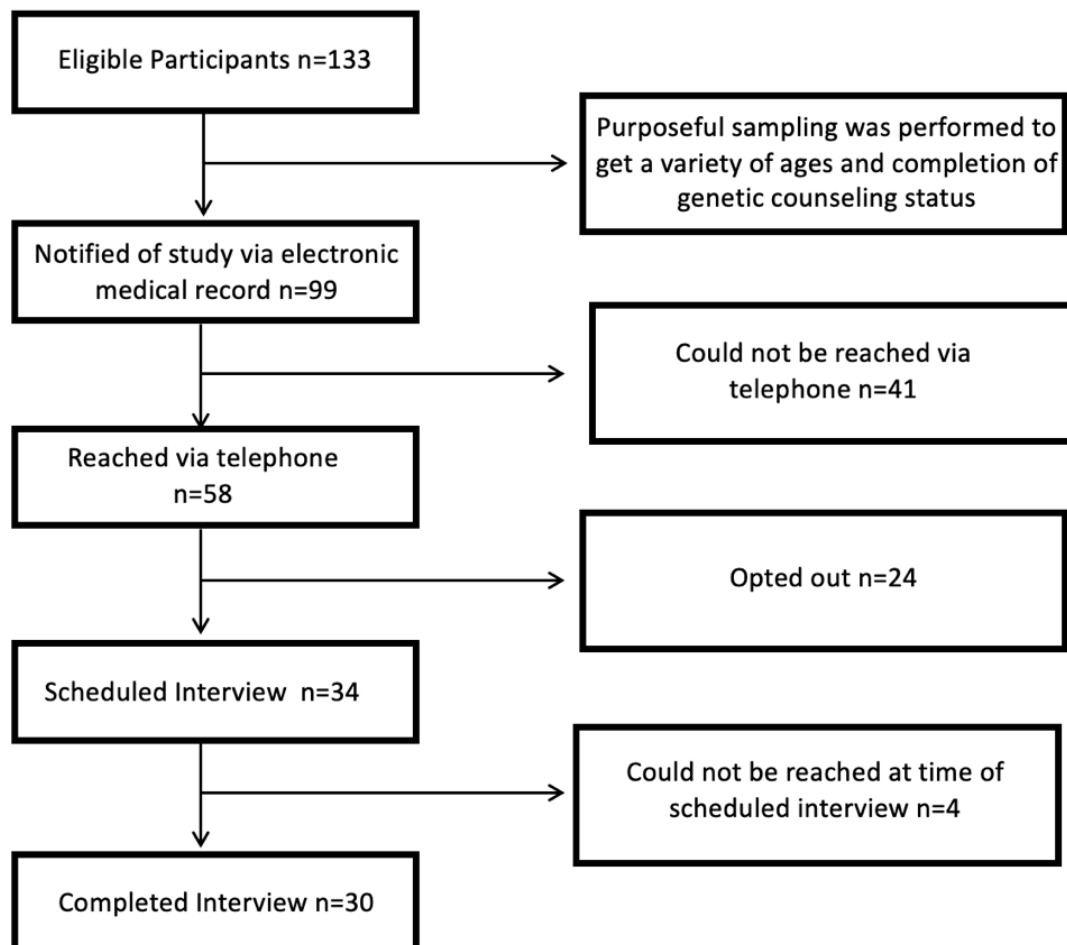
Qualitative data analysis was guided by grounded theory approach using ATLAS.ti software, version 9.07 [20, 21]. Each de-identified transcript was coded and analyzed to determine overall themes. The preliminary code book was created by M.M. and reviewed with a second coder (J.C.). The primary and secondary coders reviewed five transcripts throughout the coding process and an inter-coder reliability of at least 85% was reached and maintained. Throughout the coding process, any coding discrepancies were discussed until a consensus of codes was reached. The remaining 25 transcripts were coded by the primary author.

