Published in final edited form as:

Genet Med. 2017 September ; 19(9): 1064–1070. doi:10.1038/gim.2017.8.

The Psychosocial Effects of the Li-Fraumeni Education and Early Detection (LEAD) Program on Individuals with Li-Fraumeni Syndrome

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Abstract

Purpose—In the past five years new screening protocols have been developed that provide improved cancer screening options for individuals with Li-Fraumeni Syndrome. Very little has been published on the psychosocial impact of these screening protocols. The goals of this study were to determine how participation in screening impacts individuals psychosocially, to examine the benefits and drawbacks of screening, and to evaluate possible barriers to continued screening.

Methods—We performed a qualitative study consisting of semi-structured phone interviews conducted from December 2015-February 2016 with 20 individuals attending the LFS screening program at M.D. Anderson Cancer Center.

Results—Data analysis showed that benefits of screening include early detection, peace of mind, centralized screening, knowledge providing power, and screening making LFS seem more livable. Perceived drawbacks included logistical issues, difficulty navigating the system, screening being draining, and significant negative emotional reactions such as anxiety, fear, and skepticism. Regardless of the emotions that were present, 100% of participants plan on continuing screening in the program.

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Conflicts of Interest: The authors declare no conflict of interest

Supplementary information is available at the *Genetics in Medicine* Website.

Conclusion—Our data indicates that the perceived benefits of screening outweigh the drawbacks of screening. Individuals in this screening program appear to have improved psychosocial well-being because of their access to the screening program.

Keywords

Li-Fraumeni Syndrome; LEAD program; comprehensive screening; psychosocial effects; screening barriers

INTRODUCTION

Li-Fraumeni Syndrome (LFS) is a rare hereditary cancer predisposition syndrome that is caused by mutations in the *TP53* gene.^{1,2} Classically, this cancer syndrome has been associated with sarcomas, pre-menopausal breast cancer, brain cancer, adrenocortical carcinomas, and leukemia.² However, in recent years, more cancer types have been found to be associated with LFS, including colon, pancreatic, stomach, kidney, endometrial, ovarian, prostate, lung, and skin cancers.³ Overall, by the age of 31, there is a 50% risk of developing cancer with this risk nearing 100% by the age of 70.⁴ Close to 50% of individuals that have one cancer diagnosis will develop another cancer within 10 years.⁴ Moreover, young children may also be affected by cancers.⁵

The risk and occurrence of these multiple cancers creates not only a large physical burden but also a psychosocial burden. For individuals going through the genetic testing process for LFS, 23% had clinically relevant distress.⁷ Such distress has been attributed to higher levels of cancer worry and greater perceived risks.⁸ In addition, because 80-93% of individuals with LFS inherit it^{9,10}, the prevalent cancer history in the family can also lead to an increase in overall distress.⁸ Individuals with multiple cancers in their family due to LFS have been found to be “psychologically fragile” and they fear passing on “doom and death” to their children.¹¹ It has also been reported that individuals with LFS feel that their diagnosis is always on their mind and their anxiety and distress can increase dramatically during a personal or family medical crisis.¹²

To address the large concern for these cancer risks, an important step is to take part in a cancer screening program. The available screening methods for LFS patients dramatically changed in 2011 when a study performed by Villani et al. (2011) showed significant survival benefits for individuals following a new comprehensive screening protocol that combines ultrasound, urinalysis, blood tests, breast mammograms, colonoscopies, annual brain MRIs, and rapid whole body MRIs (WB-MRI).¹³ Under this screening regimen, cancers were detected early in asymptomatic individuals, and after 5 years the survival rate of the screening group was 88.8%. Conversely, individuals that chose not to undergo screening had a 5 year survival rate of 59.6%.^{13, 14} In order to provide support for using WB-MRI's on children with LFS, a study using WB-MRI on children with hereditary cancer syndromes found a sensitivity of 100% for detecting cancers.¹⁵ These studies have allowed for new screening modalities to be offered to individuals with LFS. Before Villani et al.'s¹³ study was published, guidelines produced by groups such as The National Comprehensive Cancer Network (NCCN), only provided LFS patients with specific screening recommendations for

breast cancer and colon cancer.¹⁶ However, with the new findings, the 2015 and 2016 NCCN guidelines adopted additional recommendations, including WB-MRI.^{17, 18} The expansion of these guidelines may potentially improve the clinical picture and prognosis of LFS.

