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Psychological impact of risk-reducing surgery for gynecologic cancer among women with Lynch syndrome

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ABSTRACT

Objective: Prophylactic total hysterectomy and bilateral salpingo-oophorectomy are risk-reducing surgeries (RRS) that can be offered to women with Lynch syndrome (LS) as they reduce the incidence of ovarian and endometrial cancer. Few studies have examined facilitators to RRS or the experiences of women with LS post-surgery. This qualitative study explored the experiences of women with LS who underwent RRS.

Methods: Women with LS who had undergone RRS within the prior 10 years were recruited from a genetic cancer registry and a tertiary care medical centre in Canada. Participants completed interviews over the phone. A qualitative descriptive methodological approach was taken, and interviews were analyzed using thematic analysis.

Results: Fifteen participants completed interviews. Themes identified included: 1) facilitators to RRS including desire for peace of mind, completed family planning, presence of physical symptoms associated with gynecologic cancer, burden of screening, personal or family history of cancer, age, and trust in healthcare providers (HCPs); 2) women's experiences with RRS including post-surgical recovery, long-term physical changes post-surgery, impact of surgery on sexual health, psychological impacts of managing risk, and post-surgical care from HCPs; 3) experiences managing menopausal symptoms and use of hormone replacement therapy; and 4) unmet informational needs including managing expectations prior to surgery, understanding risk related to other health conditions, and questions about the ongoing need for gynecologic cancer surveillance.

Conclusions: HCPs should consider facilitators to surgery in women with LS contemplating RRS. HCPs should also provide women with LS more detailed post-surgery information on what to expect, and risks of other health conditions.

1. Introduction

Lynch syndrome (LS) is an autosomal dominantly inherited condition caused by heterozygous germline pathogenic variants in one of the DNA mismatch repair (MMR) genes: *MLH1, MSH2, MSH6* and *PMS2* or in *EPCAM* (National Comprehensive Cancer Network, 2024). Gynecological cancer is common in women in LS and risk levels are dependent on the MMR gene inherited (National Comprehensive Cancer Network, 2024). In the more penetrant genes, including *MLH1*, *MSH2*, and *EPCAM,* the lifetime risk of endometrial cancer is 50 % and ovarian cancer is 12–15 % (Watson et al., 2008). Per the practice guidelines published by the National Comprehensive Cancer Network (NCCN) in Oncology (Genetic/Familial High-Risk Assessment: Colorectal, Endometrial, and Gastric Version) prophylactic total hysterectomy and bilateral salpingo-oophorectomy (TH-BSO) is offered to women with LS over age 40, as it significantly reduces the incidence of endometrial and ovarian cancers (National Comprehensive Cancer Network, 2024,; Schmeler et al., 2006). Per NCCN Practice Guidelines, hysterectomy with delay of BSO until closer to menopause may be considered for some individuals based on the MMR gene, as well as personal and family

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history (National Comprehensive Cancer Network, 2024). However, as TH-BSO eliminates reproductive capacity in women, it is not recommended until child bearing is complete among women who desire biological children (National Comprehensive Cancer Network, 2024).

Despite risk-reducing surgery (RRS) being an option for reducing gynecological cancer risk for women with LS, only a few studies have explored the experiences of women who have undergone RRS. For example, Etchegary et al. (Etchegary et al., 2015) conducted a qualitative study of 10 women with LS who underwent RRS and found women were motivated to receive RRS to reduce cancer risk and ease cancer worry. Although participants reported obtaining adequate information to make decisions about RRS, they underscored not having received enough information about post-surgical effects such as menopause; the need for hormone replacement therapy (HRT); and symptom management. In addition, this sample reported that RRS had a negative impact on their sexual functioning (Etchegary et al., 2018) Despite this, participants described positive effects post-surgery such as making better health behaviour choices with diet and exercise. Moldovan et al. (Moldovan et al., 2015) in a mixed methods study of 15 women with LS who underwent RRS reported similar findings about needing more information about menopause and HRT, but also noted the positive effect of surgery on reducing cancer worry. Finally, a review by Oxley et al. also noted less cancer-related worry following RRS surgery in women with LS (Oxley et al., 2022).

