Exploring Genetic Testing Conversations in the Context of Hematopoietic Cell Transplant Survivors: A Thematic Analysis

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Abstract

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Background:

Hematopoietic cell transplant (HCT) survivors face complex medical decisions throughout their long-term follow up (LTFU) care, including considerations around genetic testing. While research has examined genetic testing in various oncology settings, little is known about how HCT survivors engage with genetic testing conversations in LTFU care.

Methods:

We conducted a mixed-methods study with 23 HCT survivors receiving LTFU care. Semi-structured interviews exploring genetic testing experiences were conducted with 23 survivors who responded to genetics-specific questions (13 with original genetics questions and 10 with updated questions). Interviews were analyzed using thematic analysis.

Results:

Three key usage patterns emerged in how survivors engaged with genetic testing conversations: active integration (n=8), treatment-focused use (n=10), and non-integration (n=5). Family communication emerged as a central mechanism influencing engagement with genetic information. Key barriers included limited access to genetic services and varying levels of family involvement. Age-related differences appeared in how survivors approached genetic testing conversations, with younger survivors more focused on future implications and older survivors emphasizing immediate treatment decisions.

Conclusions:

Findings suggest opportunities to better support HCT survivors in genetic testing conversations through systematic approaches that consider age, family communication patterns, and timing of genetic services in LTFU care.

Exploring Genetic Testing Conversations in the Context of Hematopoietic Cell Transplant Survivors: A Thematic Analysis

Introduction

Hematopoietic cell transplant (HCT) survivors face complex medical decisions throughout their long-term follow-up (LTFU) care, including considerations around genetic testing. With advances in transplant medicine leading to improved survival rates, there is growing recognition of the importance of comprehensive LTFU care that addresses both immediate and long-term health considerations (Wingard et al., 2011). Genetic testing has emerged as an increasingly relevant component of this care, particularly as our understanding of genetic factors in hematologic malignancies continues to evolve (Hamilton et al., 2023).

Genetic testing in HCT care serves two distinct purposes. First, HLA typing and other transplant-specific genetic tests are essential for donor matching and immediate treatment planning. These tests examine genetic markers crucial for transplant compatibility and are standard practice in HCT care. Second, hereditary risk assessment through germline genetic testing may be indicated for some patients to identify inherited cancer predisposition syndromes. However, not all hematologic malignancies have inherited components requiring germline testing (Bochtler et al., 2018). Understanding these distinctions is crucial as survivors navigate genetic information throughout their care trajectory (Hamilton et al., 2023). The timing, relevance, and implications of these different types of genetic testing vary significantly, presenting unique challenges for both healthcare providers and survivors in LTFU care.

However, the role of genetic testing conversations in HCT survivorship care remains poorly understood. While previous research has examined genetic testing in various oncology

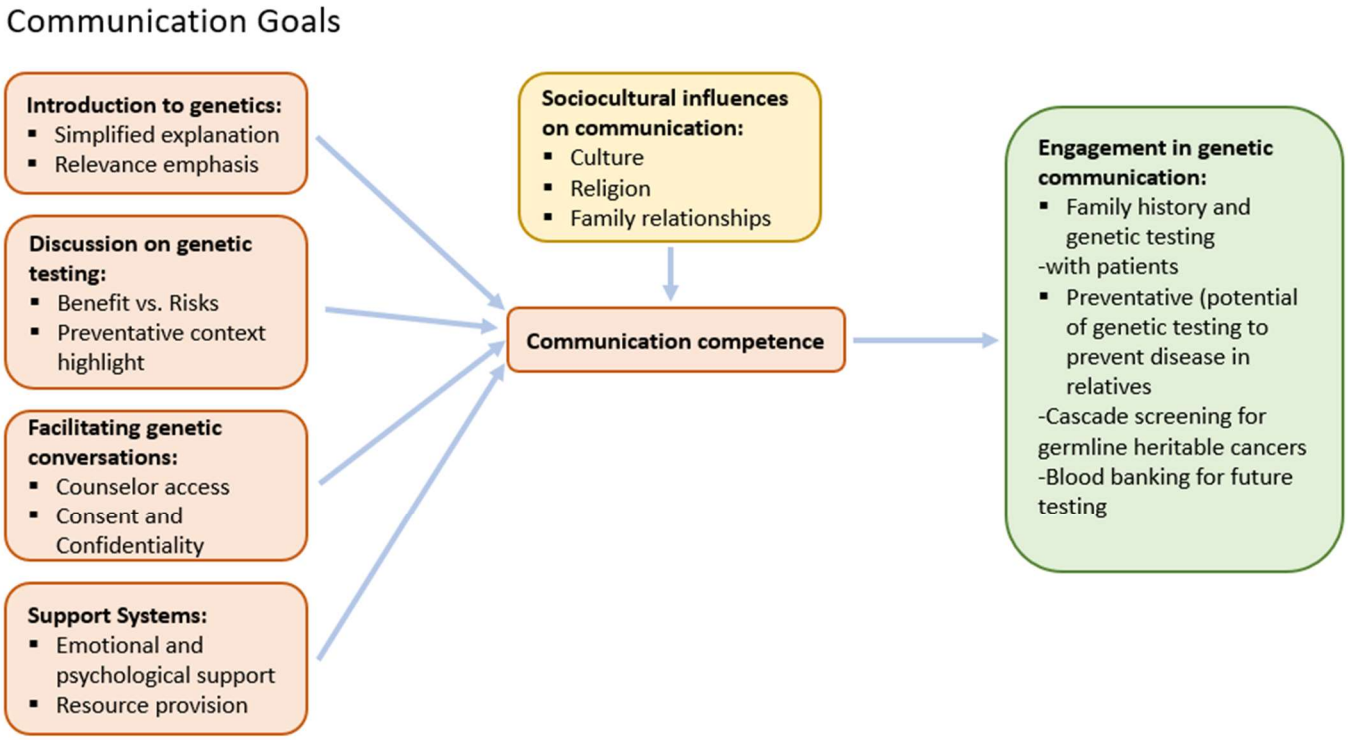
settings (Quillin et al., 2018), few studies have explored how HCT survivors specifically engage with genetic information during their LTFU care. This gap is particularly notable given that HCT survivors face unique considerations around genetic information, including potential implications for family members and future health monitoring (Desai et al., 2017).

The timing and context of genetic testing conversations in HCT care presents distinct challenges and opportunities. While genetic testing is often conducted during initial diagnosis and treatment planning for donor matching, questions about hereditary risk factors and implications for family members may arise throughout survivorship care (White et al., 2023). Understanding how survivors process and utilize this genetic information during their LTFU care is crucial for developing appropriate support systems and communication strategies.

Family communication patterns play a particularly important role in how genetic information is processed and utilized. Research in other oncology settings suggests that genetic information can significantly influence family health communication and decision-making (Wiens et al., 2013). For HCT survivors, who often rely heavily on family support throughout their treatment and recovery, the family context may be especially relevant to how genetic information is interpreted and acted upon.

To address these gaps in understanding, we investigated how HCT survivors in LTFU care think about and engage with genetic testing experiences. Our research specifically focused on understanding: Patterns in how survivors engage with genetic testing conversations, the role of family communication in genetic testing experiences, age-related differences in approaches to genetic testing conversations, and barriers and facilitators to engaging with genetic information in LTFU care.

Figure 1. Conceptual model for the role of communication competence and social psychological influences on engagement in genetics communication for HCT survivors in LTFU care at the Fred Hutchinson Cancer Center ("Fred Hutch").



By examining these aspects, we aim to inform the development of more effective approaches to integrating genetic testing conversations in HCT survivorship care that consider both individual and family contexts.

Methods

Study Design

We conducted a convergent parallel mixed-methods study examining genetic testing experiences among HCT survivors in LTFU care. Following approaches used in prior mixed-

methods studies with complex patient populations (Shen et al., 2023), we conducted semi-structured interviews and collected quantitative demographic data to understand how HCT survivors engage with both transplant-related genetic testing (e.g., HLA typing for donor matching) and hereditary risk assessment testing when indicated. All study procedures were approved by the Fred Hutch Institutional Review Board (IRB).

Participants and Recruitment

Participants were recruited from the LTFU program at Fred Hutch between March 10, 2023 to November 8, 2024. Eligibility criteria included: (1) age ≥18 years, (2) history of HCT, (3) current enrollment in LTFU care, and (4) ability to complete an interview in English. We used purposive sampling to ensure representation across three age groups (18-40, 41-64, and ≥65 years), as age was hypothesized to influence genetic testing experiences.

The genetics-specific questions were implemented in two phases: Phase 1: 13 participants completed the original genetics protocol focusing on general genetic testing experiences. Phase 2: 10 participants completed an updated protocol with enhanced questions about family health history documentation, informed by initial Phase 1 analysis.

Data Collection

Semi-structured interviews were conducted via telephone by trained interviewers and lasted 45-60 minutes. The semi-structured interview guide explored four key domains: (1) experiences with different types of genetic testing, including both HLA typing for donor matching and hereditary risk assessment when applicable; (2) family communication patterns about genetic information, including how participants shared results with family members and documented family history; (3) barriers and facilitators to engaging with genetic information in LTFU care; and (4) variations in genetic testing experiences across different life stages. Phase 1

interviews focused primarily on general genetic testing experiences, while Phase 2 added enhanced questions about family health history documentation based on initial findings. Sample questions included "Can you tell me about your experience with genetic testing?" and "How have you shared genetic information with your family members?" See Appendix A1 for complete interview guide. Interview recordings were transcribed verbatim.

Analysis

Qualitative Analysis

We conducted thematic analysis following Miles & Huberman (1994) and Patton (1990). Initial coding was performed by two independent coders who developed preliminary codes for both transplant-related and hereditary risk genetic testing experiences. The team developed a structured codebook through regular meetings, with specific attention to distinguishing between HLA typing/donor matching experiences and hereditary risk assessment when applicable. All transcripts were systematically coded using Dedoose software.

Quantitative Analysis

Descriptive statistics were calculated for demographics, clinical variables, patterns of genetic testing engagement (both transplant-related and hereditary), and family communication patterns. Variables included: Demographics (age, sex, race/ethnicity, education, employment); Clinical characteristics (diagnosis, transplant type, treatment history); Genetic testing history (HLA typing, hereditary risk assessment if applicable); Family communication metrics; Age-group comparisons (Young adults (18-40), Middle-aged (41-64), Older adults (≥ 65)).

Integration of Analysis

Qualitative and quantitative findings were integrated through joint displays examining patterns across data types, team discussions of convergent/divergent findings, and development of typologies capturing different approaches to genetic testing engagement. Given the sample size, age-group comparisons were descriptive rather than statistical.

Results

Sample Characteristics

Our final sample included 23 HCT survivors who completed genetic-specific questions across two study phases (13 in Phase 1, 10 in Phase 2). Participants represented diverse age groups and were approximately balanced by sex (see Table 1 for complete demographic characteristics). Most participants received allogeneic transplants (95.7%) and primary diagnoses included acute myeloid leukemia (34.8%), myelodysplasia/myelofibrosis (30.4%), and acute lymphocytic leukemia (13.0%). Clinical characteristics are detailed in Table 2.

