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Couples coping with screening burden and diagnostic uncertainty in Li-Fraumeni syndrome: Connection versus independence

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Abstract

Purpose: Li-Fraumeni Syndrome (LFS) is an inherited tumor predisposition syndrome with lifetime cancer risks approaching 100% and evolving risk-management strategies. This study evaluated couples' coping with LFS-related burdens.

Research approach: Constructivist grounded theory and anticipatory loss frameworks guided design and analysis.

Sample and methods: Twenty-six individuals enrolled in the NCI LFS Family Study completed semi-structured interviews with their partner during annual screening visits. An interdisciplinary team completed open and focused coding to identify patterns of coping and adaptation.

Findings: Couples described living with ambiguous danger, a state of chronic apprehension resulting from LFS-associated uncertainties. Most couples communicated openly and alternated shouldering the burden, while others engaged in protective buffering to shield each other from distress and sustain the appearance of normalcy.

Interpretation: Optimally, coping reduces shared psychosocial distress, yet some strategies may inadvertently increase disconnection.

Implications: Mental health support is critical for both partners coping with LFS, together and separately.

Keywords

coping; couples; family; hereditary cancer; Li-Fraumeni syndrome; qualitative

Introduction

Family experiences with LFS and their psychosocial impact

Li-Fraumeni Syndrome (LFS) is an autosomal dominant, hereditary cancer predisposition syndrome, caused by germline pathogenic variants (*i.e.*, mutations) in the *TP53* gene. Individuals with LFS experience high lifetime risks of multiple cancers at an early age, and often develop multiple primary cancers over a lifetime; more than half of women with LFS are diagnosed with at least one cancer by age 31, and half of men have had at least one cancer by age 46.¹ Intensive LFS cancer screening strategies require frequent evaluation of multiple body sites from infancy to late adult life. This comprehensive cancer screening enables early detection, has resulted in modest reductions in mortality, and is recommended for individuals with *TP53*-positive LFS.^{2,3}

Families with LFS may experience multiple, concurrent cancer diagnoses, often across multiple generations, starting early in childhood. This heavy disease burden may lead to higher cancer distress and reduced quality-of-life compared with *TP53*-negative individuals.⁴ *TP53* germline genetic testing and surveillance protocols are critical to early detection and decreased early mortality yet may be emotionally exhausting for patients and their families. Still, the perceived burden of cancer screening, although intense, may not outweigh the perceived benefits.⁵ Screening compliance may influence or shape family dynamics, and has been associated with receipt of emotional and social support within families.⁶ However, the precise impact of screening on family members with or without LFS remains poorly understood.

Research has shown that the family system can influence each member's distress related to each cancer occurrence because family members' emotional experiences are interrelated.⁷ Nascent literature regarding families' needs for social support yield mixed results. We have previously reported that LFS patients do not lack emotional, tangible, or spiritual forms of social support.⁸ Conversely, in an earlier study both bloodline and nonbloodline LFS family members reported clinically significant levels of distress (depression, anxiety, somatization) and a desire for increased mental health support for themselves and their family.⁹ These contradictory findings require reconciliation, to better understand the emotional, social support, and mental health needs of families faced with a high cancer risk.

Cancer and couple relationships

The spousal dyad is among the most important family relationships, serving as the foundation for family formation in traditional family structures. Intimate partner relationships are the single largest source of happiness, and of distress, thus greatly influencing health and well-being.¹⁰ The daily transactions of social support between intimate partners affect psychological functioning of each individual partner, their health behaviors and outcomes.¹¹ However, limited research addresses the complexity of couple

dynamics regarding cancer predisposition syndromes. Unlike previous studies of communication patterns and perceptions, this work studied each partner separately, rather than focusing on couples as the study unit.¹²

One study of 50 partners of individuals with LFS or Von Hippel Lindau syndrome (VHL), reported >25% clinically relevant levels of distress related to the syndrome that correlated with their at-risk partner's distress levels; younger partners and those with less social support reported higher distress levels.¹³ Thus, ongoing elevated degree of cancer worry affects their daily functioning. Most participants expressed interest in routine professional psychosocial support for the couple dyad.