Given the small extant literature, the current study sought to examine the psychosocial impacts of RRS among women with LS. Specifically, we examined the factors impacting women's decision to undergo surgery, the physical and psychological impact of surgery, experiences of managing menopause, interactions with health care providers (HCPs), and unmet information needs both prior to RRS and post-RRS.

2. Methods

2.1. Participants

Data from this study are part of a larger project exploring screening attitudes and risk management in women with LS, which have been previously described (Huband et al., 2025). As part of their clinical care, participants receive counseling on LS gene-specific endometrial and ovarian cancer risks. This includes the risks, benefits, and limitations of screening methods such as endometrial biopsy and transvaginal ultrasound. Risk-reducing surgery is also discussed, including both benefits and potential risks, with decisions about whether and when to proceed with surgery being individualized based on the specific Lynch syndrome pathogenic mutation, personal and family history. When appropriate, the option of hormone replacement therapy after surgery is also discussed.

To be eligible for the current analysis participants had to: 1) have already received either total hysterectomy and/or bilateral salpingo-oophorectomy, 2) be age 18 years or older, 3) be diagnosed with LS (as confirmed by genetic testing, documented in the medical record), 4) be able to provide informed consent, and 5) be able to communicate in written and spoken English. Women who had not had RRS were excluded from these analyses.

2.2. Recruitment

For this study, participants from the Familial Gastrointestinal Cancer Registry (FGICR) at the Zane Cohen Centre were mailed an invitation letter and consent form if they had previously consented to be contacted for other research studies. After letters were mailed, study staff contacted potential participants to determine study interest and obtain informed consent. Participants were also recruited from one of the study investigator's gynecologic oncology clinics that provides speciality care for women with LS. Study staff approached potential participants during medical appointments, where study information was presented and informed consent was obtained. This qualitative study was approved by the Research Ethics Boards at Sinai Health System, University Health Network, and Toronto Metropolitan University.

2.3. Procedure

As previously described (Huband et al., 2025) participants provided their demographic, medical, and family history information via a questionnaire and participated in a qualitative interview. The FGICR and the gynecologic oncology clinic databases provided information on pathogenic variants. Interview questions focused on how participants made the decision to undergo RRS, the benefits and challenges of RRS, knowledge gaps about RRS and symptom management post-surgery, interactions with HCPs, and unmet needs with regard to symptom management post-RRS. Prior to beginning recruitment, two women diagnosed with LS and three genetic counsellors with LS specialization provided feedback on the interview guide.

All study participants took part in a semi-structured interview, which was conducted by a Master's level research associate. Each interview lasted approximately 45–60 min. Interviews were audio-recorded and then transcribed. All study data were securely stored at the study site on an internal server.

2.4. Data analysis

As previously described (Huband et al., 2025), interview data were analyzed using a qualitative descriptive methodological approach, which focused on the description of participants' shared or common experiences in the healthcare system (Kim et al., 2017). To determine themes and to interpret content meaning across interviews, thematic content analysis was used (Hsieh and Shannon, 2005). As part of thematic analysis codebook construction, two Master's level research staff each developed a list of themes from each participant interview. The study team involved in coding then compared and contrasted the themes and sub-themes from each of their codebooks. Disagreements and non-overlapping themes were discussed with the principal investigator, and ultimately resolved by consensus. Based on these processes, a final codebook was developed after a final review of all data from the transcripts.