Table 1. Demographic Characteristics of Study Participants (N=23)

Characteristic	Total Sample (N=23)
Age	
Mean years (SD)	54.2 (17.17)
Young adults (18-40), n (%)	8 (34.8%)
Middle-aged (41-64), n (%)	5 (21.7%)
Older adults (≥ 65), n (%)	10 (43.5%)
Sex	
Female, n (%)	11 (47.8%)
Male, n (%)	12 (52.2%)
Race/Ethnicity	

White/Caucasian, n (%)	21 (91.3%)
Hispanic/Latino, n (%)	2 (8.7%)
Education	
High school or less, n (%)	8 (34.8%)
College degree, n (%)	9 (39.1%)
Post-graduate degree, n (%)	6 (26.1%)
Employment	
Employed full-time, n (%)	9 (39.1%)
Retired, n (%)	12 (52.2%)
Other, n (%)	2 (8.7%)

Most participants allogeneic transplants (95.7%) and underwent total body irradiation (60.9%). Primary diagnoses included acute myeloid leukemia (34.8%), myelodysplasia/myelofibrosis (30.4%), acute lymphocytic leukemia (13.0%), and other diagnoses (21.7%). Clinical characteristics are detailed in Table 2.

Table 2. Clinical Characteristics of Study Participants (N=23)

Characteristic	Total Sample (N=23)
Primary Diagnosis	
Acute myeloid leukemia, n (%)	8 (34.8%)
Myelodysplasia/myelofibrosis, n (%)	7 (30.4%)
Acute lymphocytic leukemia, n (%)	3 (13.0%)
Other, n (%)	5 (21.7%)
Transplant Type	
Allogeneic, n (%)	22 (95.7%)
Autologous, n (%)	1 (4.3%)
Number of Transplants	

Single transplant, n (%)	21 (91.3%)
Multiple transplants, n (%)	2 (8.7%)
Treatment History	
Received total body irradiation, n (%)	14 (60.9%)

Thematic Analysis

Our analysis revealed five key themes characterizing how survivors engaged with genetic testing conversations. These themes encompassed patterns of engagement, family communication mechanisms, age-related differences, barriers and facilitators, and the integration of these factors across different survivor groups.

Among participants, all 23 had experience with HLA typing for donor matching, while 12 reported having hereditary risk assessment testing. The engagement patterns described below reflect both types of genetic testing experiences, with treatment-focused users (n=10) primarily engaging with HLA typing, while active integrators (n=8) typically engaged with both types of testing.

Theme 1: Patterns of Genetic Testing Engagement

Active Integration (n=8): These survivors demonstrated proactive engagement with genetic information, incorporating it into both healthcare decisions and family communication. They actively sought information beyond immediate treatment needs and maintained detailed records of genetic test results and family history. One participant explained:

> *Yes, it did [influence decisions] because even though the genetic issues I have were not hereditary, I still want my siblings to know about it (Patient 2021).*

Active integrators characterized their approach through regular communication with healthcare providers about genetic implications and systematic sharing of information with family members.

***Treatment-Focused Use (n=10)*:** The treatment-focused group engaged with genetic testing primarily for immediate clinical decisions, particularly donor matching and treatment planning. Their engagement was typically time-limited and focused on specific clinical outcomes. As one survivor described:

> *Well, I guess it told me that I didn't have any relatives... So that's how the genetic testing helped us get matched with that guy in Germany (Patient 2020).*

These participants demonstrated less interest in broader genetic implications, focusing instead on immediate treatment relevance.

Non-Integration (n=5): These survivors showed minimal engagement with genetic testing beyond required clinical testing. This pattern often stemmed from either perceived lack of relevance or limited access to genetic services. One participant noted:

> *I don't think that was offered to me really. When the first two times I was diagnosed I was a kid. So, yeah, those weren't really offered (Patient 2026).*

This group typically had less detailed understanding of their genetic information and minimal family communication about genetic implications.

Theme 2: Family Communication as a Central Mechanism

Active Information Sharing: A subset of survivors implemented comprehensive family communication strategies about genetic information. These participants regularly updated family

members about potential health implications and provided specific recommendations for health monitoring. One survivor explained their approach:

> *I share everything with my kids because they need to know what might affect them later. We keep a family health journal now (Patient 2015).*

Selective Disclosure: Other survivors adopted a more strategic approach to family communication, carefully considering timing and relevance. They often tailored information based on perceived risk and readiness of family members, as illustrated by one participant:

> *I waited until after my daughter's wedding to discuss the genetic results. I didn't want to worry her before then, but now she's starting her own family, so it's important (Patient 2019).*

These participants focused on providing actionable recommendations while balancing awareness with potential anxiety.

Limited Communication: Some participants reported minimal family communication about genetic information, often due to knowledge gaps or uncertainty. This pattern was particularly evident among those with limited family health history information:

> *I can't find any record of either my mother or father's side of the family. I've heard indirectly on my dad's side, some kind of cancer...but nothing definitive (Patient 2012).*

Theme 3: Age-Related Differences in Engagement

Young Adults (18-40 years): Younger survivors demonstrated distinct patterns focused on long-term implications and future planning. They showed greater interest in understanding

genetic implications for family planning and future health monitoring. As one participant explained:

> *I need to know what this means for having kids someday. It's not just about me anymore (Patient 2017).*

Middle-Aged Adults (41-64 years): This group balanced immediate and future considerations while emphasizing implications for their children's health. They often served as information conduits between older and younger generations:

> *I'm trying to piece together what happened with my parents while making sure my kids know what to watch for (Patient 2014).*

Older Adults (≥65 years): Older survivors primarily focused on immediate treatment decisions and showed less emphasis on future implications. Their approach often reflected established patterns of health communication:

> *At my age, I'm more concerned about managing what's happening now than worrying about what might happen later (Patient 2016).*

Theme 4: Barriers and Facilitators

System-Level Barriers: Participants identified several institutional challenges affecting genetic testing engagement. Limited access to genetic counseling services emerged as a primary barrier, with many reporting long wait times or difficulty securing appointments. Integration of genetic information into routine care varied significantly, with some participants reporting fragmented communication between specialists and primary care providers. Knowledge gaps among healthcare providers about genetic implications for HCT survivors also emerged as a significant barrier.

Personal-Level Barriers: Individual-level challenges included uncertainty about the relevance of genetic information to their specific situation. Many participants struggled with incomplete family health histories, particularly those from adopted families or with limited contact with biological relatives. Competing health priorities often relegated genetic considerations to a lower priority, especially during active treatment phases. This pattern was particularly pronounced among older survivors, who often managed multiple chronic health conditions alongside their HCT follow-up care. The complexity of their ongoing health management appeared to influence how they prioritized and engaged with genetic information.

Facilitating Factors: Strong provider relationships emerged as a key facilitator, particularly when providers actively integrated genetic discussions into routine care. Family support systems played a crucial role in information management and decision-making. Clear communication channels between healthcare teams and family members enhanced engagement with genetic information.

Theme 5: Integration of Findings Across Domains

The relationship between age groups and engagement patterns is summarized in Table 3, which integrates demographic characteristics, genetic testing engagement, and communication patterns across age cohorts. This analysis demonstrates how factors like employment status (60% employed in young adults vs. 80% retired in older adults) correspond with different approaches to genetic information. Young adults showed higher genetic testing engagement (80%) compared to older adults (40%), with distinct patterns in how this information was utilized. The patterns manifest across multiple domains, highlighting the complex interplay between age, family communication, and genetic testing engagement. This integrated analysis suggests that age-

appropriate interventions considering family communication patterns may be most effective in supporting genetic testing engagement among HCT survivors.

Table 3. Age-Related Patterns in Genetic Testing Engagement and Communication

Domain	Young Adults (18-40)	Middle-Aged Adults (41-64)	Older Adults (65+)
Demographics	Mean age: 32.1 years 60% female 40% employed	Mean age: 52.4 years 50% female 70% employed	Mean age: 71.2 years 45% female 80% retired
Genetic Testing Patterns[1,2,3]	High engagement (80%) Proactive information seeking Focus on future implications	Moderate engagement (60%) Family-centered approach Balanced immediate/future focus	Lower engagement (40%) Treatment-focused approach Emphasis on immediate decisions
ACP Engagement	Early-stage planning Family-oriented decisions Future-focused concerns	Active engagement Integration with existing plans Family communication focus	Well-established plans Updates to existing documents Implementation focus
Key Integration Themes	Preventive planning Family risk assessment Long-term implications	Family communication Shared decision-making Balanced integration	Immediate care decisions Established patterns Limited new integration
Representative Quotes	It changed how I told my family members because they were worried about themselves as well.	Well, I mean, I just shared with all of my kids... So I've shared that any of those that are in the family...	My dad died but he was 86 when he got his prostate cancer... So, I don't think he'd call that history.
Integration Patterns	Active Integration Future-focused Family-centered	Balanced Integration Comprehensive Communication-focused	Selective Integration Treatment-focused Established patterns
Barriers	Limited access Knowledge gaps Navigation challenges	Communication gaps Family coordination Time constraints	Limited perceived relevance Established routines Provider communication

Facilitators	Family involvement Provider support Information access	Family communication Existing ACP Provider relationships	Established care plans Family support Provider continuity

[1] Engagement patterns reflect thematic analysis of interview transcripts
[2] Percentages represent proportion of participants within each age group
[3] Data drawn from semi-structured interviews and demographic surveys

Discussion

While previous research has examined genetic testing in various oncology settings (Quillin et al., 2018), our study extends these findings to the unique context of HCT survivorship, where genetic testing serves dual purposes: HLA typing for donor matching and immediate treatment planning as well as hereditary risk assessment through germline genetic testing. The Wiens framework (2013) focused on family communication patterns broadly but did not explicitly distinguish between immediate clinical utility and hereditary risk information. Rather, their work revealed that communication decisions were influenced by perceptions of relevance, responsibility, and utility - factors that could apply differently across both immediate clinical needs (like HLA typing) and hereditary risk assessment. Our findings build on this by demonstrating how these different types of genetic information may be processed and communicated differently by HCT survivors.

Understanding this distinction between immediate clinical and hereditary risk testing is crucial for healthcare providers in determining appropriate guidance for family communication. While HLA typing results may require immediate sharing with potential donors, the communication of hereditary risk information often involves more complex timing and psychosocial considerations. Our findings suggest that providers may need to tailor their guidance based on the type of genetic information being shared. For treatment-focused users, providers might emphasize immediate clinical implications and specific family members who

need to know for treatment purposes. In contrast, for those engaging with hereditary risk information, providers may need to offer more comprehensive guidance about long-term implications and broader family communication strategies. This tailored approach aligns with recent work highlighting the importance of context-specific genetic counseling (Bochtler et al., 2018).

This distinction has important clinical implications - not all hematologic malignancies have inherited components requiring germline genetic testing (Bochtler et al., 2018). While most survivors had experience with HLA typing and other transplant-related genetic testing, engagement with hereditary risk information varied significantly. Understanding these variations is crucial for healthcare providers in determining appropriate timing and relevance of genetic counseling referrals, as well as guiding patients in communicating different types of genetic information to family members.

The identification of three distinct engagement patterns - active integrators, treatment-focused users, and non-integrators - builds on previous work examining how cancer patients process genetic information (Quillin et al., 2018). Active integrators demonstrated behaviors similar to those described in studies of hereditary cancer syndromes, where genetic information significantly influences long-term health management decisions (White et al., 2023). Treatment-focused users' experiences align with research showing that immediate medical decisions often take precedence over long-term genetic implications in acute care settings (Desai et al., 2017).