Based on the significant survival benefit demonstrated by Villani et al.¹³, in 2013, MD Anderson Cancer Center initiated a similar screening program through their Cancer Prevention Center, called the Li-Fraumeni Education and Early Detection (LEAD) program. The goal of this program is to provide screening and education to individuals with LFS in an effort to improve their survival and medical management. For specific screening guidelines offered by the LEAD program, please refer to the Supplementary Materials.

Although the main goal of the LEAD program is to increase survival in patients with LFS, the psychosocial impact of undergoing this novel comprehensive screening is largely unknown. Previous research on screening for LFS, prior to the introduction of comprehensive screening, showed that individuals felt screening provided early detection and a sense of control and security.¹⁹ In contrast, there has been one case study showing that an individual in a comprehensive screening program reported “exhaustion” with the amount of screening and number of cancer diagnoses she received.²⁰ At this time, no other psychosocial studies have been performed to examine these effects across more extensive LFS populations. The aims of this study were to identify the psychosocial impact of LFS comprehensive screening options on individuals with LFS and determine whether psychosocial factors may influence screening adherence.

MATERIALS AND METHODS

This study was approved by the institutional review boards at The University of Texas Health Science Center at Houston (HSC-MS-15-0410) and The University of Texas MD Anderson Cancer Center (BS99-038).

Participants

Individuals were eligible for this study if they were 18 years or older, English-speaking, had a germline *TP53* mutation, and completed at least one LFS screening visit in the LEAD program at MD Anderson Cancer Center. A total of 34 participants were initially eligible for this study.

Study Design

Potential participants received a study invitation, followed by a phone call from study personnel to determine interest in participating. After informed consent, participants completed semi-structured interviews by phone or in person that included questions regarding their experience with LFS screening. Interview questions addressed emotional reactions to screening and test results, satisfaction and perceived efficacy of screening, drawbacks of the screening process, future screening intentions, and financial and logistical implications of screening. Interviews were audiotaped and transcribed using Adept Word Management professional transcription services.

Analysis

Qualitative analysis was guided by the grounded theory approach using ATLAS-ti software (ATLAS.ti Scientific Software Development GmbH, Berlin).²¹ Each transcript was coded and analyzed in order to determine overarching themes. A preliminary codebook was created by the primary author (J.R.) and reviewed with a second coder (R.Y.). The primary and second coders reviewed and coded five transcripts until an inter-coder reliability of greater than 80% was reached. Coding discrepancies were discussed until consensus was reached. The primary author coded the remaining transcripts. Codes were grouped into the following categories: benefits and drawbacks of participating in LFS screening and plans for future participation.

RESULTS

A total of 34 individuals met the eligibility criteria of our study. Of these, 10 (29%) did not respond or could not be reached, 4 (12%) declined participation, and 20 (59%) consented and were interviewed. Interviews were ceased when there was saturation of new themes. The final sample included 16 women and 4 men, which matched the gender distribution of the eligible population. Most participants had at least one previous cancer diagnosis. At the time of the interview, 5 individuals had previous incidental findings on WB-MRI or brain MRI that required follow up imaging or biopsy. Prior to screening, all participants discussed the program with a healthcare provider in order to learn more about the perceived physical benefits and limitations of screening: 11 met with a genetic counselor, 7 with a nurse practitioner, and 2 with a physician.

Due to the screening protocol's flexibility, participants were at different stages in their screening process at the time of their interview. Some participants had multiple WB-MRI's, others had one, and 4 had not yet had a WB-MRI. Of those 4, all had brain MRIs and 3 have had WB-MRI's since the interview period. Although the availability of WB-MRI is a key feature of the LEAD program and may affect the participant's responses in our interview, there were no detectable difference in responses between the groups. Those without a WB-MRI were able to comment on other screenings they had, such as the brain MRI.

Demographic characteristics and screening history are shown in Table 1.