The experiences of couples coping with sporadic cancers sheds light on the range of psychosocial challenges LFS couples might face.¹⁴ During cancer-specific discussions, women discussing early-stage breast cancer diagnoses with partners reported less distress when their partners responded with reciprocal self-disclosure and humor, and when partners did not immediately intervene with proposed solutions for new issues. Partner responsiveness played an important role in helping women adapt to their diagnosis; specifically, increasing reciprocal self-disclosure, using humor appropriately, and avoiding premature problem-focused coping might improve adaptation and relationship intimacy during and after this stressful life event.¹⁴

Prior studies that have examined participants' perceptions of relationships in heritable cancer syndromes have focused on heterosexual, mostly male, partners of *BRCA1/2* mutation-positive individuals.¹⁵ Participants reported feeling fear and anxiety regarding the disclosure of *BRCA1/2* mutation status to new intimate partners, although many participants reported that disclosure had a positive effect on their relationship, if the partner was able to respond with interest, empathy, and affection.

Theoretical framework

We used a Family Resilience Framework¹⁶ to identify strategies couples described in the face of persistently high cancer risk. A basic premise guiding this framework is that stressful events, crises, and persistent challenges influence the entire family and, in turn, specific family processes mediate the recovery (and resilience or not) of each family member and the family as a whole. Interventions that employ this framework are aimed at building family strengths when addressing problems, thereby reducing risk and vulnerability. Hopefully, as families become increasingly resourceful, their ability to meet future challenges improves. Family resilience differs from family to family, although there are some common characteristics that distinguish which families can successfully cope *versus* families that are unable to regroup after a major stressful event, such as an LFS diagnosis. Families may leverage social and economic resources to strengthen resilience by practicing flexibility in their structure and demonstrating connectedness within the family unit and beyond to social networks. We define resilience as the ability to adapt, cope, and develop a process of dealing with chronic and ongoing stress rather than one specific stressor. Since resilience does not mitigate a family's inherited cancer risk, resilience must be developed in preparation for future events that potentially threaten family functioning.

Consideration of anticipatory loss, defined as “the experience of living with possible, probably, or inevitable loss,” may provide an additional valuable framework for investigating the emotional experiences and meaningmaking processes of families dealing with LFS.^{17,18} Research investigating other conditions (such as early-onset dementia or parental aging) have applied this concept to how families prepare for the death of a loved one or decline in health. Worry, sadness, and gratitude comprised attributes of anticipatory loss commonly seen in these families.^{19,20} Worry about future loss was balanced with gratitude regarding current good health. Anticipatory loss sometimes acted as an impetus for family members to connect and enjoy their time together.

Objectives

Qualitative psychosocial research addressing family experiences with heritable cancer is generally limited to studying individuals, a strategy that oversimplifies a complex family process. The present study seeks to address this gap. We present the first study, to our knowledge, to qualitatively investigate dyadic partner relationships between heterosexual individuals with LFS and their spouses. Towards this end, we evaluated family experiences within LFS kindred, focusing on how couples respond to threats affecting the health and well-being of family members. We obtained in-depth, qualitative interviews with couples in which one partner has LFS, to:

1. Identify challenges unique to couples coping with LFS.
2. Evaluate coping strategies used to manage emotional and pragmatic daily life challenges, including strategies through which couples approach LFS as a shared burden.

This research addresses couple dynamics and their range of stress management strategies. Our findings elucidate their collective experience and may guide clinical and psychosocial management of these families.

Methods

Individuals with LFS and their family members were enrolled in the National Cancer Institute’s (NCI) IRB-approved longitudinal LFS Study (Protocol #11-C-0255; Identifier NCT-01443468; www.lfs.cancer.gov).¹ A subset of LFS patients with germline *TP53* mutations were invited to NCI for annual cancer screening and voluntary psychosocial evaluations, including family interviews. Written informed consent was obtained from all participants, including permission to share de-identified family information with carefully-vetted scientific collaborators, and to audio-record the family interview.

Individuals with LFS and their enrolled/consented family members completed in-depth, semi-structured family interviews focused on within-family communication issues, reproductive decision-making, couple relationships, cancer prevention behaviors, and choices regarding genetic testing for adults and children. The transcripts were stored on a secure, password-protected NIH computer, as were the interview data analysis files (in DedooseTM). Of 64 family interviews conducted between 2012 and 2017, 26 included only couple pairs, which formed the focus of this study (Table 1). Family interviews that were not

couple-specific (*i.e.*, if children or other family members were present) were not included in this analysis.