While some patterns of limited engagement might initially appear as barriers to communication, our findings suggest that some survivors intentionally chose to limit their engagement with genetic information based on their personal values and preferences. This distinction is important - what might appear as 'non-integration' could actually represent an

informed choice aligned with personal values rather than a failure to engage. This understanding has implications for how providers approach genetic counseling, suggesting the need to respect and work within patients' values rather than assuming all patients should maximize their engagement with genetic information.

Family communication emerged as a crucial mechanism in genetic information processing, consistent with established frameworks for genetic risk communication (Wiens et al., 2013). Our interviews revealed that pre-existing family communication patterns often influenced how genetic test results were shared. Families with established open communication channels were more likely to engage in active sharing of genetic information, while those with more reserved communication styles tended toward selective disclosure. These underlying family dynamics appeared particularly influential in how hereditary risk information was communicated, though they seemed less impactful for sharing immediate clinical information like HLA typing results. The varying patterns we identified suggest the need for targeted support strategies that consider existing family communication dynamics. This aligns with recent work highlighting the importance of family-centered approaches in genetic counseling (Buras et al., 2022).

Age-related differences in approaches to genetic information have important implications for practice. Younger survivors' focus on future implications suggests the need for comprehensive genetic counseling that addresses reproductive planning and long-term health monitoring. In contrast, older survivors' emphasis on immediate clinical implications may reflect their complex health needs and ongoing medical management priorities. However, this treatment-focused approach should not preclude comprehensive genetic counseling discussions. Rather, providers may need to adapt their counseling approach - addressing immediate clinical

needs while ensuring older adults still receive complete information about hereditary implications for family members.

Limitations

Our sample's demographics (predominantly White, well-educated, single-institution) limit generalizability. Additionally, focusing on survivors actively engaged in follow-up care may miss perspectives of those less engaged with healthcare. Our study period coincided with evolving genetic testing technologies and guidelines, potentially affecting participants' experiences.

While our convergent mixed-methods approach allowed us to examine both quantitative patterns and qualitative experiences simultaneously, this design has inherent limitations. The concurrent data collection meant we couldn't use early quantitative findings to inform our qualitative interviews, or vice versa. This may have limited our ability to probe more deeply into emerging patterns. Additionally, some discrepancies between quantitative and qualitative findings about engagement patterns were challenging to reconcile due to the concurrent nature of data collection.

Future Directions

Future research could build on these findings through a sequential mixed-methods design, where initial patterns of genetic testing engagement could inform more targeted investigation of specific user groups. A larger quantitative study could help validate the engagement patterns we identified and develop screening tools to help providers anticipate patient needs. Additionally, intervention studies could test tailored approaches for different engagement patterns, particularly examining how age and family communication dynamics influence intervention effectiveness. Such work would help translate our descriptive findings into actionable clinical protocols.

Another critical area for future research is the management of genetic test information after a patient's death. Questions remain about how to balance deceased patients' expressed wishes regarding genetic information sharing with potential benefits to surviving family members. This is particularly relevant in the HCT context, where genetic information might have immediate clinical utility for family members' health decisions. Future studies should examine how providers and institutions handle these complex situations, including development of protocols that respect both patient autonomy and family benefit.

Implications for Practice

Healthcare providers should systematically assess survivors' readiness for genetic testing discussions while considering age-appropriate timing. This requires determining clinical indications for germline testing based on disease type and family history (Bochtler et al., 2018). Family-centered approaches should support varied communication patterns and documentation needs.

Conclusion

This study reveals how HCT survivors engage with genetic testing conversations in distinct ways that are shaped by age, family communication patterns, and healthcare system factors. The identification of three engagement patterns - active integration, treatment-focused use, and non-integration - highlights both opportunities and challenges in supporting survivors' genetic testing experiences. While some survivors successfully integrate genetic information into their long-term health management, others encounter barriers that limit their engagement.

Our findings emphasize the central role of family communication in mediating how genetic information is processed and utilized, supported by extensive research in genetic

counseling and family health communication. This suggests that efforts to enhance genetic testing conversations in HCT survivorship care should consider both individual and family contexts. Age-related differences in approaches to genetic information further indicate the need for flexible, tailored strategies that align with survivors' life stage and circumstances.

These insights provide a foundation for developing more systematic approaches to genetic testing conversations in HCT survivorship care. Future practice models should consider: The timing and context of genetic testing discussions; The role of family communication patterns; Age-appropriate approaches to information sharing; Support for both immediate and long-term information needs.

As survivorship care continues to evolve, supporting meaningful engagement with genetic testing conversations will become increasingly important for optimizing long-term outcomes for HCT survivors and their families. The patterns identified in this study suggest opportunities for more tailored, systematic approaches that consider both clinical indications for genetic testing and the broader context of survivorship care.

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Appendix

Appendix A1: Patient Qualitative Interview Guide

Patient Qualitative Interview Guide (HCT Survivors and ACP)

Introduction: Let me start by thanking you for your time today. The purpose of this study is to understand how HCT survivors think about and talk about advance care planning. We want to understand what you know about the term "advance care planning" as well as your preferences for talking about it. For instance, who you would like to present for conversations about advance care planning and how and where you would like to have them. Your responses will help us to find ways to help communicate advance care planning options to HCT survivors in a way that is best able to help support them and their loved ones.

Ground rules: There is no "right" or "wrong" answer to any of the questions that I will ask you today. No matter what your responses are to the questions that follow, your insight is very helpful. Because there are multiple questions I hope to ask today, I may need to move on to new questions during our discussion to make sure that we finish in time. If at any point you are uncomfortable with the discussion, please let me know and we can skip that question or stop the interview. I will also be available after the interview to answer any questions you have or to listen to any additional comments you may have. Just as a reminder, I will be audio recording our conversation today. If at any time you want me to stop recording, just let me know. Please know that all information you share will be kept strictly confidential, and your name or anything else that could identify you will not be included in the transcript of this interview. May I begin audio recording our discussion now?

Introductory question (5 min): As you know, I am interested in understanding your experience with advance care planning. Can you tell me about your understanding of or experience with that term?
**Note, after getting patient's feedback, inform them that "In our time today, I'd love to learn more about your understanding and preferences for learning about and being supported in advance care planning. Advance care planning refers to the process of planning for your future medical care in the event you are unable to communicate your wishes, such as a hospitalization or a coma. It includes conversations around your goals of care (with doctors and family/loved ones) specifically for care received at the end of life. In addition to having conversations about the care you want, advance care planning also includes completion of two forms: (1) An advance directive/living will, which outlines what type of end-of-life care you want and (2) and healthcare proxy form which says who can be your decision-maker for medical decisions if you are unable.*
Transitional question (5 min): Have you engaged in any form of advance care planning? What was that experience like? How did it occur?

- Who are the people you have talked with about your goals of care, advance care planning, or end-of-life care planning?
    - Anyone on your healthcare team? Family or loved ones? Others?

- What documents have you completed?
    - Living will/advance directive? Healthcare proxy form?

- *If NO, why have you not yet engaged in advance care planning?

Key questions (20-30 min)

1. Have you thought about the type of care you might want to receive if you were ever sick enough to be unable to communicate your wishes, such as during a hospitalization?
    a. Why or why not?

   b. Who would you want to talk to about these types of care decisions?
2. What type of planning, as it relates to your own health, is most important to you right now?
   a. How do you see advance care planning being a part of that?

3. What makes it difficult to have conversations about advance care planning?

4. What makes it easier to have conversations about advance care planning?

5. I'm going to ask you a few questions about your preferences for how you would like to have conversations about advance care planning.
   a. What would help you feel comfortable having conversations about advance care planning?
   b. What would help you feel motivated to plan for your goals of care?
   c. Who would you want present in advance care planning conversations?
   d. How would you like your doctor involved in the process of advance care planning?
   e. How would you like your loved ones involved in the process of advance care planning?
   f. Where would you want to have these conversations?
      i. In a medical setting? In your home? Over the phone? Other?
   g. How would you want these conversations to incorporate your personal values and beliefs?
      i. What beliefs and values would be important to incorporate in these conversations?

6. Would you want technology-based support for advance care planning, such as websites or apps to guide you through the process? If yes, what type of support would you like?

7. Do you have children under the age of 18?
   a. Is yes, have you nominated a guardian for your child(ren)? (if no, move to next question)

8. As it relates to work, parenting, and financial stressors (e.g., lack of health insurance, mortgage) how do these areas impact your ability to engage in advance care planning?

9. Do you have a history of cancer in your family?
   a. If so, were any of your first-degree relatives (parent, sibling, or child) diagnosed with the same type of cancer you have? If yes, who in your family was diagnosed with the same type of cancer?
   b. If so, were any of your second-degree relatives (aunt, uncle, grandparent, niece, nephew, half-sibling) diagnosed with the same type of cancer you have? If yes, who in your family was diagnosed with the same type of cancer?

   c. Were you ever screened either here (at Fred Hutch) or elsewhere with a family health history questionnaire since your cancer diagnosis?

These next few questions are going to be about cancer and your genes. Specifically, we are going to ask you some questions about germ line genetic testing for inherited cancer risk. Genetic testing refers to a blood test that looks for a marker of cancer risk that can be passed on in families like other traits. Having a genetic change does not mean that the tested individual will definitely develop the cancer.

10. Has anyone discussed with you that your cancer could be inherited from others in your family? If so, who was that conversation with?

11. Did you ever receive genetic counseling after receiving your cancer diagnosis?
    a. If yes, how did you use that information? How did it influence how you communicate about your cancer with your family members?
    b. If no, what barriers (if any) did you face?

12. Did you ever receive germ line genetic testing for inherited cancer risk after receiving your cancer diagnosis?
    a. If yes, how did you use that information? How did it influence how you communicate about your cancer with your family members?
    b. If no, what barriers (if any) did you face?

13. How did your decision to get (or not get) genetic testing influence your engagement in advance care planning?

14. What else would be helpful for me to know about how to incorporate advance care planning into your own health and planning goals?

15. Is there anything else you think I should know about advance care planning for HCT survivors that we haven't discussed today?

Appendix A2: Quantitative Survey – Demographics & Clinical Characteristics

Engagement in Advance Care Planning

Demographics and Clinical Characteristics

Instructions: Thank you very much for participating in this study. This component of the study is an interview that will last about 45-60 minutes. It will be split up into different sections, and I will give you a brief introduction to each section. If at any time during the interview you need to take a break, please do not hesitate to ask. I will be audio-recording our conversation so that we capture all of your feedback accurately. Do you have any questions before we begin? I am going to start our interview by asking you questions about your background.

DEMOGRAPHICS

1. What is your age? _____

2. Gender assigned at birth:

___Male
___Female

3. Gender Identity:

___Male
___Female
___Non-Binary
___Other
___Not Reported
___Don't Know
___Refuse
___Missing
Other:_____

4. What race do you identify as?

___White or Caucasian
___Black or African American
___Asian
___American Indian or Alaskan Native
___Native Hawaiian or Other Pacific Islander
___Multi-racial
___Other (specify)
___Other (Hispanic or Latino/Latina)
___Don't Know
___Refuse
___Missing
Other race:_____

5. [If multi-racial]: Which races? (select all applicable):

___White or Caucasian

___Black or African American

___Asian

___American Indian or Alaskan Native

___Native Hawaiian or Other Pacific Islander

___Other (specify)

___Don't Know

___Refuse

___Missing

Other race(s):_____

6. Do you consider yourself to be Hispanic or Latino/Latina?

___Yes

___No

___Don't Know

___Refuse

___Missing

7. (IF YES to Question 5) What is your family's country of origin? [If patient/caregiver indicates multiple, ask him/her to select the one that he/she identifies with most strongly.]