Perceived Benefits of Participation in the LEAD Program

Early Detection—Participants indicated that early detection of cancer is a benefit of screening and they perceived that if cancer were to develop, it would be caught early and with a better outcome. Some reported that early detection was the sole reason they participated in screening. When thinking about what would happen if the program didn't exist it was indicated that, *"Early detection is key to... fighting off cancer. So I don't know how you'd do it without screening."*

Peace of Mind—Individuals expressed that having access to screening has provided peace of mind, which they attributed to having lessened worry about their cancer risk and to knowing their current health status. Specifically, one person explained that individuals with LFS worry that every illness they have is a sign of cancer and that screening has helped

mitigate those feelings: “*The screenings- when they told me... you’re good. Everything’s fine. Later on, if I get a flu or something, I’m fine because I already know my screenings are good.*” When asked how screening affects their feelings about their LFS cancer risk, one person said, “*It’s lessened my feelings about feeling worried about future cancer. I’d be naïve to think that it couldn’t happen to me again, because I know darn good and well it could. But... the goal is to catch things early before it’s too late.*”

Centralized Screening—Participants valued having screenings centralized in one location. Prior to an organized screening program, many expressed that LFS is “*so rare, most doctors haven’t heard of it.*” They indicated how difficult it was to organize screening for multiple cancers on their own: “*it was just you or going [to] each department [independently]. It was a little bit overwhelming.*” These individuals expressed that a centralized screening program provides a means of keeping track of all their screenings and assurance that the screening protocol is being followed.

Respondents also valued having healthcare providers who were knowledgeable about LFS and who could advocate for the need for screening. They noted the burden of having to explain LFS to healthcare providers who often were not knowledgeable about the syndrome, and the need to act as their own advocate in regard to LFS-related care. A participant stated that the screening program enabled affected persons to “*sit in the back seat, instead of always in the driver’s seat.*”

Knowledge is Power—The vast majority of participants also conveyed that the information gained from screening is beneficial. For some, the information about their current health status was most important while others thought that “*being a little bit more educated about... what you put in your body and what you expose yourself to,*” was important information gained. Regardless of what pieces of information each participant felt were most powerful, many expressed that if they didn’t have access to the LEAD program they would be losing vital information. As one woman explained, “*I would feel like I’d be in the dark, like I wouldn’t know anything.*”

LFS is More Livable—It was reported that screening makes LFS feel more “livable”. Prior to participation in the LEAD program, a diagnosis of LFS felt like they were being told “*you have this horrible disease and you’re going to die of cancer.*” However, with the program and its screening protocol, there is hope that LFS will be more livable as this woman indicated: “*Just knowing that it’s not a death sentence...and that it is livable for a lot of people.*”

The number of respondents for each theme can be found in Table 2. Further examples of the perceived benefits can be found in Table 3.

Perceived Drawbacks of Participating in the LEAD Program

Logistical Issues—There were a number of logistical issues that were seen as drawbacks to the screening process. For some, the time commitment was burdensome. Individuals expressed having to travel across the country multiple times a year for appointments. This time commitment proved not only to be burdensome, but also expensive. As one person

indicated, *“I’m not capable of driving all that way. So, I have to fly, which means scheduling and money and...we’re on a fixed income, so it’s a burden. But I’m doing what I can to stay alive.”*

The biggest logistical issue, however, involved insurance and whether it would cover the recommended screening. Nine participants expressed that they currently have concerns about insurance coverage. One individual’s insurance recently denied their WB-MRI and this led to a significant emotional reaction: *“I got sick from it. I was depressed. I got really sick.”* Another group of eight individuals had not had insurance difficulties but feared them in the future. The remaining three individuals did not feel that insurance coverage was a concern.

Organization and Navigation within the Program—Participants felt that the organization of the program needed improvement. The lack of organization was in relation to communication errors within the LEAD program, scheduling problems, and lack of knowledge about the program by other healthcare providers. However, many expressed great improvements in the organization of the program over time.

Other individuals expressed that trying to navigate the program (e.g. finding the location or knowing who to call with questions) was difficult and posed a barrier to screening. One individual expressed concern for other participant’s ability to navigate the system by saying, *“I know other people in this—they’re going to give up and quit.”* Although there are challenges to navigating through the program, one woman expressed improvement in this, *“I think your first time there, it’s a little confusing at times...But I think the second time is a lot easier.”*

Draining—The screening process was noted to be both physically and emotionally draining. From a physical standpoint, many of the screening techniques, particularly the WB-MRI, took a long time. Explaining how they felt during the WB-MRI, one person stated *“I want to get out... I’m just stiff...I’ll fall asleep. And once I get up, I’m like, man. I’m still here.”*