Design and data analysis

We used the tenets of constructivist grounded theory (GT) and interpretive description (ID) for data analysis.^{21–23} The coding team was comprised of four researchers trained in qualitative methods; all had extensive experience working with medical interview transcript data. Initially, three coders separately conducted open coding on three random transcripts to identify significant content and note personal reactions and reflections. The team developed preliminary definitions for *in vivo* codes. Then, the team used the preliminary list of codes to conduct focused coding on a third set of transcripts to refine, expand, and define extant codes, define parameters for their utilization, and cluster codes into thematic groups. The team also created a topic-specific thematic coding scheme reflecting sensitizing concepts such as “partnering, family development, ambiguous loss, and parenting.” Then, the lead author entered these codes and their emergent definitions and parameters for utilization into Dedoose software. Two researchers then independently coded six transcripts to test and refine the codebook and to check for inter-coder reliability. Coders discussed all coding discrepancies working towards agreement. In the final analysis phase, the coding team met to discuss interpretations and synthesize findings into recurring themes. Linguistic analysis was employed to tag specific phrases and words used that reflected aspects of participants’ identity, including pronouns coded on a scale of 0 “I” to 10 “we”. A code of 5 was assigned when a speaker alternated use of “I” and “we” in the same sentence.²⁴

Data quality

Prolonged engagement with the participant families and with the study team increased trustworthiness and credibility²⁵ of the investigators; the primary interviewer conducted all family interviews, becoming intimately familiar with study participants. Semi-structured interviews and prolonged engagement enabled the researcher to develop rapport and ongoing relationships with participants. This aided in the co-construction of meaning between the researcher and members of the LFS community. A team-based approach to coding and synthesizing findings, utilizing the consensual qualitative methods,²⁶ facilitated the validation of emergent codes and findings through crossverification from multiple sources. The research team was guided throughout the study by a seasoned qualitative researcher, and they maintained a detailed audit trail to track methodological consistency and innovation.

Findings

Twenty-six couples completed interviews (52 individuals aged 22–61) between 2012 and 2017. Twenty-one had a female partner with LFS (Table 1) and seventeen of the 26 had a partner with a history of an LFS-related cancer. Tables 1 and 2 outline the demographic details of the 26 couples interviewed. All couples were married; the average length of marriage was 15 years (range 2–32 years). Most participants reported at least graduate level education and an annual income well above the 2016 national average. Most couples had at least one child (Table 2). At the time of interview, four couples had children who had not

been tested for the familial *TP53* mutation. Three couples had experienced the death of a young child caused by an LFS-related cancer.

Shared ambiguous danger.

Couples described living with a sense of *ambiguous danger* due to the persistent uncertainty regarding when cancer might appear and threaten the family's well-being and individuals' survival. Consequently, couples remained in a chronic state of apprehension. Bert described dealing with this uncertainty:

We're both worried. After you've seen it [cancer] happen, and you've seen it happen to her, her father, her sister. You know where you finish the race, you just don't know when you're finishing the race.

Bert (46):

Bert demonstrated how he shared his wife and her family's fear regarding the uncertain nature of the cancer timeline. The perceived inevitability caused worry that his wife would develop cancer and die prematurely.

While couples hoped that screening would detect their cancers early, and thereby improve long-term survival, that hoped-for outcome came at a significant emotional cost. Some spouses described the cycle of stress regarding annual cancer screening, which brought fear of abnormal results or learning about another preventative surgery to reduce cancer risks in their partners with LFS. One couple described the anticipated life-long LFS screening: "We play Russian roulette once a year, but the game is never over."

Couple coping styles

Thematic coding of the transcripts revealed two prominent coping typologies related to screening and cancer risk. Seventeen couples "**coped in connection**," whereby both partners shared the LFS burden, demonstrating mutuality and shared identity as approaches to living with LFS. Nine couples "**coped independently**"; they regarded LFS as an individual stressor, using bi-directional protective buffering to shield their non-LFS partner. Withholding, suppressing these frightening, painful emotions increased mutual isolation and disconnection within the couple's relationship. Examples of both coping strategies are listed in Tables 3 and 4.