## **RESULTS**

A total of 133 patients were eligible to be contacted for the study, 99 were contacted via the electronic medical record. Of those contacted, 41 (41%) could not be reached by phone, 24

(24%) opted out, and 4 (4%) did not complete their scheduled interview (**Figure 1**). A total of 30 completed their interview, including 20 (67%) females and 10 (33%) males. Additionally, 21 (70%) had attended their genetic counseling appointment, and 9 (30%) were referred to genetic counseling but did not attend their appointment. There was only 1 (3%) participant who was in active treatment at the time of interview, with the rest being in surveillance and/or survivorship. A large number of participants (43%) had <1 year between their primary diagnosis and genetic counseling referral, while the rest had been diagnosed >1 year before they were referred. There were 8 (27%) participants who had a pediatric cancer diagnosis, with the remaining diagnosed in adolescence or young adulthood. Participants' specific cancer diagnosis and other demographic information is available in **Table 1**.

**Figure 1** Interview sampling flow-chart



**Table 1** Participant (n=30) demographic information at time of the study

<b>Characteristic</b>	<b>n</b>	<b>%</b>
<i>Mean age (range), years</i>	27.6 (18-38)	
18-29	17	57%
29-39	13	43%
<i>Gender</i>		
Female	20	67%
Male	10	33%
<i>Attended genetic counseling appointment</i>		
Yes	21	70%
No	9	30%
<i>Race/Ethnicity</i>		
White/Caucasian	21	70%
Hispanic	6	20%
Black/African American	2	7%
Asian	1	3%
<i>Primary Cancer Diagnosis</i>		
Sarcoma	14	47%
Leukemia	3	10%
Carcinoid tumor/carcinoma	2	7%
Desmoid tumor	2	7%
Oligodendroglioma	2	7%
Lymphoma	1	3%
Neuroblastoma	1	3%
Melanoma	1	3%
Medulloblastoma	1	3%
Meningioma	1	3%
Primitive neuroectodermal tumor	1	3%
Schwannoma	1	3%
<i>Age range of cancer diagnosis, years</i>		
Pediatric (0-14)	8	27%
AYA (15-39)	22	73%
<i>Length of time between primary diagnosis and genetic counseling appointment or referral, years</i>		
<1	13	43%
1-5	6	20%
6-10	3	10%
>10	8	27%
<i>Active or Inactive Treatment at time of Interview</i>		
Inactive	29	97%
Active	1	3%
<i>Type of insurance at time of appointment or referral</i>		
Private	25	83%
Public	1	3%
Military	3	10%
Self-pay (with patient financial assistance)	1	3%

### *Motivational Factors to Pursue Genetic Counseling and/or Testing*

Through all interviews, whether participants attended a genetic counseling appointment or not, several motivational factors emerged as playing a role in the decision-making process of whether or not to pursue genetic counseling/testing.

#### Learning about genetic counseling or hereditary cancer

Participants discussed that learning that genetic counseling and/or testing were available gave them the ability to decide if they wanted to pursue it or not. Many expressed that they were unaware of the option to pursue genetic counseling until they had conversations with a healthcare provider about this resource. One person stated, “I didn’t know I would need it...didn’t know it was available...more than anything I didn’t know I had a reason to do it.” Other participants had questions about genetics related to their cancer but didn’t know what their options were for addressing those questions. One individual said, “I had been asking these questions about genetics and heard about genetic testing and immediately said, ‘Yes, yes. I want to do it. Sign me up.’”

#### Family

Family was a motivational factor in a variety of aspects throughout the interviews. Some were concerned about other family members being at risk for cancer, including children, siblings, and nieces/nephews. One person shared, “Is my child at risk?’ That was my first, immediate, and still is a concern for me to this day.” While for others, genetic testing impacted their thoughts related to family planning. For some participants without children, genetic testing was the deciding factor on whether or not they would have children: “I realized just very deeply that if I do have this genetic version, I don’t want to have to go through what my mother did. I don’t want to have to put a child through what I went through.”

Other participants expressed that family history of cancer played a larger role in whether to pursue genetic counseling/testing. Many were concerned about cancers that had

occurred in other family members possibly being hereditary, while others were concerned by not knowing much about their family history: “Just the unknowing of my father’s family history...is there any type of cancer that I should be aware to look for?” The desire to learn more about possible hereditary factors running through the family helped motivate these individuals.

### Gaining Information

Many participants described the desire for information about their cancer as being a motivational factor. Some wanted to figure out the “why” surrounding how they got cancer, “I wanted more information about how I got it [cancer].” While others were driven by the chance to find information that they felt could help with treatment.