___US

___Puerto Rico

___Mexico

___Dominican Republic

___Other

___Don't Know

___Refuse

___Missing

8. Are you currently employed?

___Yes

___No

___Don't Know

___Refuse

___Missing

(If no, skip to question 9)

9. If you are employed, is it:

___Part-time
___Full-time
___Don't Know
___Refuse
___Missing

10. Are you retired?
___Yes
___No
___Don't Know
___Refuse
___Missing

11. What is your relationship status?
___Married
___Domestic partnership
___Divorced
___Separated
___Never Married
___Widow
___Don't Know
___Refuse
___Missing

12. How many children do you have? _____

13. What is your highest level of education obtained?
___No formal education
___Some elementary school
___Completed elementary school
___Some high school
___Graduated high school or equivalent
___Some college
___Graduated college
___Some post-graduate/professional courses
___Completed post-graduate/professional degree
___Some trade/technical/vocational school
___Completed trade/technical/vocational school

___Don't Know
___Refuse
___Missing

14. What is your religion?

___Catholic
___Baptist
___Protestant
___Jewish
___Muslim
___Pentecostal
___Atheist
___Agnostic
___Other (specify)
___Don't Know
___Refuse
___Missing
Other:_____

15. We ask about participants' socioeconomic backgrounds because we think it is important to understand how people from different backgrounds differ in their experiences with cancer and treatment choices. Would you mind telling me the annual, combined income range for all family members in your household?

___Less than $21,000
___$21,000 - $39,999
___$40,000 - $65,999
___$66,000 - $105,999
___$106,000 or more
___Don't Know
___Refuse
___Missing

16. Do you have health insurance coverage?

___Yes
___No
___Don't Know
___Refuse
___Missing

17. What is the primary way you pay for your medical treatment?

___Medicaid
___Medicare
___Private health insurance
___Health Maintenance Organization (HMO)
___Other Government funded/subsidized coverage (i.e., military coverage, Affordable Care Act coverage)
___Self-pay
___Don't Know
___Refuse
___Missing

18. How much do you worry about your ability to pay for your medical treatment?
___Not at all
___A little
___Somewhat
___Quite a bit
___A great deal
___Don't Know
___Refuse
___Missing

19. Who is your primary informal caregiver (the person who provides the most unpaid, informal care for you)?
___Spouse or partner
___Sibling
___Parent
___Son or daughter
___Aunt or uncle
___Cousin
___Niece or nephew
___Grandchild
___Godparent
___Godchild
___Friend
___Other:_____
___Don't Know
___Refuse
___Missing

MEDICAL HISTORY

1. When you had your first transplant, what was your diagnosis?
   - ☐ 1 AML (acute myeloid leukemia)
   - ☐ 2 ALL (acute lymphocytic leukemia)
   - ☐ 3 CML (chronic myelogenous leukemia)
   - ☐ 4 NHL (non-Hodgkin lymphoma)
   - ☐ 5 HD (Hodgkin disease)
   - ☐ 6 MDS (Myelodysplasia or myelofibrosis)
   - ☐ 7 Multiple myeloma
   - ☐ 8 Other disease:

     IF 'OTHER': please tell us what diagnosis you were transplanted for if it is not listed above: _____
   - ☐ 9 Don't know
   - ☐ 10 Refuse
   - ☐ 11 Missing

2. How many bone marrow or blood stem cell transplants have you had? _____

   2a. What was the date of your **last** transplant?

   (Year) _____ (Month) _____ (Day)_____

3. Have you **ever** had an allogeneic transplant (stem cells from a relative or unrelated donor)?
   - ☐ 0 No
   - ☐ 1 Yes
   - ☐ 2 Don't know
   - ☐ 3 Refuse
   - ☐ 4 Missing

4. Have you **ever** had total body irradiation (TBI) as part of your transplant?
   - ☐ 0 No
   - ☐ 1 Yes
   - ☐ 2 Don't know
   - ☐ 3 Refuse
   - ☐ 4 Missing

5. Have you **ever** had 'local' radiation therapy to your chest or head or pelvic area in addition to any treatment you had for your transplant? (*Select as many as apply to you.*)
   - ☐ 0 No, I never had local radiation therapy to my chest, head or pelvic area
   - ☐ 1 Yes, I had local radiation therapy to my chest
   - ☐ 1 Yes, I had local radiation therapy to my head or neck
   - ☐ 1 Yes, I had local radiation therapy to my pelvic area
   - ☐ 2 Don't know
   - ☐ 3 Refuse

☐4 Missing

6. Have you **ever** had chemotherapy using an 'anthracycline' or mitoxantrone (Novantrone, DHAD, or DHAQ)? (Anthracyclines include Adriamycin, daunorubicin, daunomycin, Cerubidine, doxorubicin, epirubicin, Ellence, idarubicin, Idamycin. These could be in a combination chemotherapy like ABVD, CHOP or R-CHOP, C-VAMP, CVAD or Hyper-CVAD, VAD, VAPEC-B, CLAM or GCLAM.)
   - ☐0 No
   - ☐1 Yes
   - ☐2 Don't know
   - ☐3 Refuse
   - ☐4 Missing

GVHD

1. Since your transplant, how would you describe the severity of your chronic graft-versus-host disease (GVHD) **when it was at its worst**?
   - ☐0 Never had any GVHD
   - ☐1 Mild
   - ☐2 Moderate
   - ☐3 Severe
   - ☐4 Don't know
   - ☐5 Refuse
   - ☐4 Missing

***Note: If patient answers "0 – Never had any GVHD," then skip this whole section (GVHD) and move to the next section.**

2. How would you describe the severity of your GVHD now?
   - ☐0 None
   - ☐1 Mild
   - ☐2 Moderate
   - ☐3 Severe
   - ☐4 Don't know
   - ☐5 Refuse
   - ☐4 Missing

3. Are you receiving treatment for chronic GVHD now?
   - ☐0 No
   - ☐1 Yes
   - ☐2 Don't know
   - ☐3 Refuse
   - ☐4 Missing

4. Please rate from 0 to 10 how much long-term difficulties as a result of chronic GVHD interfere with your daily life.

0	1	2	3	4	5	6	7	8	9	10
Does not interfere at all										Completely interferes with my daily life

5. Since your transplant:

   5a. How many months or years have you taken **prednisone or steroids** for GVHD (whether or not you are taking them now)?

   - ☐ 0 Not at all
   - ☐ 1 6 months or less
   - ☐ 2 7 to 12 months
   - ☐ 3 13 to 24 months (more than a year, up to 2 years)
   - ☐ 4 25 to 36 months (more than 2 years, up to 3 years)
   - ☐ 5 37 to 60 months (more than 3 years, up to 5 years)
   - ☐ 6 More than 5 years
   - ☐ 4. Don't know
   - ☐ 5. Refuse
   - ☐ 6 Missing

   5b. How many months or years have you taken oral medication **other than prednisone or other steroids** (pills or liquid such as cyclosporine, tacrolimus, MMF, etc.) for GVHD (whether or not you are taking them now)?

   - ☐ 0 Not at all
   - ☐ 1 6 months or less
   - ☐ 2 7 to 12 months
   - ☐ 3 13 to 24 months (more than a year, up to 2 years)
   - ☐ 4 25 to 36 months (more than 2 years, up to 3 years)
   - ☐ 5 37 to 60 months (more than 3 years, up to 5 years)
   - ☐ 6. More than 5 years
   - ☐ 2 Don't know
   - ☐ 3 Refuse
   - ☐ 4. Missing

Discussion of Advance Directives

1. Have you and your doctor discussed any particular wishes you have about the care you would want to receive if you were dying?

___Yes

___No

___Don't Know

___Refuse

___Missing

2. Have you and your doctor discussed completing a Do-Not-Resuscitate (DNR) order?

___Yes

___No

___Don't Know

___Refuse

___Missing

3. Have you and your doctor discussed creating a Living Will/Advance Directive?

___Yes

___No

___Don't Know

___Refuse

___Missing

4. Have you and your doctor discussed naming a Health Care Proxy or Durable Power of Attorney?

___Yes

___No

___Don't Know

___Refuse

___Missing

5. Have you and your family discussed any particular wishes you have about the care you would want to receive if you were dying?

___Yes

___No

___Don't Know

___Refuse

___Missing

6. Have you and your family discussed completing a Do-Not-Resuscitate (DNR) order?

___Yes
___No
___Don't Know
___Refuse
___Missing

7. Have you and your family discussed creating a Living Will/Advance Directive?

___Yes
___No
___Don't Know
___Refuse
___Missing

8. Have you and your family discussed naming a Health Care Proxy or Durable Power of Attorney?

___Yes
___No
___Don't Know
___Refuse
___Missing

Completion of Advance Directives (to be verbally asked, verified for inclusion in medical chart if accessible)

1. Have you completed a Do-Not-Resuscitate (DNR) order?

___Yes
___No, I want resuscitation to be attempted
___No, I am still considering whether I want one
___No, I was not aware of it
___Don't Know
___Refuse
___Missing

2. [If yes to previous question]: Was the DNR ever asked to be reversed for a procedure and/or surgery?

___Yes
___No
___Don't Know
___Refuse
___Missing

3. Have you signed a Living Will/Advance Directive?

___Yes
___No
___Don't Know
___Refuse
___Missing

4. [If yes to previous question]: Which of the following options for care did you select?

___Comfort measures only
___Limited medical interventions
___No limitations on medical interventions
___Don't Know
___Refuse
___Missing

5. Have you signed a Health Care Proxy or Durable Power of Attorney?

___Yes
___No
___Don't Know
___Refuse
___Missing

6. [If yes to previous question]: Who did you name as your Health Care Proxy?

___Caregiver
___Spouse or partner
___Sibling
___Parent
___Son or daughter
___Aunt or uncle
___Cousin
___Niece or nephew
___Grandchild
___Godparent
___Friend
___Clergy member
___Other:_____
___Don't Know
___Refuse

___Missing

7. [If patient has NOT signed a Health Care Proxy or Durable Power of Attorney]: If you were unable to make medical decisions for yourself, who would be most responsible for making them for you?

___Caregiver
___Spouse or partner
___Sibling
___Parent
___Son or daughter
___Aunt or uncle
___Cousin
___Niece or nephew
___Grandchild
___Godparent
___Friend
___Clergy member
___Other:_____
___Don't Know
___Refuse
___Missing

8. Before making an important medical decision, please indicate all of the following family members with whom you would need to discuss the decision (Check all that apply):

___Nobody
___Caregiver
___Spouse or partner
___Sibling
___Parent
___Son or daughter
___Aunt or uncle
___Cousin
___Niece or nephew
___Grandchild
___Godparent
___Friend
___Clergy member
___Other:_____
___Don't Know
___Refuse

___Missing

9. Who has access to these documents (ie, DNR, Living Will/Advance Directive, Health Care Proxy)? Indicate all.

___Nobody
___You
___Caregiver
___Spouse or partner
___Sibling
___Parent
___Son or daughter
___Aunt or uncle
___Cousin
___Niece or nephew
___Grandchild
___Godparent
___Friend
___Clergy member
___Other:_____
___Don't Know
___Refuse
___Missing

Appendix A3: Genetic codes (Dedoose)

Family health history Is Weighted: False Description

Excerpt - Document: Patient_2019_Interview.docx, Position: 13970-14196

I have to believe I did. It's been so many years and it was such a long process from diagnosis to when I went in for my transplant. I have to believe that that was probably one of the forms I filled out or was interviewed for.