Coping in connection

The majority of couples engaged in cohesive coping styles, reinforcing a sense of togetherness through vast uncertainty. The three behaviors that served as indicators of mutuality were:

Viewing LFS as a "We-stress."—These couples used plural pronouns in conversation. Couples' use of "we" gave a sense of joint ownership of the challenges of LFS and the non-LFS partner's involvement.

We didn't have a choice but to be strong and hold on together. We're dealing with something serious and don't have time to worry about little, stupid things. We reached a different level in our relationship.

Veronica (31):

Balance and taking turns: Some couples illustrated how they stayed attuned to each other's needs and took turns sharing LFS-related stress by alternating who would be the emotionally "strong"/capable/supportive partner, while giving the other partner space to temporarily withdraw from family responsibility, to rest, grieve and adapt.

I withdraw before and after the test. "Don't give me one more thing to do. Don't mess with me until this is over." Because I cognitively slow down. The things I have to do take longer, so I want to put everything off until this is handled.

Lucy (48):

I have to deal, process wise, what's the contingency plan?

Phil (51):

This woman with LFS described the struggle of anticipating bad news but also expressed gratitude to her husband for taking on more of the planning and decision-making responsibilities. Many couples agreed that the process of experiencing cancer risk or being diagnosed with LFS tested their relationship but made them stronger as a family.

Coping independently

Couples who coped independently viewed LFS as an individual, personal stressor and their stories were less internally consistent than those reported by the other 17 couples. They relied on individual strengths and focused on their own perspectives. The protective buffering behaviors that partners engaged in emerged from a sense of compassion and sympathy for their partner's position, but often resulted in (inaccurate) assumptions about what might best meet their partners' needs. The two themes that indicated independent coping between partners in these couples were:

Bi-directional protective buffering: Partners often acted to shield their spouse from stress related to cancer worries or prevention responsibilities. This process of protective buffering was bi-directional, *i.e.*, both partners used this tactic relative to the other.

LFS partner protective buffering.: Many couples had devoted years of their relationship to cancer treatment, recovery from surgery, or cancer screening. Some LFS subjects felt guilt for the time their partners spent caring for them or making hospital visits, and tried to relieve their spouses from those health-specific responsibilities. Consequently, partners tended to hide worries and fears from each other, or avoided talking about the disease out of consideration for their "healthy" partner. This type of break that Jessica (39), a person with LFS, provided her partner Andrew (43), did not result from a specific request from him. Rather, her recognition of his distress produced an unspoken expression of caring that meant putting his needs first.

Non-LFS partner protective buffering.: Often the non-LFS partner felt the need to spare the other emotional pain or to avoid increasing fear or stress that their partner was experiencing. Further, non-LFS partners protected themselves from experiencing additional worry by minimizing open dialog with their LFS spouses. This style of support created barriers to communication and introduced opportunity for discord and misunderstanding. Gender differences played a role in these findings. Many male partners of female patients reported wanting to act, yet feeling helpless with no way for them to support or provide tangible assistance to their wives. These patterns solidified over time; couples reported these patterns were hard to change. A few interactions outlined how protective buffering between a couple dealing with cancer increased isolation from the other. Cordelia (29) recognized her desire to share her emotional distress with her partner: *"I thought to myself: 'if I could have someone that I could cry with, that would make me feel so much better.'"* The experience of being interviewed about these issues often evoked strong emotional reactions, especially for male participants, who were accustomed to minimizing their own worries and focused their attention on their spouse as the person with valid concerns worthy of support.

Use of "I" language: The partner with LFS often used "I" pronouns to describe their coping experiences with cancer diagnoses and management. Several couples did not share a coping narrative and did not seek support from each other during times of notable stress, and instead focused on their own emotional process. Fred and Rebecca discussed the death of their son from an LFS-related brain tumor:

I just kind of dealt with it on my own terms, the good days and the bad days.

Fred (49):

I don't know if I could have handled it, 'cuz I'm still having a rough time.