Several individuals wanted to know if they were at risk for other cancers, specifically if screening or prevention would be an option in the future: “When the opportunity was afforded, it was just kind of a no-brainer...if I can prevent what I’ve already gone through now again, if it was a possibility, I would take it.” After going through one cancer diagnosis, they wanted to do anything they could to avoid going through cancer again.

### Affordability

Some individuals indicated they were more willing to pursue genetic counseling/testing due to it being affordable, “I was told very early on that it would be affordable...and it was.” Some participants reported that they would have pursued genetic counseling no matter the cost, while others scheduled the appointment at a time that they knew it fit into their budget, “It was one of those things when looking at it, it was just, okay, well, if we can’t afford it this trip, then we can make it a priority to be able to afford it next time we come out.” Over the last several years the cost of genetic testing has decreased, which may influence some patients finding it affordable.



## Easing Worry

For several participants, worry about the possibility their cancer was hereditary drove them to pursue genetic counseling and testing quicker. They described the worry about the unknown being worse than taking the steps to get an answer. One person said, “It was more of, I guess, the anxiety of not knowing... but that anxiety and the stress was minimal to what I could possibly learn.” Others described a worry as soon as they were diagnosed, and that stress was the driver behind looking for answers. For this individual, worry also combined with the motivational factor of family. “I think worry and stress were probably huge motivators. I was definitely immediately worried when I got diagnosed about my daughter.” While this is one example of multiple factors influencing a patient’s decision, most participants described a combination of the motivational factors playing a role in their decision making.

The number of respondents for each motivational factor are shown in **Table 2** with further examples shown in **Table 3**.

**Table 2** Number of participant responses per motivational factor

<b>Motivational Factor</b>	<b>n</b>	<b>%</b>
<i>Learning about genetic counseling or hereditary cancer</i>	18	60%
<i>Family</i>	26	87%
<i>Gaining Information</i>	19	63%
<i>Affordability</i>	17	57%
<i>Easing Worry</i>	5	17%

**Table 3** Motivational factors to pursue testing (n=30)

<b>Themes</b>	<b>Participant Responses</b>
<i>Learning about genetic counseling or hereditary cancer</i>	"Them [my healthcare providers] making me aware of testing, 100%, because I wouldn't have even known that was something people did or it was an option."
<i>Family</i>	"One of the reasons I wanted to get genetic testing is because I wanted to make sure that my niece and nephew wouldn't run into anything. I wanted to make sure that my sister wouldn't get anything. I wanted to at least make sure we were prepared for anything."
<i>Gaining Information</i>	"I'd like to be armed with all of the facts going through life. Especially being a young adult and knowing that I have to go and be on my own and have my own healthcare, but knowing for a fact that, 'Yes, this is something that could come up later in life,' for me is something that was very important."
<i>Affordability</i>	"The cost was no cost to me due to my insurance, and so it costs me nothing."
<i>Easing Worry</i>	"When I first heard that there was a possibility that it could be a hereditary form of cancer that affected me ... it made me want to get tested."

### *Barriers to Pursue Genetic Counseling or Testing*

For those participants who did not attend a genetic counseling appointment, several themes emerged as barriers to accessing genetic counseling/testing.

#### *Scheduling or other priorities*

For some people, the idea of adding another appointment mid-treatment or quickly after spending so much time at the hospital was too overwhelming. Others traveled to MD Anderson for appointments and had difficulties getting an appointment while they were in town, "The worst part of it for me what just having to go to another appointment." Some individuals expressed needing time to focus on their cancer diagnosis and treatment, and that they were not able to add anything else to their plate until they were in a better place. "I want to make sure that stuff is figured out where I can start actually doing the rest of my treatment first, before I start really looking into other things." Life events such as going to college, finding a job, and raising a family were also higher priority for several participants, "I don't see the necessity of going to a genetic counselor right now...I have other stuff on my mind."

## Worry

While some participants described worry as a motivational factor, for many it was a barrier keeping them from pursuing genetic counseling and testing. One participant describes: “As a cancer survivor, there’s been just a lot of anxiety kind of processing, as an adult, the trauma that I went through as a child. And so I have to be very mindful and careful of what I choose to reopen and expose myself to. And to worry kind of about the future of what that could entail with hereditary cancer just kind of makes me anxious. And at this moment it’s not really something I really want to focus on.”