3. Results

Table 1 provides study demographic and medical information. Participants ranged in age from 30–70 years (M = 50.47, SD = 10.3). The majority were White, married/partnered, had at least two children, employed full time, college-educated, and had a yearly income over 75,000 dollars. The following pathogenic variants were represented in the sample: *MSH6* (n = 6), *MSH2* (n = 3), *PMS2* (n = 3), *MLH1* (n = 2) and *EPCAM* (n = 1). Time since RRS was approximately 4 years (M = 4.33, SD = 2.58). Thirteen women had received TH-BSO, of which two participants first underwent TH (2012 and 2016, respectively) and later received BSO. Two women had undergone TH (one with *EPCAM* and the other with *PMS2*), and were planning to have BSO at a later time. Nine participants reported prior cancer in the following sites: colorectal (n = 3), breast (n = 3), ovarian (n = 1), thyroid (n = 1), and renal (n = 1). No participants reported more than one prior cancer. Average time since prior cancer diagnosis was over 7 years (M = 7.67, SD = 7.04) Ten participants reported a first-degree family member with prior cancer (some had several first-degree relatives with a cancer history), with colorectal cancer as the most common type.

Theme 1: Facilitators to Risk-Reducing Surgery.

During interviews, participants discussed several factors that motivated them to proceed with RRS as detailed in Table 2.

Table 1
Patient Demographics and Medical Information (N = 15).

Age	M = 50.47 years (SD = 10.3)
Range	30–70 years
Time since RRS	M = 4.33 years, SD = 2.58
Time since cancer diagnosis (n = 9)	M = 7.67 years, SD = 7.04
	N (%)
Pathogenic Variant	
MLH1	2 (13.3 %)
MSH2	3 (20 %)
MSH6	6 (40 %)
PMS2	3 (20 %)
EPCAM	1 (6.7 %)
Site of Prior Cancer Diagnosis (n=9)	
Colorectal	3 (33.3 %)
Breast	3 (33.3 %)
Ovarian	1 (11.1 %)
Thyroid	1 (11.1 %)
Renal	1 (11.1 %)
History of Types of Cancer in First-Degree Relatives (n = 10)	
Colorectal	6 (60 %)
Endometrial	2 (20 %)
Renal	2 (20 %)
Ureter	1 (10 %)
Breast	1 (10 %)
Lung	1 (10 %)
Pancreas	1 (10 %)
Stomach	1 (10 %)
Duodenal	1 (10 %)
Liver	1 (10 %)
Relationship Status	
Married/Partnered	13 (86.7 %)
Separated	1 (6.7 %)
Widowed	1 (6.7 %)
Participants with Biological Children	15 (100 %)
2 children	10 (66.7 %)
3 children	4 (46.7 %)
4 children	1 (6.7 %)
Employment Status	
Full-time	9 (60 %)
Part-time	3 (20 %)
Retired	2 (13.3 %)
Not employed	1 (6.7 %)
Income	
0–40 K	5 (33.3 %)
40–75 K	2 (13.3 %)
Over 75 K	8 (53.3 %)
Education	
Some College/University	2 (13.3 %)
College/University	11 (73.3 %)
Graduate School	2 (13.3 %)
Ethnicity	
White	12 (80 %)
Indigenous	1 (6.7 %)
Other	1 (6.7 %)
Missing	1 (6.7 %)

3.1. Burden of screening

The burdens associated with ongoing gynecologic cancer surveillance contributed to some participant’s decision to undergo RRS. Participants described feeling like they could no longer bear the emotional and physical toll of endometrial biopsies. Others discussed how the lack of certainty that the currently available gynecologic screening tests would be able to detect cancerous growth facilitated their decision for RRS. The nuisance of scheduling appointments and complicated logistics required to attend screening appointments also motivated some decisions to choose RRS.

Table 2
Theme 1 Demonstrative Quotes: Facilitators to risk reducing surgery.