Rebecca (49):

The couples who coped independently from each other found a rhythm and pattern of distinct coping that avoided reliance on their spouse. For some, coping alone was easier than conversations with their partner that forced them to face painful emotions of grief, fear, and anxiety. The protective buffering behaviors that non-LFS partners employed emerged from a sense of compassion and sympathy for their partner's position, but based on (not always accurate) assumptions about what their partner truly needed.

Discussion

Living with LFS is a challenging, dynamic process for families and their healthcare providers. This qualitative study highlights the ongoing and understudied challenges faced by couples facing the persistent and chronic risk of a new or recurrent cancer. The 26 couples all identified ways in which LFS had influenced their lives and their relationships. Participants with LFS reported that their spouses were considerably engaged and knowledgeable in their decision-making processes and care, with most couples communicating and coping cohesively. This study's analysis culminated in a rich, deep description of two types of couple coping in the context of LFS.

Previous cancer patient literature has shown that, commonly, the spouse in the caregiving role is more likely to protectively buffer the partner with cancer.²⁷ Interestingly, our data show the opposite phenomenon, with the individual with LFS shielding their partner more frequently than vice versa. Our data echoed prior research in LFS and Von Hippel Lindau disease, both hereditary cancer conditions with frequent pediatric onset, in which the noncarrier partner experienced a fair amount of stress connected to the carrier partner's cancer risk.¹³ This facet of distress was rarely discussed within the household but, during the interview, many male partners of women with LFS expressed grief and sadness about past cancer hardships and the possibility of future losses, including new cancers and death. Many women with LFS also expressed concern over the future burden to be carried by their partners, who seemed likely to outlive them and would need to care for surviving children (some with LFS). Men employed protective buffering to hide their own feelings of inadequacy and frustration regarding not being able to take definitive action, to protect carrier partners or 'fix' the situation.

Resilience in couples coping with LFS

Couples' strength and resilience lay in their ability to develop long-term dyadic strategies for managing the ups and downs of LFS. Partners' flexibility in roles and identities in relation to health, was mirrored in their language of "we" and "I" in the process of coping from a relational perspective; this has been explored in previous cancer literature and for other genomic testing technologies.^{28,29} When a demanding experience was viewed as a dyadic "we" stressor, couples were more likely to believe they were "in it together" and more readily had open dialog. In our study, the increased use of "we" by non-LFS spouses indicated a higher level of involvement in care. Couples developed different strategies for managing longitudinal stress, which included sharing emotional experiences with their partner or taking space to autonomously manage anxiety.

Anticipation of and fear regarding a cancer diagnosis were shared concepts between couples, who reported significant concerns regarding the uncertain nature of the LFS cancer timeline. Many couples claimed that this knowledge and the attendant potential for shortened relationship length propelled them to accelerate achieving life goals, traveling more, and leaving jobs that were not satisfactory. For couples who were forming a new relationship, anticipatory loss and living with LFS-related ambiguity put problems and conflicts into perspective, leading them to resolve disagreements more quickly and to focus on spending quality time together.

Implications for psychosocial oncology practice

The management of complex, hereditary cancer susceptibility syndromes takes a village of genetics-oriented clinicians to achieve success. In the early years of treating members of syndromic cancer-prone families, it was routine for patients to see a genetic counselor once or twice, as the diagnosis was being made and a management plan formulated. From today's perspective, our data suggest that ongoing involvement of a multidisciplinary team, including those with behavioral, counseling and psychosocial expertise, is essential for high-risk family members to achieve optimal outcomes.

Mental health practitioners in psychosocial oncology should be aware of the particular and constantly evolving coping styles that couples employ at different stages in their LFS journey. To facilitate family well-being, clinicians may consider supporting partners' mutual disclosure of distress as one means to facilitate shared coping over time and to encourage open communication. The facilitated conversations between couples being interviewed in the current study were described as "healing," "helpful," "insightful," and "revealing" by study participants, providing evidence for a dyadic, systematic, comprehensive approach to handling this life-threatening syndrome and the intense cancer screening that it requires. Communication and relationship training can be integrated into systems of care, as early as the moment when LFS or LFS-related cancers are diagnosed in a family system. Clinicians can pay attention and utilize language that mirrors the pronouns that patients use when referring to themselves or their families and employ more "we" or "you both" to include both partners linguistically. The skills and management strategies offered by medical family therapists³⁰ can supplement the services available through genetic counselors, nurse practitioners, and appropriately-trained physicians. Additionally, there are significant social and economic disparities in access to mental health care, and in LFS, there is an often-overwhelming degree of cancer-related medical complications that can make access to and time for mental health support especially challenging. Clinicians should be aware of these challenges and strive to facilitate appropriate care to accompany genetic counseling, cancer screening, and general care for individuals with LFS and their family members.