For these individuals, living in the unknown of whether or not their cancer was hereditary is less worrisome than undergoing genetic testing to get the answer. The thought of making decisions about family, screening, and knowing that they are at risk for other cancers would be more detrimental to their mental health than being unsure if their cancer was hereditary. One person explained: “You just have to believe everything is okay and you can’t live with the fear,” in reference to how they coped living in the unknown before they were ready for the potential information genetic testing may bring.

## Cost

For some the largest barrier was being unable to afford genetic counseling/testing. One participant discussed lack of insurance coverage and limited personal funds making it too difficult to attend the appointment. “That’s specifically been my biggest hurdle is I just don’t have the funds to just go see a [genetic counselor] with my personal funds.” While insurance companies sometimes cover genetic testing, people sometimes worry about the cost of their genetic counseling appointment and if that will be covered by insurance or be cost prohibitive. Individuals who get referred during or right after their cancer treatment may have to prioritize treatment costs over genetic counseling or testing until a later time.

While these participants discussed barriers keeping them from having attended the genetic counseling appointment at the time of the interview, 6 (67%) of the participants who did

not attend their appointment indicated they were interested in eventually pursuing genetic counseling/testing.

The number of respondents for each barrier are shown in **Table 4** with further examples in **Table 5**.

**Table 4** Number of participant responses per barrier (n=9)

<b>Barriers</b>	<b>n</b>	<b>%</b>
<i>Scheduling or other priorities</i>	6	67%
<i>Worry</i>	5	56%
<i>Cost</i>	1	11%

**Table 5** Barriers to pursue testing

<b>Themes</b>	<b>Participant Responses</b>
<i>Scheduling or other priorities</i>	"We never went in and did genetic testing, just because there was so much [going on] at the time."
<i>Worry</i>	"It's such a complicated emotional relationship with something that's from your own body, but that's killing your own body. And then it might kill your family, and then it's just terrifying."
<i>Cost</i>	"If it was going to be expensive, I wasn't going to do it."

## DISCUSSION

To the authors' knowledge, this study is the first to describe the motivational factors and barriers of AYAs when considering hereditary cancer genetic counseling/testing. The finding that patients pursue genetic testing in part because it was offered by a healthcare provider has been described in other patient populations, specifically in patients with a family history of cancer, but no personal history. Our study highlights the importance of healthcare providers initiating these conversations and educating patients about their options as they navigate their cancer treatment and survivorship. These initial conversations allow patients to take ownership of their decision to pursue genetic services and provide an opportunity for patients to reflect on what information is most helpful to them as they navigate the decision of whether or not pursue genetic counseling/testing.

Similar to other patient populations whose motivational factors have been described, the AYA population is motivated to pursue genetic counseling/testing to gain information for family members who might be at risk. A unique factor of the AYA population, however, is due to their younger age, many patients don't have children at the time of their cancer diagnosis or genetic counseling appointment. Along with wanting information for other family members, they also want to know the risk of having a child with a hereditary cancer syndrome. The weight of the decision to have biological children or not is particularly stressful for this younger patient population who may not have had children but are often at reproductive ages. Similarly, for those AYA patients with children, their children tend to be younger in age, which for this patient population may be close in age to their own diagnosis. This can lead to increased worry related to whether their child may be at risk for cancer in the near future. This differs from adult cancer clinics where the primary hereditary cancer syndromes do not increase the risk for a pediatric cancer diagnosis. While anyone at risk for a hereditary cancer syndrome may worry about cancer in their children, for those in the AYA population, that worry may start when children are at a much younger age.

While several motivational factors identified in this study have been described in other patient populations, it is important to remember the unique aspects of the AYA population when discussing these themes. When desire for more information is a factor in a patient's decision making, those who develop cancer at younger ages may spend more time thinking about what caused the early onset cancer and they may place higher value in the "why" that genetic testing could give them than someone who was diagnosed later in life. Similarly, worry has been described as both a barrier and motivational factor in other patient populations. However, as discussed above, the subject of some of these worries may differ in this patient population. Knowing this, genetic counselors can have targeted conversations with patients about what specifically concerns them the most and work together to overcome barriers created by worry to make a plan about when in their cancer journey would be best time to consider genetic testing.