Sub-theme	**Demonstrative Quotes**
Desire for peace of mind	*“I wanted peace of mind more than I didn’t want another surgery, so I think that’s what clinched it for me” (056)* *“If I can be preventative, I’m going to do it” (075)*
Family planning	*“I was done having children at that time and I knew I didn’t want to have more kids… I did put it off for a couple of years just because I didn’t feel physically ready to undergo a major surgery until she was kind of two years old because I was still nursing her at that time” (077)* *“If you don’t need the parts, then why keep them is kind of the way I look at it” (067)*
Presence of physical symptoms	*“I had been having a lot of problems with my period, I was suffering quite a bit, so I sat down with my gynecologist to talk about how much pain I was in and how much the bleeding was affecting my day-to-day life and not to mention the stress of like what is going on? Is this okay? And it was like well why keep it at this point, you know?” (014)* *“I also had a cyst on my ovaries that.. it wasn’t cancerous but it wasn’t going away so that was another reason to have the hysterectomy” (025)*
Burden of screening	*“Endometrial cancer is not an easy one to catch until it’s almost too late. And they’re very painful. Endometrial biopsies are very painful… So I guess for me why getting a hysterectomy instead of just continue with the screenings because they weren’t 100 % anyway” (030)* *“What was most important to me was that they told me that there was no screening for ovarian cancer and that’s why it’s called the silent killer. There’s no ultrasound, there’s no blood test, nothing and honestly it’s the only reason that I decided to get it done” (023)*
Personal or family history of cancer	*“I think I would have gone for it because of that, right, because I watched them suffer from it and go through all that” (056)* *“My mom had uterine cancer at 40, and I was just, you know, a couple years younger than she had her first cancer so to me, it was kind of, you know, it was a no brainer. Just get rid of that option… so it made the decision a lot easier just because, you know, I’ve seen what they’ve been through with everything” (067)* *“…It was reducing my risk of getting cancer again, I never wanted to sit in that chemo chair ever again… [early menopause] was still less of a risk than ever being diagnosed with cancer again” (076)*
Age	*“Number one, I was 45… being between 45 and 52, when I would naturally get it [menopause]… It wasn’t that big of a difference for me to deal with the risk” (050)* *“I don’t really see any drawbacks [from the surgery].. but it might be different for somebody who wasn’t already in menopause” (060)*
Trust in healthcare provider’s advice	*“Trusting your doctors is a lot of it and her experience. You know, I just felt very comfortable making that decision based on her recommendation” (062)* *‘Her [gynecologic oncologist] advice was really valuable to me because she was very clear about everything. Not that she pushed one way or another”* (077) *“She said typically they feel fairly confident that the laparoscopic will work, but because of my previous surgery, she wanted me to understand that it was more than just a little bit of a possibility that they were going to have to open, so for me, it was good though because I was prepared. When I woke up, I was excited that that didn’t have to happen, but I would have been ready if it did”* (014)

3.2. Desire for peace of mind

Participants discussed the psychological impact of managing their LS diagnosis and the anxiety associated with ongoing surveillance. Many of these participants discussed how their decision to undergo RRS was facilitated, at least in part, by the desire to reduce or entirely eliminate their risk for developing gynecologic cancer. In one example, a participant described a desire for “peace of mind” more than she did not want another surgery.

3.3. Family planning

Participants in this study had between two to four children (see Table 1). Every participant mentioned being finished with having children as contributing to their readiness to undergo RRS. Participants discussed various aspects of family planning, such as waiting until breastfeeding was finished and/or not needing their reproductive organs anymore, which made the decision to undergo RRS more straightforward. Furthermore, a number of women commented that being around for their children to grow up was a motivator in the decision to undergo RRS.

3.4. Presence of physical symptoms

For some participants, the presence of at least one physical gynecological symptom contributed to their decision to opt for RRS. Examples of physical symptoms described were gynecologic discomfort or pain, irregular bleeding, evidence or knowledge of cysts, and endometriosis. Some participants vividly described how ruptured cysts and the associated pain were impacting their quality of life. Moreover, the identification of unusual or precancerous cells in some cases was the catalyst for RRS because practitioners and patients alike did not want to take the risk.

3.5. Personal or family history of cancer

A personal or family history of cancer was another factor that many participants identified as contributing to their readiness for RRS. Participants described watching loved ones suffer or die from gynecologic cancer, which motivated them to be proactive about RRS to avoid a similar fate. Furthermore, for the nine participants who had prior cancer diagnoses, RRS surgery was appealing in order to reduce or eliminate the risk of developing gynecologic cancer altogether.