Others expressed that from an emotional standpoint, *“there are still times you just get tired of it and you just... don’t want to do it anymore.”* Sometimes screenings also brought up old memories, as one individual indicated: *“If you had something detrimental happen or take a trip down memory lane – it might get you in the gut a little bit.”*

Negative Emotions—The vast majority of participants expressed negative emotions throughout the screening process, with three emotions being most prevalent: anxiety, fear, and skepticism. The most reported negative emotion was anxiety, or as many explained, *“We call it scan-xiety.”* This so called “scan-xiety” is related to the uncertainty of what will be found during screenings. For some, this anxiety is so severe that they report taking medication to control it. While some experience anxiety prior to screening, others report that waiting for the results is the worst part *“worse than when they actually give you the results...it makes you crazy.”* Although the anxiety associated with the initial screening process can be intense, around half felt their anxiety decreased with additional screenings.

Half of the participants also expressed experiencing fear related to screening, which was often related to claustrophobia during the MRI's; one person expressed, *"I have to be strapped down."* Another cause of fear was inconclusive or benign findings on the screening exams; another person explained, *"I was so scared, and I thought I had breast cancer. But no, it was just...fat."*

A small proportion of the participants also experienced skepticism regarding whether the screening results or the doctors themselves would be correct. When asked about receiving a normal screening result, one participant indicated, *"I feel relieved, but I feel like 'are they sure?' I need to read it myself, like I'm going to find something they didn't."*

Although there were significant negative emotions for many individuals, some individuals expressed not having negative emotions related to screening. These people felt like a *"rare breed"* because of their lack of screening related emotions. Some individuals expressed that without screening they would have *"panic attacks"*; as explained, *"If I get a cough, I think I have throat cancer. Or if my head is hurting or my eyes are hurting, something's going on with me. Something's back."*

The number of respondents for each category can be found in Table 4. Further examples of the perceived drawbacks can be found in Table 5.

Plans for Future Screening—All of the participants expressed that they would like to continue screening within the LEAD program. Reasons given for why they would like to continue include *"I think it would be foolish of me not to"* and *"I want to stay alive."*

A few individuals discussed that a family member has quit screening in the LEAD program for reasons including: being physically and emotionally tired of the screening process, moving away from M.D. Anderson, and lack of communication between the individual and the LEAD program.

We also asked each participant what potential barriers may prevent them from continuing screening. Most individuals expressed that loss of insurance coverage was the largest barrier. Another barrier was moving to new locations where they may not have direct access to screening, a concern noted particularly in young individuals who may decide to move away for college or future jobs. One young adult explained, *"If I ever want to transfer out of state... that kind of scares me, because I'm like, 'What am I supposed to do?' All my testing and everything is here."*

DISCUSSION

This study, to the authors' best knowledge, is the first multi-participant study looking at the psychosocial effects of a comprehensive LFS screening program. Similar to findings in a previous study involving screening prior to the comprehensive protocol, we also found that LFS screening provides patients with a sense of security, and the largest perceived benefit was early detection of cancers.¹⁹ However, our study was found to be in contrast to a previous case study that expressed concern that comprehensive screening may lead to testing fatigue and may put a significant emotional strain on patients.²⁰ Although these concerns

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were shared by some of our participants, our study showed that the benefits gained from screening significantly outweigh the perceived drawbacks, as seen by the fact that 100% of patients plan to continue screening within the LEAD program. Although screening increased some negative emotions, such as the so-called “scan-anxiety”, fear associated with screening, and skepticism of the tests and doctors, some negative emotions were also eliminated because of screening. Participants felt less worried about their personal and family cancer risks, were less fearful about LFS, and became less focused on their mortality. They also expressed that LFS feels less overwhelming and more livable with access to the LEAD program.

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The information we gained in this study contrasts with an article by Gopie et al. (2012) which found increased distress and lower quality of life in individuals receiving screening for hereditary cancer syndromes.²² The LFS patients in that study underwent screening prior to 2012 which consisted of breast MRI and targeted screening dependent on family history; which is in contrast to the comprehensive screening in the LEAD program. Prior to comprehensive screening, there may have been significant distress and lower quality of life for individuals with LFS. With our study, however, although not measured directly, we heard from patients that participating in comprehensive screening actually lowered distress and improved quality of life. This shows that comprehensive screening programs are important to patients’ well-being.