Although multiple participants discussed that scheduling or attending many other appointments was a barrier, increased access to telehealth and more flexible scheduling may expand opportunities for some to pursue genetic counseling/testing. Improved access to telehealth does not address individuals delaying genetic counseling/testing for reasons such as the need to get through treatment before being “ready” to pursue testing; however, it may be able to provide better access to genetic services for some. Additionally, better access to genetics services does not eliminate the barrier that some individuals may have more important priorities they would like to focus on, such as life events of attending college or starting a career. For those who have barriers related to scheduling, or for individuals who report their “plate” is too full due to treatment or other responsibilities, it is important for genetic counseling to be offered again, possibly later in the patient’s cancer journey or into survivorship when these barriers may be reduced or no longer be in place. This is particularly important since most of the patients interviewed who did not attend a genetic counseling appointment stated it is something they would consider in the future.

### *Implications for Clinical Practice*

Our findings can be used to help guide clinical practice and improve patient care for this unique patient population. AYA healthcare providers as well as genetic counselors can use this information to tailor their discussions about genetic counseling and testing in order to highlight what is most applicable and important to these patients. For healthcare providers seeing patients who have a personal or family history concerning for a hereditary cancer syndrome, a conversation regarding what genetic counseling is and what it can offer patients is vital, since many patients stated that their driving motivational factor came from learning that genetic counseling is an option. Since our study showed that not all patients are ready to pursue genetic counseling during or immediately after treatment, this conversation should happen again at future appointments if a referral is initially declined. Additionally, if a patient does not attend their genetic counseling appointment, efforts should be made to discuss why they were

unable to attend and help determine when they would feel more comfortable discussing genetic counseling/testing options.

For genetic counselors meeting with AYA patients, it is important to keep in mind many of the motivational factors and barriers that their patients may be facing. It may be more important to explore a patient's desire to have children, and how genetic test results might impact that decision. When appropriate, in vitro fertilization and pre-implantation genetic testing should be discussed with the patient so they can better understand their reproductive options. Additionally, patient worries should be used to help guide the decision-making process to help the patient determine if and when pursuing genetic testing is the right decision for them emotionally. Finally, barriers, including cost and other important life events that the patient might be going through, should be explored. The genetic counselor and patient should work together to overcome these barriers when possible.

### *Limitations*

One limitation of our study is the lower rates of participation in males, as well as the lower participation in those who did not attend their genetic counseling appointment. Females answered the phone more often than males did, allowing for higher rates of participation. Additionally, participants who did not attend their genetic counseling appointment were less interested in participating in a study, although they were contacted at the same rate of those who attended their appointment. Many of those interviewed who did not attend their genetic counseling appointment stated that it was something they would consider eventually, but the barriers discussed above prevented them from attending their appointment. Since we have a low response rate in this group, we may not have elicited additional barriers of those who did not attend their genetic counseling appointment and may have no interest in pursuing it later on.

While overall our findings should be largely generalizable, one limitation of the study is that the patient population of MD Anderson has higher rates of private insurance coverage

compared to many community or county hospitals. Our finding of affordability being a motivational factor at a higher rate than cost being a barrier may not be generalizable to the entire AYA population, particularly in underinsured patients.

Additionally, the overwhelming majority of those who pursued genetic testing disclosed that they tested negative, which may add bias to our study for participants feeling more reassured by genetic testing results. This specifically could play a role in the motivational factor of easing worry. It is possible that our study over-represents those who were reassured by their genetic testing results, enabling them to look back and say that the concerns they had were eased by genetic testing. Comparatively, those who did not attend their genetic counseling appointment did not have the opportunity to have been reassured by genetic testing results and described their worry more as a barrier. It may be beneficial for future studies to explore how patients who tested positive for a hereditary cancer syndrome describe their motivational factors within the AYA population.