Excerpt - Document: Patient_2023_Interview.docx, Position: 11611-11884

I think I was at [de-identified] or when I was first diagnosed, I was at [de-identified] and then I got transferred to [de-identified] for the transplant. So I know that they asked me about family history. I just don't remember specifically what questionnaires were asked.

Excerpt - Document: Patient_2023_Interview.docx, Position: 12015-12031

Oh, sure. Sure.

Excerpt - Document: Patient_2028_Interview.docx, Position: 11182-11228

At [de-identified] but also at [de-identified]

Completed family health history questionnaire Is Weighted: False Description

Excerpt - Document: Patient_2035_Interview_RG1122855_LTFU.docx, Position: 12757-12874

I'm sure I have. It would be there at [de-identified] but I can't specifically remember an instance where I did that.

Excerpt - Document: Patient_2035_Interview_RG1122855_LTFU.docx, Position: 12987-13148

Yes. Okay. Yeah. I remember doing something very similar to that when I first started my treatment, but that was in the hospital, not at [de-identified] itself.

Excerpt - Document: Patient_2032_Interview_COMBINED.docx, Position: 23209-23225

Yes. They have.

Excerpt - Document: Patient_2036_Interview_RG1122855_LTFU.docx, Position: 10162-10180

I believe so. Yes.

Excerpt - Document: Patient_2038_Interview_RG1122855_LTFU.docx, Position: 11480-11509

I'm pretty sure I did. Yeah.

Excerpt - Document: Patient_2037_Interview_RG1122855_LTFU.docx, Position: 16076-16092

Yes, I think so.

Did not complete family health history questionnaire Is Weighted: False Description

Excerpt - Document: Patient_2033_Interview_RG1122855_LTFU.docx, Position: 15803-15871

No. I don't think so. Not outside the usual than pets that they run.

Excerpt - Document: Patient_2034_Interview_RG1122855_LTFU.docx, Position: 15160-15244

I cannot remember. I feel like maybe, but I don't specifically remember doing that.

Family health history not available Is Weighted: False Description

Excerpt - Document: Patient_2012_Interview-2.docx, Position: 26452-26773

I can't find any record of either my mother or father's side of the family. I've heard of indirectly on my dad's side, some kind of cancer that you're talking, before I think they could identify

certain diseases and stuff, but nothing definitive and I've been told myelofibrosis that they don't know where it comes from.

Excerpt - Document: Patient_2014_Interview.docx, Position: 25942-26091
So, I don't know if I'm making sense, but here the records are there for you to go back and check, but over there nothing like that, you understand?

Excerpt - Document: Patient_2020_Interview.docx, Position: 14632-14815
Just one that I'm aware of, it would be my mother's dad, so my grandfather on my mom's side. He had some kind of cancer. I think it was in the lungs, but we're not certain about that.

History of cancer in the family Is Weighted: False Description
Excerpt - Document: Patient_2015_Interview_.docx, Position: 10490-10591
Grandparents. I had a grandmother with a breast cancer tumor and colon cancer. And I think that's it.

Excerpt - Document: Patient_2015_Interview_.docx, Position: 10729-10810
My mother's grandfather was diagnosed with leukemia, but we don't know what type.

Excerpt - Document: Patient_2015_Interview_.docx, Position: 10729-10810
My mother's grandfather was diagnosed with leukemia, but we don't know what type.

Excerpt - Document: Patient_2015_Interview_.docx, Position: 10968-11030
o my grandpa was diagnosed with prostate and then lung cancer.

Excerpt - Document: Patient_2022_Interview.docx, Position: 11521-11537
Yup. Both sides.

Excerpt - Document: Patient_2012_Interview-2.docx, Position: 26304-26336
Some, yes. My father had cancer.

Excerpt - Document: Patient_2012_Interview-2.docx, Position: 28974-29282
So, my dad had colon cancer. They detected it, they removed it, they considered it back in the old days, cured cancer. Seven years later, metastasized to his liver. That's what he died of, that's kind of there. Somebody thinks that somebody's aunt or uncle had some, they didn't call it leukemia. But maybe.

Excerpt - Document: Patient_2031_Interview.docx, Position: 17977-18134
My dad died but he was 86 when he got his prostate cancer and colon cancer. So, I don't think he'd call that history. He was elderly by then. I'm coming up.

Excerpt - Document: Patient_2019_Interview.docx, Position: 13496-13628
My grandfather had colon cancer at the very end, but he was 80 plus and he had many other issues which really is what took him down.

Excerpt - Document: Patient_2016_Interview.docx, Position: 10881-11030
It's no history, except for a current brother of mine who has a blood cancer. We're the only two in our whole extended family that have had anything.

Excerpt - Document: Patient_2025_Interview.docx, Position: 16650-16654

Yes.

Excerpt - Document: Patient_2013_Interview.docx, Position: 15215-15219
Yes.

Excerpt - Document: Patient_2035_Interview_RG1122855_LTFU.docx, Position: 12388-12456
I don't know anyone in my family who's had the same type of cancer.

Excerpt - Document: Patient_2035_Interview_RG1122855_LTFU.docx, Position: 12514-12556
Other types, certainly, but not leukemia.

Excerpt - Document: Patient_2035_Interview_RG1122855_LTFU.docx, Position: 13343-13369
My mom had breast cancer.

Excerpt - Document: Patient_2023_Interview.docx, Position: 11003-11008
Yes.

Excerpt - Document: Patient_2023_Interview.docx, Position: 11374-11410
No, I'm the first one in my family.

Excerpt - Document: Patient_2032_Interview_COMBINED.docx, Position: 22364-22491
Well, I had breast cancer myself right before COVID. But other than other kind of cancers in the family, no. I'm the only one.

Excerpt - Document: Patient_2026_Interview.docx, Position: 12260-12327
My dad had Melanoma when he was young man. But other than that, no.

Excerpt - Document: Patient_2036_Interview_RG1122855_LTFU.docx, Position: 9683-9757
No. I mean, my grandparents each had different types of cancers, but not--

Excerpt - Document: Patient_2036_Interview_RG1122855_LTFU.docx, Position: 9683-9756
No. I mean, my grandparents each had different types of cancers, but not-

Excerpt - Document: Patient_2028_Interview.docx, Position: 10811-10816
Yes.

Excerpt - Document: Patient_2021_Interview.docx, Position: 20402-20486
Yes, my dad had pancreatic cancer, which is a different cancer than my blood cancer.

Excerpt - Document: Patient_2038_Interview_RG1122855_LTFU.docx, Position: 10945-10950
Yes.

Excerpt - Document: Patient_2018_Interview.docx, Position: 6901-7159
One, I signed up for every study there was because I wanted to make sure they could find as much about this disease as they could for my kids and other family members, because it looks like it's genetic. At first they didn't think it was years ago, but now -

Excerpt - Document: Patient_2018_Interview.docx, Position: 26267-26334
Well, I have a history of this particular cancer in my family. Yes.

Excerpt - Document: Patient_2018_Interview.docx, Position: 26522-26649

They had versions of it, but when they looked at all their information, they decided it was probably similar to the same thing.

Excerpt - Document: Patient_2018_Interview.docx, Position: 27040-27204
My father had it, his brother had it, his brother's son had it, and his sister's son had it, and all four of those are deceased, and it was related to that disease.

Excerpt - Document: Patient_2018_Interview.docx, Position: 27729-27855
And one of my cousins had had it that was not that much older than me and had died. And then the fourth cousin that I had died

Excerpt - Document: Patient_2020_Interview.docx, Position: 14632-14815
Just one that I'm aware of, it would be my mother's dad, so my grandfather on my mom's side. He had some kind of cancer. I think it was in the lungs, but we're not certain about that.

Same type of cancer as patient Is Weighted: False Description
Excerpt - Document: Patient_2015_Interview_.docx, Position: 10729-10810
My mother's grandfather was diagnosed with leukemia, but we don't know what type.

Excerpt - Document: Patient_2018_Interview.docx, Position: 26522-26649
They had versions of it, but when they looked at all their information, they decided it was probably similar to the same thing.

Excerpt - Document: Patient_2018_Interview.docx, Position: 27040-27204
My father had it, his brother had it, his brother's son had it, and his sister's son had it, and all four of those are deceased, and it was related to that disease.

Biological relation to patient Is Weighted: False Description
Excerpt - Document: Patient_2015_Interview_.docx, Position: 10729-10810
My mother's grandfather was diagnosed with leukemia, but we don't know what type.

Aunt/Uncle Is Weighted: False Description
Grandparent Is Weighted: False Description
Other Is Weighted: False Description
Excerpt - Document: Patient_2015_Interview_.docx, Position: 10729-10810
My mother's grandfather was diagnosed with leukemia, but we don't know what type.

Parent Is Weighted: False Description
Sibling Is Weighted: False Description
No history of cancer in the family Is Weighted: False Description
Excerpt - Document: Patient_2033_Interview_RG1122855_LTFU.docx, Position: 15597-15600
No.

Excerpt - Document: Patient_2019_Interview.docx, Position: 13436-13438
No

Excerpt - Document: Patient_2030_Interview.docx, Position: 21315-21328
No, I don't.

Excerpt - Document: Patient_2030_Interview.docx, Position: 21315-21328
No, I don't.

Excerpt - Document: Patient_2030_Interview.docx, Position: 22120-22167
I've asked that question and the answer is no.

Excerpt - Document: Patient_2036_Interview_RG1122855_LTFU.docx, Position: 9539-9541
No

Excerpt - Document: Patient_2037_Interview_RG1122855_LTFU.docx, Position: 15891-15894
No.

Excerpt - Document: Patient_2014_Interview.docx, Position: 26230-26241
cancer, no.

Excerpt - Document: Patient_2034_Interview_RG1122855_LTFU.docx, Position: 14740-14744
No.

Genetic counseling Is Weighted: False Description
Excerpt - Document: Patient_2033_Interview_RG1122855_LTFU.docx, Position: 17418-17440
No. I don't think so.

Barriers to genetic counseling Is Weighted: False Description
Confused by genetic counseling Is Weighted: False Description
Cost Is Weighted: False Description
Doesn't want to know Is Weighted: False Description
Impact on engagement in ACP Is Weighted: False Description
Impact on treatment decisions Is Weighted: False Description
Not interested Is Weighted: False Description
Excerpt - Document: Patient_2030_Interview.docx, Position: 23761-23765
No.

Not offered Is Weighted: False Description
Excerpt - Document: Patient_2031_Interview.docx, Position: 21996-21999
No.

Excerpt - Document: Patient_2019_Interview.docx, Position: 15167-15170
No.

Excerpt - Document: Patient_2025_Interview.docx, Position: 17329-17400
No. Because I've never been given the option of having genetic testing.

Excerpt - Document: Patient_2030_Interview.docx, Position: 23295-23334
I'd say I've never really come across.

Excerpt - Document: Patient_2028_Interview.docx, Position: 12308-12312
No.

Excerpt - Document: Patient_2028_Interview.docx, Position: 12793-12862
Nope, it just wasn't necessary given the type of cancer that I have.

Other Is Weighted: False Description

Uncertain if the results would be helpful Is Weighted: False Description

Received genetic counseling Is Weighted: False Description

Excerpt - Document: Patient_2015_Interview_.docx, Position: 11274-11278
Yes.