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Screening through the LEAD program has also provided reassurance about participants’ current health status. Many people expressed that prior to the screening program, they worried that every bruise, headache, or illness was a sign of cancer. Now, they rely on their normal screening results as reassurance that these ailments are not indicative of cancer. This has allowed people with LFS to live without the constant mental draw of worrying about cancer and be more focused on everyday life.

Implications

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Our study can be used not only to help grow the LEAD program, but also by centers around the world that are implementing improved screening for LFS. Some participants stated that they have family members who cannot access appropriate screening because there are no screening programs in their area. These testimonies support the need for easier access to screening programs worldwide. Currently there are other groups utilizing screening protocols similar to the LEAD clinic, such as the University of Utah, the National Cancer Institute, the National Institute of Health, Dana-Farber Cancer Institute, Gustave Roussy Institute in Paris, the Institute of Cancer Research in Surrey, United Kingdom, and the Australasian Sarcoma Study Group in Victoria, Australia (contact authors for contact information). It will be important to compare data from these sites to continue to learn how to develop successful screening programs.

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Despite the significant benefits to screening, there are still notable drawbacks that limit participation. In particular, significant negative emotions can arise surrounding the screening process. All healthcare providers who interact with these individuals should be aware of these emotions and be able to provide appropriate referrals if necessary.

Finally, many individuals interviewed desired improvements to insurance coverage. Some stated that screening is the only thing keeping them alive and when screening wasn't covered by insurance, they expressed significant negative emotional reactions. While insurance coverage may be out of the hands of healthcare providers, we hope that by providing more research based evidence showing that screening is necessary for patients' physical and emotional well-being, the insurance companies will follow suit and coverage will no longer be a barrier to screening.

Study Limitations

One of the limitations of this study is its small sample size. Although small, we obtained a 59% response rate from the eligible participants and an 83% response rate from those we reached. Since this condition is rare, it is challenging to observe a large LFS population at one cancer center. Despite the small sample size, we reached saturation in terms of identifying new themes in the interviews. Therefore, we feel that having a larger samples size would not change our findings significantly.

Another limitation of the study is that for many individuals, their last screening was weeks or months prior to our interview. This time period may have affected the participant's memories of their emotions surrounding that screening experience. Also important to note, most individuals received normal screening results at their last visit, which may have led to a more positive memory of their experience. However, the one individual in whom cancer was found at their last screening visit, did not feel negatively towards the screening process.

There may also be bias introduced when the participants met with a healthcare provider to discuss the potential physical benefits and limitations of screening prior to beginning the program. Most individuals were likely told that the reason this program exists is to help detect cancers and improve survival. These conversations make it hard to determine whether participants independently identified these as benefits of screening, or whether the conversations with healthcare providers prompted these responses.

Importantly, since this study was done at one point in time and not over many years, it can't be known whether these patients would eventually develop testing fatigue. Participants in our study all expressed desire to continue screening, however if followed longer, we may learn more about the risk for study fatigue long-term. Interestingly, there was no difference in responses between participants that were in the screening program for a few years versus ones that just joined the program.

Finally, there were four individuals who declined to participate in our study whose unique perspectives were not captured. These individuals may have had negative experiences that they did not feel comfortable sharing with people at the institution where they receive their care. They may also be less likely to participate in screening in the future, in which case we would not have an accurate representation of their perspective.

Future Directions

Although our study investigated individuals' experiences with LFS and the LEAD program, many noted a large familial impact as well. It appears that family members are affected both

by the participants' diagnosis of LFS as well as their participation in screening. Further research should investigate screening's impact on the family, since familial support is important to many cancer patients.^{12, 23} Relatedly, many participants have children that are enrolled in the pediatric LEAD program. It would be beneficial to interview these children to learn about the psychosocial impact of screening on children.

Finally, it would be important to talk with individuals who either quit or declined initial participation in screening. These individuals were not captured in our study and understanding their motivations could help improve the program to include as many high-risk LFS individuals as possible.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

The authors thank Dr. Ralf Krahe, Ph.D for his assistance in the creation of this project as well as valuable feedback provided throughout the course of this study.

This study was completed as a part of a thesis project at the University Of Texas Graduate School Of Biological Sciences. The abstract is posted on their website (http://digitalcommons.library.tmc.edu/utgsbs_dissertations/662/) and the full article will be available there beginning April 26th, 2017.