### *Future Directions*

Although our study described the motivational factors and barriers to pursuing genetic counseling and testing in a variety of AYA patients, in order to expand how generalizable our results are, it would be beneficial to explore these factors through interviews or surveys of patients seen in other settings, including community hospitals or institutions who do not have a specific AYA program. Additionally, work should be done to further characterize the barriers to pursuing genetic counseling and testing in order to best find a way to minimize them. This may be accomplished through quantitative studies via chart review to quantify the length of time from diagnosis to genetic counseling appointment for AYA patients, as well as reviewing the cost of the genetic counseling appointment and testing for patients, in order to better understand the barriers of scheduling and cost. Finally, it would be beneficial to learn more about how healthcare providers currently handle discussing hereditary cancer and genetic



counseling in their own practice. This could be accomplished through a survey to AYA healthcare providers across the nation.

Our study provides a base for future work to build and expand upon based on the conclusions of our study. Conversations about genetics services should be initiated and continued by health care providers throughout a patient's cancer journey, as not all barriers preventing a patient from attending a genetic counseling appointment are permanent. Additionally, the unique aspects of the AYA population's motivational factors should be used to tailor conversations to best serve this patient population.

## APPENDIX A: Qualitative Interview Guide

### *Questions for all participants.*

1. In your own words, tell me about your experience with diagnosis and treatment of cancer?
2. Tell me about your family.
  - a. Are your parents living?
  - b. Do you have children?
3. What is your understanding of hereditary cancer?
4. Tell me about your experience getting referred to genetic counseling?
  - a. Where there other events going on in your life around the time of your referral?
5. Did your doctor talk to you about hereditary cancer in anyway before you were referred to genetic counseling?
  - a. How, if any, did that change your perception about that appointment?
  - b. How, if any, did that change your perception about genetic testing?
6. What, if anything, had been told to you about your appointment when the referral was made to genetic counseling?
7. How important to you was learning if your cancer was hereditary or not?

### *Questions for participants who did not attend their genetic counseling appointment after referral.*

1. Tell me about why you decided to pursue or not pursue genetic counseling?
2. Did you feel that genetic counseling was an important part of your health care? (*Health belief model perceived severity question*)
3. What did you think were the pros and cons of genetic counseling? (*Health belief model perceived benefits question*)
4. Was there a specific moment or experience that made you chose to pursue or not pursue genetic counseling? (*Health belief cues to action question*)
5. Did you feel confident in your decision to pursue or not pursue genetic counseling? Why or why not? (*Health belief model self-efficacy question*)
  - a. Did you feel that you were capable of attending your genetic counseling appointment? Why or why not?
6. After being referred, did you have a “gut feeling”, or intuition about if your cancer might be hereditary? Why or why not? (*Health belief model perceived susceptibility question*)

*Questions for participants who did not attend their genetic counseling appointment after referral, or who have not yet been to their scheduled genetic counseling appointment.*

1. Tell me about why you decided to pursue or not pursue genetic counseling?
2. Did you feel that genetic counseling was an important part of your health care? (*Health belief model perceived severity question*)
3. What did you think were the pros and cons of genetic counseling? (*Health belief model perceived benefits question*)
4. Was there a specific moment or experience that made you chose to pursue or not pursue genetic counseling? (*Health belief cues to action question*)
5. Did you feel confident in your decision to pursue or not pursue genetic counseling? Why or why not? (*Health belief model self-efficacy question*)
  - a. Did you feel that you were capable of attending your genetic counseling appointment? Why or why not?
6. After being referred, did you have a “gut feeling”, or intuition about if your cancer might be hereditary? Why or why not? (*Health belief model perceived susceptibility question*)
7. In what ways did family have an influence on your decision to pursue or not pursue genetic testing?
  - a. Did friends, significant-others, or religious/spiritual leaders have any influence on your decision to pursue or not pursue genetic testing?
8. In what ways did the cost of testing influence your decision to pursue or not pursue genetic testing?
9. In what ways did privacy of test results influence your decision to pursue or not pursue genetic testing?
10. In what ways did worry or stress about the results influence your decision to pursue or not pursue genetic testing?
11. In what ways did your family history influence your decision to pursue or not pursue genetic testing?
12. In what ways did physician recommendation influence your decision to pursue or not pursue genetic testing?
13. In what ways did medical management options such as screening or risk reducing options influence your decision to pursue or not pursue genetic testing?
14. In what ways did test results from other family members influence your decision to pursue or not pursue genetic testing?
15. Tell me about how, if at all your life has changed since pursuing genetic testing?
16. Has anyone in your family pursued genetic testing since you received your test results?