Excerpt - Document: Patient_2021_Interview.docx, Position: 20755-20759
Yes.

Excerpt - Document: Patient_2021_Interview.docx, Position: 21416-21622
-- that were hereditary, mine were acquired. Myelofibrosis is an acquired one. It's not a hereditary gene mutation. So, yes, I have gone through extensive genetic counseling as well as some genetic testing.

Excerpt - Document: Patient_2018_Interview.docx, Position: 28545-28703
Yes. Well, I had genetic -- when we started talking to the genetic counselor, yeah. I'll let my wife tell you this. Because she's the most familiar with this.

Excerpt - Document: Patient_2014_Interview.docx, Position: 26954-27453
I had a counseling, but not a genetic test. No, I had a counseling. Yeah, initially when I was diagnosed with it I had a counseling where they try to go back and see if there was a history or maybe the sort of work that I was doing that might contribute to sort of work that I was doing that might contribute to Leukemia. I had it there was a little bit of counseling, but I don't know details about it. You know, not the way you put it. Testing, no, I don't know. Testing no, but counselling yeah.

Excerpt - Document: Patient_2020_Interview.docx, Position: 15513-15741
Yeah, I think we did along the line. And basically I think the conclusion was that you really don't. This isn't hereditary, this type of cancer that I've got. That it doesn't come from your relatives. It's from your blood chain.

Did communicate about genetic findings with relatives Is Weighted: False Description

Excerpt - Document: Patient_2015_Interview_.docx, Position: 11501-11847
It changed how I told my family members because they we're worried about themselves as well. And so that put their mind at ease that genetically so far we haven't found anything that's tying to. And then relieving their stress as well of what other cancers am I prone to, which thankfully was not anything. So, yeah, I guess I answered that all.

Excerpt - Document: Patient_2018_Interview.docx, Position: 27857-28061
I had the genetic testing and was talking to all the family members, even him and others, saying, you need to get tested now. Well, he was tested and he found out he had it. And he was younger than I was.

Excerpt - Document: Patient_2014_Interview.docx, Position: 27692-28744
Yeah, I did, because I have an auntie here she's probably like 79. So, I kind of try to dig as much information I can get from her in the sense, you know, try to a lot of information I was able to obtain then I try as much as possible to see information that I can get in relation to what I'm going

through. And so, I kind of share that too with my wife and my boy. Yeah, the little information that I had it wasn't what I was looking for. It wasn't what I was looking for, because I didn't get much there, you understand? So, I based whatever I have to share with my family with my experience, you understand? My experience. So, you're trying to make sure this is not genetic something where your kids might end up having, you know? Try as much as possible to ask questions when you meet those caregivers or people that are taking care of you to make sure this is no genetic or something like, because my son has to be the donor. My son was the donor. So, you try as much as possible to see is this genetic or is this something that I pick up at work?

Did not communicate genetic findings with relatives Is Weighted: False Description

Use of genetic counseling information Is Weighted: False Description

Excerpt - Document: Patient_2018_Interview.docx, Position: 28545-28703

Yes. Well, I had genetic -- when we started talking to the genetic counselor, yeah. I'll let my wife tell you this. Because she's the most familiar with this.

Excerpt - Document: Patient_2018_Interview.docx, Position: 30054-30609

Well, I mean, I just shared with all of my kids. It seems to be prevalent in the men, but some people think that a few of the women have it also. We haven't had a woman that's been diagnosed with it. But some felt that my aunt had it also and that. So I've shared that any of those that are in the family, particularly the male and start to approach, that they start getting complete blood counts and watch their blood and everything for this early in their lives and just pay attention to it just so that if there's any changes, they can be on top of it.

Recommended genetic testing for relatives Is Weighted: False Description

Genetic testing Is Weighted: False Description

Excerpt - Document: Patient_2033_Interview_RG1122855_LTFU.docx, Position: 17137-17175

t would have been with my oncologist.

Barriers to genetic testing Is Weighted: False Description

Confused by genetic testing Is Weighted: False Description

Excerpt - Document: Patient_2022_Interview.docx, Position: 12062-12097

I don't know, but I don't think so.

Cost Is Weighted: False Description

Doesn't want to know Is Weighted: False Description

Impact on engagement in ACP Is Weighted: False Description

Excerpt - Document: Patient_2023_Interview.docx, Position: 13996-14000

No.

Impact on treatment decisions Is Weighted: False Description

Not interested Is Weighted: False Description

Not offered Is Weighted: False Description

Excerpt - Document: Patient_2019_Interview.docx, Position: 14748-15025

I don't remember that ever being brought up. I know they did genetic testing to determine the specific type of MDS I had possibly. I know there's multiple variations of it, but no, as far as genetically linked to my family or anything, I don't believe that was ever brought up.

Excerpt - Document: Patient_2019_Interview.docx, Position: 15334-15334

Excerpt - Document: Patient_2023_Interview.docx, Position: 12792-12891
Not about the leukemia, to my knowledge, to my memory, they didn't talk to me about familial risk.

Excerpt - Document: Patient_2023_Interview.docx, Position: 13076-13103
Not after the leukemia, no.

Excerpt - Document: Patient_2023_Interview.docx, Position: 13302-13442
I don't think so. hat does not sound familiar to me. I certainly had genetic markers for risk, I should say for prognosis with my leukemia.

Excerpt - Document: Patient_2026_Interview.docx, Position: 12799-12933
I don't think that was offered to me really. When the first two times I diagnosed I was a kid. So, yeah, those weren't really offered.

Other Is Weighted: False Description

Uncertain if the results would be helpful Is Weighted: False Description

Did not receive genetic testing Is Weighted: False Description

Excerpt - Document: Patient_2031_Interview.docx, Position: 21333-21461
No, nobody suggested that this came from anything but well, you have to go back to the original issue with [inaudible] in 1980.

Excerpt - Document: Patient_2031_Interview.docx, Position: 21752-21811
No. Nobody suggested that my cancer is genetic in any way.

Excerpt - Document: Patient_2031_Interview.docx, Position: 22710-22781
I have not. And should it be inherited cancer risk after my diagnosis?

Excerpt - Document: Patient_2016_Interview.docx, Position: 11310-11465
I don't think so, not genetic wise. I've done like an ancestry type thing, but not like the 23andMe health or something through the hospital or anything. ,

Excerpt - Document: Patient_2025_Interview.docx, Position: 16973-16976
No.

Excerpt - Document: Patient_2025_Interview.docx, Position: 16973-16976
No.

Excerpt - Document: Patient_2025_Interview.docx, Position: 17139-17139

Excerpt - Document: Patient_2035_Interview_RG1122855_LTFU.docx, Position: 13650-13699
No. My impression was that it was not inherited.

Excerpt - Document: Patient_2035_Interview_RG1122855_LTFU.docx, Position: 14935-14972
No, I don't believe we've done that.

Excerpt - Document: Patient_2030_Interview.docx, Position: 22309-22313
No.

Excerpt - Document: Patient_2030_Interview.docx, Position: 22626-22630
No.

Excerpt - Document: Patient_2032_Interview_COMBINED.docx, Position: 24125-24192
We have discussed that and we determined that it's not hereditary.

Excerpt - Document: Patient_2032_Interview_COMBINED.docx, Position: 25288-25330
No, because they knew this wasn't genetic.

Excerpt - Document: Patient_2026_Interview.docx, Position: 12636-12659
Not that I know of. No.

Excerpt - Document: Patient_2028_Interview.docx, Position: 12627-12631
No.

Excerpt - Document: Patient_2038_Interview_RG1122855_LTFU.docx, Position: 12145-12163
I don't think so.

Excerpt - Document: Patient_2037_Interview_RG1122855_LTFU.docx, Position: 16961-17123
I'm trying to remember. I don't think so because I don't have any history of it in my family. I think we were all just like, "What the hell? How did this happen?"

Excerpt - Document: Patient_2034_Interview_RG1122855_LTFU.docx, Position: 15533-15759
I don't know if it's from others. Actually, just last week, a doctor told my wife and I that it would not have been inherited or I would not have inherited it from anybody in my family. That's what you're talking about, right?

Excerpt - Document: Patient_2034_Interview_RG1122855_LTFU.docx, Position: 16371-16375
No.

Received genetic testing Is Weighted: False Description
Excerpt - Document: Patient_2015_Interview_.docx, Position: 11274-11278
Yes.

Excerpt - Document: Patient_2015_Interview_.docx, Position: 12095-12154
It didn't. It was offered and I thought it was a good idea.

Excerpt - Document: Patient_2033_Interview_RG1122855_LTFU.docx, Position: 16596-16676
Yes. I do think that was discussed, and I think I've actually had the test done.

Excerpt - Document: Patient_2033_Interview_RG1122855_LTFU.docx, Position: 17718-17740
I think I might have.

Excerpt - Document: Patient_2021_Interview.docx, Position: 20755-20759
Yes.

Excerpt - Document: Patient_2021_Interview.docx, Position: 21416-21622

-- that were hereditary, mine were acquired. Myelofibrosis is an acquired one. It's not a hereditary gene mutation. So, yes, I have gone through extensive genetic counseling as well as some genetic testing.

Excerpt - Document: Patient_2018_Interview.docx, Position: 28545-28703

Yes. Well, I had genetic -- when we started talking to the genetic counselor, yeah. I'll let my wife tell you this. Because she's the most familiar with this.

Excerpt - Document: Patient_2018_Interview.docx, Position: 31255-31673

Well, I think that the genetic testing just confirmed -- well, having it confirmed it, but I mean it just tells you that you're susceptible and the other family members to understand. You're susceptible to this, because it seems genetically to be a part of our makeup, DNA. And you need to be aware of that and so that, and who knows, because of this genetic testing and other things, it may lead to some sort of cure.

Excerpt - Document: Patient_2020_Interview.docx, Position: 15889-15913

Yeah, I must have. Yeah.

Excerpt - Document: Patient_2020_Interview.docx, Position: 16550-16946

Well, I guess it told me that I didn't have any relatives. I only have one brother that was younger than me, but they considered him too old. He was 65 I think. Well, that ruled that out there trying to do that first. And then they went to a non-donor instead and got a 10 for 10 match over in Germany. So, I think that's how the genetic testing helped us get matched in with that guy in Germany.

Did communicate genetic results with relatives Is Weighted: False Description

Excerpt - Document: Patient_2021_Interview.docx, Position: 20927-21346

Yes, it did because the particular genetic issues that I have were not hereditary, but I still want my siblings to know about it. But at the same time, my brother was diagnosed with a lung disease which is hereditary. So I underwent additional testing because each of my siblings was tested to see if they would be a match for the stem cell. The brother, that was a perfect match, found out he had some genetic issues.

Excerpt - Document: Patient_2018_Interview.docx, Position: 30054-30609

Well, I mean, I just shared with all of my kids. It seems to be prevalent in the men, but some people think that a few of the women have it also. We haven't had a woman that's been diagnosed with it. But some felt that my aunt had it also and that. So I've shared that any of those that are in the family, particularly the male and start to approach, that they start getting complete blood counts and watch their blood and everything for this early in their lives and just pay attention to it just so that if there's any changes, they can be on top of it.

Excerpt - Document: Patient_2018_Interview.docx, Position: 30904-31055

Yeah, we talked to them all and I've shared the information and that these tests and that these are the things that you can do at a young age, you know

Did not communicate genetic results with relatives Is Weighted: False Description

Impact on engagement in ACP Is Weighted: False Description

Excerpt - Document: Patient_2034_Interview_RG1122855_LTFU.docx, Position: 16607-16611

No.