3.6. Age

For participants, being over 40 years was a factor in feeling ready to undergo RRS. Participants generally described how having already experienced peri- or post-menopausal symptoms facilitated their decisions to undergo RRS.

3.7. Trust in healthcare provider's advice

While many participants had read articles and done their own research about RRS, some described how the trusted advice of their HCP ultimately helped them to decide that surgery was the right choice . In fact, several participants spontenously mentioned being appreciative to have autonomy in making the decision to undergo RRS and not being forced into it by their HCP. Participants also discussed how their doctor's assurance that minimally invasive surgery could be perfomed facilitated their decision. In other examples, women relied on the advice of their HCPs to decide whether to remove their ovaries at the same time as their uterus. Although in the minority, a few participants did describe having to argue with HCPs to receive RRS, as some HCPs were resistant to the idea.

Theme 2: Women's Experiences of Surgery.

Participants discussed their experience with surgery during interviews, which included their physical recovery and physical changes post-surgery, as well as the sexual and psychological impacts of surgery, detailed in Table 3.

Table 3
Theme 2 Demonstrative Quotes: Women's experiences of surgery.

Sub-theme	Demonstrative Quotes
Long-term physical changes post-surgery	*"I had really heavy, painful periods, those are gone. I no longer struggle with the yeah, like the pains or the anything like that. So for me, honestly, I feel just as I did before I went in for my surgery, I can be as physical as I was, I'm as active as I was, I am normal in any other sense of the word… I just don't cycle anymore, so it really has been a positive thing for me"* (030) *"I don't know why I didn't think of this but it does kind of weird me out that my vagina just kind of ends.. like a sewn up tube.. so that kind of freaks me out a bit" (026)*
Impact on sexual health	*"It's just you used to be able to have longer periods of intimacy with your partner now it's kind of like a quick and fast thing or he has to be able to use other things to help and it's hard to accept that change"* (076) *"It had an effect on my personal sexual life or you know satisfaction, but I'm not regretful to that. I'm still happy I did it" (062)* *"I totally lost my sex drive" (025)*
Psychological impact of managing risk post-surgery	*"So, psychologically, for me, it was a great change because before - because my mother died at 47 - subconsciously, I was growing up thinking I'm going to have a short life span. But once I had the surgeries, something changed that I felt like now I can plan for the next 40 years because before I was thinking, 47, 48, is it. But now I'm thinking I'm going to the 90s. So it was very good. I think, from the risk factor, at least, psychologically, I feel much better" (050)* *"After my hysterectomy, for sure, I feel much more comfortable. I feel a lot more at ease now. Before, if I had any kind of cramp or anything, my brain would run really quickly to cancer and the worst possible thing… so yeah, definitely has calmed my nerves down a lot to know that it's no longer an issue… my anxiety about getting endometrial cancer has gone way down" (030)*
Post-RRS care from health care providers	*"She walked me through it [going on estradiol] and told me what to do and then said, you know, when you do decide, gradually increase it, and then when you come off it, you gradually decrease and she was the one who explained it all to me so yeah, that was a really big, big help for me"* (056) *"He coordinated my surgery with my gastroenterologist because he was worried that there might be some adhesions after my previous colorectal resection. So he actually had [doctor's name] come in when he first started my laparoscopic procedure to make sure there was no adhesions that would get in the way of him doing the hysterectomy. So he actually like partnered up with her, which was like, pretty wonderful"* (076) *"Then I was like is discharge still normal? Because I was having discharge as if I never even had my hysterectomy and she was like no you shouldn't have any… I kind of felt unheard, which wasn't nice"* (030) *"I don't know what I expected or what I wish it would have been otherwise.. I guess maybe more back and forth like do you have this? Do you have this? …like yes it makes the appointments a little bit longer but like I have numbness on my left thigh after my surgery… I'm like is this normal? She's like, I've never heard of that before… Yeah like well what do I do now?"* (030) *"I felt rushed and pushed and I felt like there's not enough time in the system to go through this with me"* (050)

3.8. Recovery post-surgery

Participants' experiences of physically recovering from RRS differed vastly. Some participants who had surgery done laparoscopically described the speed and ease of recovery. For other participants, tissue damage from previous surgeries or medical needs necessitated an open approach via laparotomy, which took longer to heal. One participant was adamant about three tools that assisted her physical recovery post-RRS including an abdominal binder, an electric heating pad, and medication that facilitated the release of gas.