### *Probes*

- Would you give me an example of what you mean?
- Please tell me more about that. Can you elaborate on that idea?
- What you are sharing (or have said) is important. Can you say more? Would you explain that further?
- I'm not sure I understand what you're saying.
- How does your experience before that time compare to your experience now?
- Tell me more about that experience (or that time)?
- How do you see that (or yourself) in the future?
- If you could change anything about that experience, what would it be?
- Is there anything else?

## Bibliography

1. Smith, A.W., N.L. Seibel, D.R. Lewis, K.H. Albritton, D.F. Blair, C.D. Blanke, W.A. Bleyer, D.R. Freyer, A.M. Geiger, B. Hayes-Lattin, J.V. Tricoli, L.I. Wagner, and B.J. Zebrack, *Next steps for adolescent and young adult oncology workshop: An update on progress and recommendations for the future*. Cancer, 2016. **122**(7): p. 988-99.
2. Soliman, H. and S.V. Agresta, *Current issues in adolescent and young adult cancer survivorship*. Cancer Control, 2008. **15**(1): p. 55-62.
3. Reed, D., R.G. Block, and R. Johnson, *Creating an adolescent and young adult cancer program: lessons learned from pediatric and adult oncology practice bases*. J Natl Compr Canc Netw, 2014. **12**(10): p. 1409-15.
4. Ripperger, T., S.S. Bielack, A. Borkhardt, I.B. Brecht, B. Burkhardt, G. Calaminus, K.M. Debatin, H. Deubzer, U. Dirksen, C. Eckert, A. Eggert, M. Erlacher, G. Fleischhack, M.C. Fruhwald, A. Gnekow, G. Goehring, N. Graf, H. Hanenberg, J. Hauer, B. Hero, S. Hettmer, K. von Hoff, M. Horstmann, J. Hoyer, T. Illig, P. Kaatsch, R. Kappler, K. Kerl, T. Klingebiel, U. Kontny, U. Kordes, D. Korholz, E. Koscielniak, C.M. Kramm, M. Kuhlen, A.E. Kulozik, B. Lamottke, I. Leuschner, D.R. Lohmann, A. Meinhardt, M. Metzler, L.H. Meyer, O. Moser, M. Nathrath, C.M. Niemeyer, R. Nustede, K.W. Pajtler, C. Paret, M. Rasche, D. Reinhardt, O. Riess, A. Russo, S. Rutkowski, B. Schlegelberger, D. Schneider, R. Schneppenheim, M. Schrappe, C. Schroeder, D. von Schweinitz, T. Simon, M. Sparber-Sauer, C. Spix, M. Stanulla, D. Steinemann, B. Strahm, P. Temming, K. Thomay, A.O. von Bueren, P. Vorwerk, O. Witt, M. Wlodarski, W. Wossmann, M. Zenker, S. Zimmermann, S.M. Pfister, and C.P. Kratz, *Childhood cancer predisposition syndromes-A concise review and recommendations by the*

- Cancer Predisposition Working Group of the Society for Pediatric Oncology and Hematology. Am J Med Genet A, 2017. 173(4): p. 1017-1037.*
5. Scollon, S., A.K. Anglin, M. Thomas, J.T. Turner, and K. Wolfe Schneider, A *Comprehensive Review of Pediatric Tumors and Associated Cancer Predisposition Syndromes. J Genet Couns, 2017. 26(3): p. 387-434.*
  6. National Comprehensive Cancer Network. *Genetic/Familial High-Risk Assessment: Breast, Ovarian, and Pancreatic (Version 2.2021).* 2021 [cited 2021 March 24, 2021]; Available from: <https://www.nccn.org/guidelines/guidelines-detail?category=2&id=1503>.
  7. National Comprehensive Cancer Network. *Genetic/Familial High-Risk Assessment: Colorectal (Version 1.2020).* 2021 [cited 2021 March 24, 2021]; Available from: <https://www.nccn.org/guidelines/guidelines-detail?category=2&id=1436>.
  8. Garber, J.E. and K. Offit, *Hereditary cancer predisposition syndromes. J Clin Oncol, 2005. 23(2): p. 276-92.*
  9. Zhang, J., M.F. Walsh, G. Wu, M.N. Edmonson, T.A. Gruber, J. Easton, D. Hedges, X. Ma, X. Zhou, D.A. Yergeau, M.R. Wilkinson, B. Vadodaria, X. Chen, R.B. McGee, S. Hines-Dowell, R. Nuccio, E. Quinn, S.A. Shurtleff, M. Rusch, A. Patel, J.B. Becksfort, S. Wang, M.S. Weaver, L. Ding, E.R. Mardis, R.K. Wilson, A. Gajjar, D.W. Ellison, A.S. Pappo, C.H. Pui, K.E. Nichols, and J.R. Downing, *Germline Mutations in Predisposition Genes in Pediatric Cancer. N Engl J Med, 2015. 373(24): p. 2336-2346.*
  10. Mallen, A.R., C.C. Conley, L. Fuzzell, D. Ketcher, B.M. Augusto, M. McIntyre, L.V. Barton, M.K. Townsend, B.L. Fridley, S.S. Tworoger, R.M. Wenham, and S.T. Vadaparampil, *"I think that a brief conversation from their provider can go a*