Impact on treatment decisions

Is Weighted: False Description

Excerpt - Document: Patient_2021_Interview.docx, Position: 20927-21346

Yes, it did because the particular genetic issues that I have were not hereditary, but I still want my siblings to know about it. But at the same time, my brother was diagnosed with a lung disease which is hereditary. So I underwent additional testing because each of my siblings was tested to see if they would be a match for the stem cell. The brother, that was a perfect match, found out he had some genetic issues.

Excerpt - Document: Patient_2018_Interview.docx, Position: 31255-31673

Well, I think that the genetic testing just confirmed -- well, having it confirmed it, but I mean it just tells you that you're susceptible and the other family members to understand. You're susceptible to this, because it seems genetically to be a part of our makeup, DNA. And you need to be aware of that and so that, and who knows, because of this genetic testing and other things, it may lead to some sort of cure.

Excerpt - Document: Patient_2020_Interview.docx, Position: 16550-16946

Well, I guess it told me that I didn't have any relatives. I only have one brother that was younger than me, but they considered him too old. He was 65 I think. Well, that ruled that out there trying to do that first. And then they went to a non-donor instead and got a 10 for 10 match over in Germany. So, I think that's how the genetic testing helped us get matched in with that guy in Germany.

Use of genetic testing results

Is Weighted: False Description

Excerpt - Document: Patient_2033_Interview_RG1122855_LTFU.docx, Position: 16773-16886

I think they might have run it after the fact, and he's like, let's see if this is genetic or not. I don't know.

Excerpt - Document: Patient_2033_Interview_RG1122855_LTFU.docx, Position: 17915-17955

No. I don't think I used it in any way.

Excerpt - Document: Patient_2021_Interview.docx, Position: 20927-21346

Yes, it did because the particular genetic issues that I have were not hereditary, but I still want my siblings to know about it. But at the same time, my brother was diagnosed with a lung disease which is hereditary. So I underwent additional testing because each of my siblings was tested to see if they would be a match for the stem cell. The brother, that was a perfect match, found out he had some genetic issues.

Excerpt - Document: Patient_2018_Interview.docx, Position: 27469-27666

Well, what happened was, even before I found out I had it, after my father died in that, and I learned I wanted to find out what I needed to do to watch for this, because I knew my father and uncle

Excerpt - Document: Patient_2018_Interview.docx, Position: 28545-28703

Yes. Well, I had genetic -- when we started talking to the genetic counselor, yeah. I'll let my wife tell you this. Because she's the most familiar with this.

Excerpt - Document: Patient_2014_Interview.docx, Position: 29417-29652

I don't have anything to prove that that's what caused the Leukemia. So, you try as much as possible to learn what you have to learn and live with it. Try to see how best you can guide your loved ones or your immediate family members.

Appendix A4: Survey results

LTFU Aim 1 Tables and Figures

Table 1: **Sociodemographic data** from patients enrolled in LTFU Aim 1. Data is from all patients (N=31) who completed their interview.

Demographics	**Patients (N = 31)**	
Age (years)	**Mean (SD)**	52.4 (17.29)
	N (%)	
Age (categorical)		
18-40 years	10 (32.3%)	
41-64 years	10 (32.3%)	
65+ years	11 (35.4%)	
Sex Assigned at Birth		
Male	17 (54.8%)	
Female	14 (45.2%)	
Hispanic/Latino		
Yes	3 (9.7%)	
No	28 (90.3%)	
Race		
White or Caucasian	28 (90.3%)	
Black or African American	1 (3.2%)	
Asian	0 (0.0%)	
American Indian or Alaskan Native	0 (0.0%)	
Native Hawaiian or Other Pacific Islander	0 (0.0%)	
Multi-Racial	0 (0.0%)	
Other (Hispanic or Latino)	2 (6.5%)	
Other	0 (0.0%)	
Don't know/decline to answer	0 (0.0%)	
Relationship Status		
Married/partnered	22 (71.0%)	
Not married/partnered	9 (29.0%)	
Number of Children		
0	12 (38.7%)	
1-2	11 (35.5%)	
3+	8 (25.8%)	
Employment Status		
Employed, full time	13 (41.9%)	
Employed, part time	2 (6.5%)	
Not employed, retired	15 (48.4%)	
Not employed, not retired	1 (3.2%)	
Highest Education Level Completed		
Graduated high school or equivalent	3 (9.7%)	
Some college	6 (19.4%)	
Graduated college	12 (38.7%)	
Some postgraduate/professional courses	1 (3.2%)	
Completed post-graduate/professional degree	8 (25.8%)	
Completed trade/technical/vocational school	1 (3.2%)	
Total Household Income (Annual)		
Less than $21,000	0 (0.0%)	

$21,000 - $39,999	1 (3.2%)
$40,000 - $65,999	5 (16.1%)
$66,000 - $105,999	8 (25.8%)
$106,000 or more	16 (51.6%)
Don't know/decline to answer	1 (3.2%)
Health Insurance Status	
Insured	30 (96.8%)
Not insured	1 (3.2%)
Primary Method of Medical Treatment	
Medicaid	5 (16.1%)
Medicare	10 (32.3%)
Private health insurance	15 (48.4%)
Other Government funded/subsidized coverage (i.e., military coverage, Affordable Care Act coverage)	1 (3.2%)
Clinical Characteristics	**Patients (N = 31)**
Diagnosis at first transplant	
AML (acute myeloid leukemia)	10 (32.3%)
ALL (acute lymphocytic leukemia)	5 (16.1%)
CML (chronic myelogenous leukemia)	1 (3.2%)
NHL (non-Hodgkin lymphoma)	0 (0.0%)
HD (Hodgkin disease)	0 (0.0%)
MDS (Myelodysplasia or myelofibrosis)	9 (29.0%)
Multiple myeloma	2 (6.5%)
Other	4 (12.9%)
Number of bone marrow/stem cell transplants	
1	28 (90.3%)
2	3 (9.7%)
Have you ever had an allogeneic transplant (stem cells from a relative or unrelated donor)?	
Yes	29 (93.5%)
No	2 (6.5%)
Have you ever had a total body irradiation (TBI) as part of your transplant?	
Yes	18 (58.1%)
No	12 (38.7%)
Don't know/decline to answer	1 (3.2%)
Have you ever had 'local' radiation therapy to your chest or head or pelvic area in addition to any treatment you had for your transplant? Indicate all:*	
No, I never had local radiation therapy to my chest, head or pelvic area	24 (77.4%)
Yes, I had local radiation therapy to my chest	4 (12.9%)
Yes, I had local radiation therapy to my head or neck	2 (6.5%)
Yes, I had local radiation therapy to my pelvic area	1 (3.2%)
Don't know/decline to answer	2 (6.5%)
Have you ever had chemotherapy using an 'anthracycline' or mitoxantrone (Novantrone, DHAD, or DHAQ)?	
Yes	15 (48.4%)
No	8 (25.8%)
Don't know/decline to answer	8 (25.8%)

Some variable percentages may not equal 100% due to rounding. *Indicates questions that allowed for more than one answer, column percentage may exceed 100%

Table 2: **Graft-vs.-Host Disease Data** from patients enrolled in LTFU Aim 1. Data for first question is from all patients (N=31) who completed their interview. Remaining questions are from all patients (N=27) who reported having GVHD.

	Patients (N = 31)
Since your transplant, how would you describe the severity of your chronic graft-versus-host disease (GVHD) when it was at its worst?	
Never had any GVHD	4 (12.9%)
Mild	13 (41.9%)
Moderate	9 (29.0%)
Severe	5 (16.1%)
	Patients with GVHD (N = 27)
How would you describe the severity of your GVHD now?	
None	8 (29.6%)
Mild	14 (51.9%)
Moderate	5 (18.5%)
Severe	0 (0.0%)
Are you receiving treatment for chronic GVHD now?	
Yes	19 (70.4%)
No	8 (29.6%)
Please rate how much long-term difficulties as a result of chronic GVHD interfere with your daily life. 0 (does not interfere at all) - 10 (completely interferes with my daily life)	
Range	0-8
Mean (SD)	2.6 (2.24)
Since your transplant...	
How many months or years have you taken Prednisone or steroids for GVHD (whether or not you are taking them now)?	
Not at all	2 (7.4%)
6 months or less	8 (29.6%)
7 to 12 months	6 (22.2%)
13 to 24 months (more than a year, up to 2 years)	6 (22.2%)
25 to 36 months (more than 2 years, up to 3 years)	3 (11.1%)
37 to 60 months (more than 3 years, up to 5 years)	2 (7.4%)
More than 5 years	0 (0.0%)
How many months or years have you taken oral medication other than prednisone or other steroids (pills or liquid such as cyclosporine, tacrolimus, MMF, etc.) for GVHD (whether or not you are taking them now)?	
Not at all	6 (22.2%)
6 months or less	5 (18.5%)
7 to 12 months	2 (7.4%)
13 to 24 months (more than a year, up to 2 years)	7 (25.9%)
25 to 36 months (more than 2 years, up to 3 years)	2 (7.4%)
37 to 60 months (more than 3 years, up to 5 years)	5 (18.5%)
More than 5 years	0 (0.0%)

Some variable percentages may not equal 100% due to rounding.

Table 3: **Advance Directive Discussion Data** from patients enrolled in LTFU Aim 1. Data is from all patients (N=31) who completed their interview.

	Patients (N = 31)
Have you and your doctor discussed any particular wishes you have about the care you would want to receive if you were dying?	
Yes	16 (51.6%)
No	15 (48.4%)
Have you and your doctor discussed completing a Do-Not-Resuscitate (DNR) order?	
Yes	13 (41.9%)
No	18 (58.1%)
Have you and your doctor discussed creating a Living Will/Advance Directive?	
Yes	18 (58.1%)
No	13 (41.9%)
Have you and your doctor discussed naming a Health Care Proxy or Durable Power of Attorney?	
Yes	20 (64.5%)
No	11 (35.5%)
Have you and your family discussed any particular wishes you have about the care you would want to receive if you were dying?	
Yes	25 (80.6%)
No	6 (19.4%)
Have you and your family discussed completing a Do-Not-Resuscitate (DNR) order?	
Yes	20 (64.5%)
No	11 (35.5%)
Have you and your family discussed creating a Living Will/Advance Directive?	
Yes	25 (80.6%)
No	6 (19.4%)
Have you and your family discussed naming a Health Care Proxy or Durable Power of Attorney?	
Yes	26 (83.9%)
No	5 (16.1%)

Some variable percentages may not equal 100% due to rounding.

Table 4: **Advance Directive Completion Data** from patients enrolled in LTFU Aim 1. Data is from all patients (N=31) who completed their interview, unless otherwise noted.