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Table 1

Participants' (n=20) Demographic Characteristics at Time of Study

Characteristic	n	%
<i>Mean Age (range), years</i>	39.1 (18-61)	
18-25	3	15%
26-33	4	20%
34-41	5	25%
42-49	3	15%
50-57	2	10%
57-64	3	15%
<i>Ethnicity</i>		
Caucasian	12	60%
Hispanic	4	20%
African American	2	10%
Other	2	10%
<i>Gender</i>		
Female	16	80%
Male	4	20%
<i>Screening History</i>		
Previous WB-MRI	16	80%
Previous brain MRI only	4	20%
<i>Personal Cancer History</i>		
Previous cancer diagnosis	17	85%
Mean number of cancers (range)	2 (0-6)	
<i>Reproductive History</i>		
Number with children	11	55%
Mean number of children (range)	1.1(1-3)	
<i>Incidental Findings that required further imaging/biopsy</i>	5	

Table 2

Number of Participant Responses per Perceived Benefit Category

Benefit	n	%
<i>Early Detection</i>	13	65%
<i>Peace of Mind</i>	12	60%
<i>Centralized Screening</i>	10	50%
<i>Knowledge is Power</i>	16	80%
<i>LFS is More Livable</i>	16	80%

Table 3

Perceived Benefits of Screening

Themes	Participant Responses
Early Detection	"I think the biggest thing was I knew it was going to help catch things early, and I felt that was – with the way cancer treatment is now, it's all about catching things before they've progressed."
Peace of Mind	"The program definitely gives me more peace of mind. Like I know I still have a significantly higher chance of getting cancer than the most average person. But I have more confidence that if I do, it will be more manageable" "I just feel more confident. I feel I have more peace of mind and even for my child. I feel like it's very good for her, and she knows it now"
Centralized Screening	"Just the overall screening and not having to take care of it yourself. It's allowed me to step back from being my own doctor. I didn't go to med school, I don't know things, and people with Li-Fraumeni should not have to know as much as they do because it makes it hard to just live life. So I try and leave that to other people, and the screening has allowed me to really step back and just enjoy being me." "Just literally having it all under one roof, and having one person who really knows—what'd y'all call it? The syndrome? The disease? Someone who knows all about it."
Knowledge Is Power	"The only way to know is to screen. And that is the most beneficial. That's the reason I do it." "So, this to me is knowledge is power. You know, the more I know, the better off I am."
LFS is More Livable	"I have much more confidence that if I continue doing this, that it's more likely for me to live a long and healthy life".

Table 4

Number of Participant Responses per Perceived Drawback Category

Drawback	n	%
<i>Logistical Issues</i>	17	85%
<i>Insurance Concerns Currently</i>	9	45%
<i>Insurance Concerns for the Future</i>	8	40%
<i>Organization and Navigation within the Program</i>	9	45%
<i>Draining</i>	10	50%
<i>Negative Emotions</i>	18	90%
<i>Anxiety</i>	14	70%
<i>Fear</i>	10	50%
<i>Skepticism</i>	4	20%

Table 5

Perceived Drawbacks of Screening

Themes	Participant Responses
Logistical Issues	<p>“But some people may have to pay way more than that, so I think cost is really, really prohibitive for some people being able to do all the screenings—just because it’s—imaging is expensive.”</p> <p>“I mean the time because it’s a field trip every time you go to Anderson.”</p> <p>“My insurance doesn’t cover my whole-body MRI. So I haven’t had one of those yet.”</p>
Organization and Navigation within the Program	<p>“It seemed a little bit disorganized at first, but I think it was just—maybe I was one of the first patients that was in it. But I think that has gotten better.”</p> <p>“I think the harder thing for me is knowing who to get in touch with to figure things out. That’s a little confusing, I will say. Because I know some people do just some things in their local area and then some things out. I wish there was a social worker at my full program that I could kind of contact to ask questions.”</p>
Draining	<p>“They can be kind of draining, in terms of like energy and emotionally sometimes. Just you know, knowing that you have the condition and that you have to go do it.”</p>
Negative Emotions	<p>“It was just the anxiety that you go through every time you’ve got to go do your screening. It’s just like, ‘Oh, my God. What are they going to find now?’”</p> <p>“I think that a lot of the anxiety has subsided and kind of the nervousness and the fear of the unknown has subsided. And now they’re familiar and I know the drill.”</p> <p>“I take a Xanax in the morning, just because—you know—being in enclosed spaces really bothers me”</p>