- very long way”: Patient and provider perspectives on barriers and facilitators of genetic testing after ovarian cancer. Supportive Care in Cancer, 2020.*
11. Clark, S., L.G. Bluman, N. Borstelmann, K. Regan, E.P. Winer, B.K. Rimer, and C.S. Skinner, *Patient Motivation, Satisfaction, and Coping in Genetic Counseling and Testing for BRCA1 and BRCA2. J Genet Couns, 2000. 9(3): p. 219-35.*
  12. Claes, E., L. Denayer, G. Evers-Kiebooms, A. Boogaerts, and E. Legius, *Predictive testing for hereditary non-polyposis colorectal cancer: motivation, illness representations and short-term psychological impact. Patient Educ Couns, 2004. 55(2): p. 265-74.*
  13. Esplen, M.J., L. Madlensky, M. Aronson, H. Rothenmund, S. Gallinger, K. Butler, B. Toner, J. Wong, M. Manno, and J. McLaughlin, *Colorectal cancer survivors undergoing genetic testing for hereditary non-polyposis colorectal cancer: motivational factors and psychosocial functioning. Clin Genet, 2007. 72(5): p. 394-401.*
  14. Cameron, L.D. and J. Reeve, *Risk perceptions, worry, and attitudes about genetic testing for breast cancer susceptibility. Psychology & Health, 2006. 21(2): p. 211-230.*
  15. Hart, R.I., D.A. Cameron, F.J. Cowie, J. Harden, N.B. Heaney, D. Rankin, A.B. Jesudason, and J. Lawton, *The challenges of making informed decisions about treatment and trial participation following a cancer diagnosis: a qualitative study involving adolescents and young adults with cancer and their caregivers. BMC Health Serv Res, 2020. 20(1): p. 25.*
  16. Glanz, K. and B.K.V. Rimer, K., *Health Behavior Theory, Research, and Practice. 5th ed. 2015, San Francisco, CA: Jossey-Bass.*

17. Rollins, B.L., S. Ramakrishnan, and M. Perri, *Direct-to-consumer advertising of predictive genetic tests: a health belief model based examination of consumer response*. Health Mark Q, 2014. **31**(3): p. 263-78.
18. Dempster, N.R., B.G. Wildman, T.L. Masterson, and G.J. Omlor, *Understanding Treatment Adherence With the Health Belief Model in Children With Cystic Fibrosis*. Health Educ Behav, 2018. **45**(3): p. 435-443.
19. Kohler, A.K., S. Nilsson, T. Jaarsma, and P. Tingstrom, *Health beliefs about lifestyle habits differ between patients and spouses 1 year after a cardiac event - a qualitative analysis based on the Health Belief Model*. Scand J Caring Sci, 2017. **31**(2): p. 332-341.
20. Soratto, J., D.E.P. Pires, and S. Friese, *Thematic content analysis using ATLAS.ti software: Potentialities for researchs in health*. Rev Bras Enferm, 2020. **73**(3): p. e20190250.
21. Chapman, A.L., M. Hadfield, and C.J. Chapman, *Qualitative research in healthcare: an introduction to grounded theory using thematic analysis*. J R Coll Physicians Edinb, 2015. **45**(3): p. 201-5.



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