Strengths and limitations

This research provides insight into how couples cope with a highly-penetrant genetic risk of cancer and the need for a team care approach to optimize coping. Psychosocial research focused on LFS has illustrated the perspective of individuals with LFS, but the voice of their partners, who are also living through the experience, has rarely been evaluated. This analysis represents the richest and largest representation of couples dealing with LFS to date.

In most of our interviewed couples, the female partner had LFS. Additionally, the sample was skewed towards European ancestry, higher levels of education and socio-economic status. These demographics reflect the NCI's LFS study enrollment overall and may be significantly different from other healthcare institutions. Future research must deliberately target more diverse populations to better characterize culturally and ethnically unique responses to these stresses. Such couples, with variable access to mental health care or familiarity with complex hereditary cancer syndromes, may generate observations that are more representative of our very heterogeneous general population.

The family interview was usually the last scheduled appointment of a multi-day research clinic schedule, a time at which participants were processing the flood of information received from the team through their evaluation. Many participants had been moved to think seriously about their next steps in cancer prevention (e.g., prophylactic surgery) or were returning home to await screening results. This likely primed the couples to have LFS-related effects and management options at the front of their minds. The stress of the clinical/research visits may have altered some couples' typical coping patterns, but our study design did not permit us to address that possibility. To the extent that this may have happened, it is

possible that the visit-related stress mimicked the day-to-day pressures experienced at home as they worked to cope with life as an LFS family member.

Conclusion

Partners dealing with LFS often make health care decisions together, with the shared goal of optimizing health and well-being. Yet, with inherited, highly-penetrant cancer syndromes, this cannot be assured, since high disease burden, limited screening utility, uncertainty regarding evidence-based management options, and ongoing illness-related distress can change how couples cope with aspects of the syndrome. Our findings strengthen the argument favoring additional mental health support for partners of individuals with LFS. Additional research is needed to establish the best strategies to support family mental health and coping strengths for this population, as well as syndrome-specific, targeted mental health and family systems interventions.

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Table 1.

Demographic information.

Sample characteristics	Female (%), <i>n</i> = 26	Male (%), <i>n</i> = 26
Average age (years)	40	43
Age range	22–57	23–72
TP53-mutation positive	21 (81%)	5 (19%)
Highest education achieved (<i>missing data from 8 couples</i>)		
High school diploma	0 (0%)	1 (6%)
Vocational/trade school	1 (6%)	3 (17%)
Some college	1 (6%)	2 (11%)
Bachelor's degree	9 (50%)	4 (22%)
Some graduate school	1 (6%)	3 (17%)
Masters or doctoral degree	6 (33%)	5 (28%)
Total household annual income (<i>missing data from 8 couples</i>)		
\$10,000 to \$39,999	1 (6%)	2 (11%)
\$40,000 to \$69,999	5 (28%)	3 (17%)
\$70,000 to \$99,999	3 (17%)	4 (22%)
\$100,000 or above	9 (50%)	9 (50%)
Race/Ethnicity		
White	26	26
Hispanic/Latino	1	1
Religion (<i>missing data from 7 couples</i>)		
Catholic	3 (16%)	3 (16%)
Protestant	7 (37%)	4 (21%)
Jewish	2 (11%)	2 (11%)
LDS/Mormon	3 (16%)	3 (16%)
Methodist	2 (11%)	0 (0%)
None	2 (11%)	7 (37%)

Table 2.

Couple level demographics related to their children.

	Number of couples (%)	Total children	# of children tested for <i>TP53</i> mutations (# tested positive)	Children untested
0 children	3 (12)	0	N/A	N/A
1 child	7 (27)	7	6 (1)	1
2 children	10 (38)	20	18 (12)	2
3 children	4 (15)	12	9 (1)	3
4 or more children	2 (8)	8	4 (2)	4
Total	26	47	37 (16)	10

Table 3.