	Patients (N = 31)
Have you completed a Do-Not-Resuscitate (DNR) order?	
Yes	10 (32.3%)
No, I want resuscitation to be attempted	9 (29.0%)
No, I am still considering whether I want one	11 (35.5%)
No, I was not aware of it	1 (3.2%)
Was the DNR ever asked to be reversed for a procedure and/or surgery? (N = 10 patients who completed DNR)	
Yes	0 (0.0%)
No	9 (90.0%)
Don't know/decline to answer	1 (10.0%)
Have you signed a Living Will/Advance Directive?	
Yes	19 (61.3%)
No	12 (38.7%)
Which of the following options for care did you select? (N = 19 patients who completed Living Will/Advance Directive)	
Comfort measures only	3 (15.8%)
Limited medical interventions	5 (26.3%)
No limitations on medical interventions	10 (52.6%)
Don't know/decline to answer	1 (5.3%)
Have you signed a Health Care Proxy or Durable Power of Attorney?	
Yes	22 (70.9%)
No	9 (29.0%)
Who did you name as your Health Care Proxy? (N = 22 patients who signed Health Care Proxy or Durable Power of Attorney)	
Caregiver	1 (4.5%)
Spouse or partner	17 (77.3%)
Sibling	1 (4.5%)
Parent	2 (9.1%)
Son or daughter	1 (4.5%)
Aunt or uncle	0 (0.0%)
Cousin	0 (0.0%)
Niece or nephew	0 (0.0%)
Grandchild	0 (0.0%)
Godparent	0 (0.0%)
Friend	0 (0.0%)
Clergy member	0 (0.0%)
Other	0 (0.0%)
If you were unable to make medical decisions for yourself, who would be most responsible for making them for you? (N = 9 patients who did not sign Health Care Proxy or Durable Power of Attorney)	
Caregiver	0 (0.0%)
Spouse or partner	5 (55.6%)
Sibling	1 (11.1%)
Parent	3 (33.3%)
Son or daughter	0 (0.0%)
Aunt or uncle	0 (0.0%)
Cousin	0 (0.0%)
Niece or nephew	0 (0.0%)

Grandchild	0 (0.0%)
Godparent	0 (0.0%)
Friend	0 (0.0%)
Clergy member	0 (0.0%)
Other	0 (0.0%)
Before making an important medical decision, please indicate all of the following family members with whom you would need to discuss the decision:*	
Nobody	1 (3.2%)
Caregiver	6 (19.4%)
Spouse or partner	22 (71.0%)
Sibling	7 (22.6%)
Parent	8 (25.8%)
Son or daughter	12 (38.7%)
Aunt or uncle	1 (3.2%)
Cousin	0 (0.0%)
Niece or nephew	0 (0.0%)
Grandchild	0 (0.0%)
Godparent	0 (0.0%)
Friend	0 (0.0%)
Clergy member	0 (0.0%)
Other	1 (3.2%)
Who has access to these documents (i.e. DNR, Living Will, Health Care Proxy)? Indicate all:*	
Nobody	2 (6.5%)
Caregiver	6 (19.4%)
Spouse or partner	21 (67.7%)
Sibling	2 (6.5%)
Parent	4 (12.9%)
Son or daughter	11 (35.5%)
Aunt or uncle	1 (3.2%)
Cousin	0 (0.0%)
Niece or nephew	0 (0.0%)
Grandchild	0 (0.0%)
Godparent	0 (0.0%)
Friend	0 (0.0%)
Clergy member	0 (0.0%)
Other	2 (6.5%)
Don't know/decline to answer	1 (3.2%)

Some variable percentages may not equal 100% due to rounding. *Indicates questions that allowed for more than one answer, column percentage may exceed 100%

Table 5: **Sociodemographic data** from patients enrolled in LTFU Aim 1. Data is from all patients (N=23) who completed the genetics questions as part of their qualitative interview.

Demographics	**Patients (N = 23)**	
Age (years)	**Mean (SD)**	54.2 (17.17)
	N (%)	
Age (categorical)		
18-40 years	8 (34.8%)	
41-64 years	5 (21.7%)	
65+ years	10 (43.5%)	
Sex Assigned at Birth		
Male	12 (52.2%)	
Female	11 (47.8%)	
Hispanic/Latino		
Yes	1 (4.3%)	
No	22 (95.7%)	
Race		
White or Caucasian	22 (95.7%)	
Black or African American	1 (4.3%)	
Asian	0 (0.0%)	
American Indian or Alaskan Native	0 (0.0%)	
Native Hawaiian or Other Pacific Islander	0 (0.0%)	
Multi-Racial	0 (0.0%)	
Other (Hispanic or Latino)	0 (0.0%)	
Other	0 (0.0%)	
Don't know/decline to answer	0 (0.0%)	
Relationship Status		
Married/partnered	16 (69.6%)	
Not married/partnered	7 (30.4%)	
Number of Children		
0	9 (39.1%)	
1-2	8 (34.8%)	
3+	6 (26.1%)	
Employment Status		
Employed, full time	8 (34.8%)	
Employed, part time	2 (8.7%)	
Not employed, retired	12 (52.2%)	
Not employed, not retired	1 (4.3%)	
Highest Education Level Completed		
Graduated high school or equivalent	3 (13.0%)	
Some college	4 (17.4%)	
Graduated college	8 (34.8%)	
Some post-graduate/professional courses	1 (4.3%)	
Completed post-graduate/professional degree	6 (26.1%)	
Completed trade/technical/vocational school	1 (4.3%)	
Total Household Income (Annual)		
Less than $21,000	0 (0.0%)	

$21,000 - $39,999	1 (4.3%)
$40,000 - $65,999	4 (17.4%)
$66,000 - $105,999	6 (26.1%)
$106,000 or more	12 (52.2%)
Health Insurance Status	
Insured	22 (95.7%)
Not insured	1 (4.3%)
Primary Method of Medical Treatment	
Medicaid	3 (13.0%)
Medicare	9 (39.1%)
Private health insurance	10 (43.5%)
Other Government funded/subsidized coverage (i.e., military coverage, Affordable Care Act coverage)	1 (4.3%)
Clinical Characteristics	**Patients (N = 23)**
Diagnosis at first transplant	
AML (acute myeloid leukemia)	9 (39.1%)
ALL (acute lymphocytic leukemia)	3 (13.0%)
CML (chronic myelogenous leukemia)	0 (0.0%)
NHL (non-Hodgkin lymphoma)	0 (0.0%)
HD (Hodgkin disease)	0 (0.0%)
MDS (Myelodysplasia or myelofibrosis)	7 (30.4%)
Multiple myeloma	1 (4.3%)
Other	3 (13.0%)
Number of bone marrow/stem cell transplants	
1	21 (91.3%)
2	2 (8.7%)
Have you ever had an allogeneic transplant (stem cells from a relative or unrelated donor)?	
Yes	22 (95.7%)
No	1 (4.3%)
Have you ever had a total body irradiation (TBI) as part of your transplant?	
Yes	13 (56.5%)
No	10 (43.5%)
Have you ever had 'local' radiation therapy to your chest or head or pelvic area in addition to any treatment you had for your transplant? Indicate all:*	
No, I never had local radiation therapy to my chest, head or pelvic area	18 (78.3%)
Yes, I had local radiation therapy to my chest	3 (13.0%)
Yes, I had local radiation therapy to my head or neck	1 (4.3%)
Yes, I had local radiation therapy to my pelvic area	1 (4.3%)
Don't know/decline to answer	1 (4.3%)
Have you ever had chemotherapy using an 'anthracycline' or mitoxantrone (Novantrone, DHAD, or DHAQ)?	
Yes	10 (43.5%)
No	7 (30.4%)
Don't know/decline to answer	6 (26.1%)

Some variable percentages may not equal 100% due to rounding. *Indicates questions that allowed for more than one answer, column percentage may exceed 100%

Table 6: **Sociodemographic data** from patients enrolled in LTFU Aim 1. Data is from all patients (N=10) who completed the **updated** genetics questions as part of their qualitative interview.

Demographics	**Patients (N = 10)**	
Age (years)	**Mean (SD)**	48.4 (17.06)
	N (%)	
Age (categorical)		
18-40 years	6 (60.0%)	
41-64 years	1 (10.0%)	
65+ years	3 (30.0%)	
Sex Assigned at Birth		
Male	4 (40.0%)	
Female	6 (60.0%)	
Hispanic/Latino		
Yes	0 (0.0%)	
No	10 (100.0%)	
Race		
White or Caucasian	10 (100.0%)	
Black or African American	0 (0.0%)	
Asian	0 (0.0%)	
American Indian or Alaskan Native	0 (0.0%)	
Native Hawaiian or Other Pacific Islander	0 (0.0%)	
Multi-Racial	0 (0.0%)	
Other (Hispanic or Latino)	0 (0.0%)	
Other	0 (0.0%)	
Don't know/decline to answer	0 (0.0%)	
Relationship Status		
Married/partnered	5 (50.0%)	
Not married/partnered	5 (50.0%)	
Number of Children		
0	4 (40.0%)	
1-2	4 (40.0%)	
3+	2 (20.0%)	
Employment Status		
Employed, full time	7 (70.0%)	
Employed, part time	0 (0.0%)	
Not employed, retired	2 (20.0%)	
Not employed, not retired	1 (10.0%)	
Highest Education Level Completed		
Graduated high school or equivalent	2 (20.0%)	
Some college	2 (20.0%)	
Graduated college	3 (30.0%)	
Some post-graduate/professional courses	0 (0.0%)	
Completed post-graduate/professional degree	3 (30.0%)	
Completed trade/technical/vocational school	0 (0.0%)	
Total Household Income (Annual)		
Less than $21,000	0 (0.0%)	
$21,000 - $39,999	1 (10.0%)	
$40,000 - $65,999	3 (30.0%)	

$66,000 - $105,999	1 (10.0%)
$106,000 or more	5 (50.0%)
Health Insurance Status	
Insured	9 (90.0%)
Not insured	1 (10.0%)
Primary Method of Medical Treatment	
Medicaid	2 (20.0%)
Medicare	3 (30.0%)
Private health insurance	5 (50.0%)
Other Government funded/subsidized coverage (i.e., military coverage, Affordable Care Act coverage)	0 (0.0%)
Clinical Characteristics	**Patients (N = 10)**
Diagnosis at first transplant	
AML (acute myeloid leukemia)	4 (40.0%)
ALL (acute lymphocytic leukemia)	2 (20.0%)
CML (chronic myelogenous leukemia)	0 (0.0%)
NHL (non-Hodgkin lymphoma)	0 (0.0%)
HD (Hodgkin disease)	0 (0.0%)
MDS (Myelodysplasia or myelofibrosis)	3 (30.0%)
Multiple myeloma	1 (10.0%)
Other	0 (0.0%)
Number of bone marrow/stem cell transplants	
1	8 (80.0%)
2	2 (20.0%)
Have you ever had an allogeneic transplant (stem cells from a relative or unrelated donor)?	
Yes	10 (100.0%)
No	0 (0.0%)
Have you ever had a total body irradiation (TBI) as part of your transplant?	
Yes	6 (60.0%)
No	4 (40.0%)
Have you ever had 'local' radiation therapy to your chest or head or pelvic area in addition to any treatment you had for your transplant? Indicate all:*	
No, I never had local radiation therapy to my chest, head or pelvic area	9 (90.0%)
Yes, I had local radiation therapy to my chest	1 (10.0%)
Yes, I had local radiation therapy to my head or neck	0 (0.0%)
Yes, I had local radiation therapy to my pelvic area	0 (0.0%)
Don't know/decline to answer	0 (0.0%)
Have you ever had chemotherapy using an 'anthracycline' or mitoxantrone (Novantrone, DHAD, or DHAQ)?	
Yes	5 (50.0%)
No	3 (30.0%)
Don't know/decline to answer	2 (20.0%)

Some variable percentages may not equal 100% due to rounding. *Indicates questions that allowed for more than one answer, column percentage may exceed 100%