Coping in connection definitions and examples.^a

Typology: coping in connection: open dialog regarding concerns about the threat of cancer to their lives and family. Below are examples of how couples were attuned to each other's needs and alternated sharing the burden of LFS-related stress.	
Codes	Examples
<p>"We" language: Participants used first person plural pronouns to address themselves when talking about LFS.</p>	<p>Tim: <i>We'll deal with whatever has to happen, and the timing of that, and how it affects whatever. We'll just make a plan, and we'll do it.</i></p> <p>Danielle: <i>It's stressful that so much of our life is health and so many of our conversations and schedules revolve around health.</i></p>
<p>Balance and turn taking: Participants shared commitment or joint approach to coping with LFS-related stressors in which partners alternated emotional care-giving and -taking roles. Several of these couples encouraged each other to maintain hope and positivity to balance distress.</p>	<p>Veronica: <i>Our parents knew I was getting tested.</i></p> <p>Joe: <i>I probably made the phone calls.</i></p> <p>Veronica: <i>Yeah. I don't remember.</i></p> <p>Joe: <i>You probably didn't do it. I probably made the phone calls. You weren't in a good state of mind.</i></p> <p>Liz: <i>He's always my protector... you really shouldn't be getting the x-ray...</i></p> <p>Jared: <i>I keep telling her that there is going to be a tomorrow... that's my job.</i></p> <p>Liz: <i>So, I think "It's really hard," and I just don't want to go through that. Or I'll feel upset about not knowing, or finding out that something's there. Ignorance is kind of blissful. But he does a good job encouraging me and telling me that it has to be done. And he's right.</i></p>

^a Names have been removed from this dataset and replaced with pseudonyms, and all identifying information has been removed from the transcripts.

Table 4.

Independent coping definitions and examples.

Typology: independent coping: Defined LFS-related stressor in terms of individual impact and coped in parallel. Often did not seek emotional support from each other during times of high stress to prevent evoking additional distress. Some couples did not share a narrative regarding LFS or coping. An underlying theme was finding and focusing on each one of their own roles in the family.	
Codes	Examples
<p>"I" language: Participants with LFS used singular pronouns to describe personal experiences, demonstrating an independent orientation to coping with cancer screening, diagnosis, treatment, and recovery.</p>	<p>Fred: <i>Wilma kind of pushed me away some.</i></p> <p>Wilma: <i>I didn't want to be a burden and got kind of stoic with it. I can do this, I'm a big girl.</i></p> <p>Bill: <i>We didn't really cope because she pretty much just takes care of herself. It's not my decision what she does with her body. I just took care of the kids and everything else and let her try and get healthy.</i></p>
<p>LFS partner protective buffering: Behavior and communication to shield and isolate their partner from the negative psychosocial effects of LFS. Many of the women with LFS expressed guilt and frequently said "he has it the worst" because their husbands might 1) serve as the caregiver for them and possibly their children and 2) outlive multiple family members.</p>	<p>Jessica: <i>I pulled back and I stopped talking about it because he was under a lot of stress. I probably could've, moved forward with the study and said, "I'm ready to test." But I was nervous, because I knew the next 6 months he was under a lot of stress at work, and I thought, "This might not be the right time."</i></p> <p>Jessica: <i>When you first get your diagnosis it's on your mind 24/7. And you feel this weight and burden all the time. I would watch him watching a football game, and it's on my mind, and I want to talk about it, but I would see, "Oh, he's having a moment that's LFS free. He's getting to escape it for a minute, I don't want to take that from him."</i></p>
<p>Non-LFS partner protective buffering: Participants felt the need to shield spouses and themselves with LFS from their worries, stress, and pain.</p>	<p>Gilbert: <i>Some of the huge things, I always felt if I told her I was worried it would cause her to worry more. I thought, she had enough on her plate. I didn't want to add to it. I couldn't let myself do that. So I went into my box and just hid from her.</i></p> <p>Eve: <i>When you don't want to talk about it and I want to is the only time it's hard.</i></p> <p>Adam: <i>I probably don't want to be sad. Slaughter*)</i></p>