3.9. Long-term physical changes post-surgery

A number of participants commented on the physical changes that occurred following RRS. On one hand, many participants welcomed the physical change of no longer menstruating. On the other hand, a couple of participants reflected on the increased risk of vaginal prolapse after RRS. Furthermore, some participants reflected on the changes in sensations with intercourse after RRS, which surprised them.

3.10. Impact on sexual health

In exploring the impact that RRS had on sexual health, participants' experiences ranged considerably. A participant who underwent total abdominal hysterectomy discussed the need to communicate with her partner about the need to wait 8–10 weeks to have sex. One participant described how her sex life satisfaction decreased for a number of weeks as she experienced a pulling sensation. Another participant shared her experiences managing traumatic pain from having sex that led her to figuring out she had residual scar tissue that needed to be cauterized.

3.11. Psychological impact of managing risk post-surgery

Following RRS, participants' described how the emotional experiences of managing their gynecologic cancer risk inevitably changed. The majority of participants reflected on the positive changes that RRS had on their mental health such as improved quality of life, reduced anxiety, and less fear about the emergence of cancer.

3.12. Post-RRS care from health care providers

In discussing positive experiences with the HCPs who managed their post-operative care, participants discussed having adequate time during appointments to ask questions; HCPs listening to their concerns; effective coordination of their care; and follow-ups from HCPs offered as needed. For example, participants noted times when their HCPs listened to their concerns around unexpected pain, were responsive to finding solutions, and respected their ultimate decision-making.

Negative interactions with HCPs mostly centered around themes of feeling dismissed or neglected, rushed during appointments, and facing barriers in booking follow-up appointments with preferred HCPs (e.g., with a gynecologic oncologist when cancer in remission). Some participants expressed a desire to have follow-ups pre-booked instead of having to call and book an appointment in response to symptoms.

Theme 3: Women's Experiences Managing Symptoms of Menopause and the use of Hormone Replacement Therapy (HRT).

Participants discussed the impact of menopausal symptoms on their life, as well as the impact of HRT, detailed in Table 4.

3.13. Symptoms of menopause

All participants discussed the impact of RRS on menopause. Participants' experiences ranged considerably in terms of how long after RRS menopausal symptoms started, the number of symptoms felt, the intensity of symptoms, and to what extent their functioning was impacted. For the most part, participants discussed the negative impacts of menopausal symptoms on their lives. Some also described how their symptoms impacted their partners or family members. The most common symptoms of menopause discussed were hot flashes, night sweats, weight gain, and mood changes.

Menopausal symptoms experienced less commonly by participants included hair loss, vaginal atrophy, vaginal dryness, urinary incontinence, changes in memory, difficulties with concentration and focus, and the development of sleep apnea. Interestingly, a number of participants spoke about their confusion and ambiguity in their understanding of whether RRS caused these symptoms or just magnified symptoms that were more dormant before RRS.

Table 4

Theme 3 Demonstrative Quotes: Women's experiences managing symptoms of menopause and the use of hormone replacement therapy (HRT).

Sub-theme	Demonstrative Quotes
Symptoms of menopause	*"I had them all. I had night sweats, I have insomnia, I have brain fog. I had discomfort, I guess. All of the menopause side-effects pretty much all hit me all at once about 6 months later. All of them" (023)*
	"The other part of what was the anxieties and the hormonal imbalance, you know, the weight gain and the being in PMS mode without hormone replacement therapy… and being young for menopause and worrying about life and what would it do? What would it do to my relationship? What would it do to my husband, to my marriage? And then the heat, the hot flashes were not easy" (050)
	"My ovarian surgery actually made all of my menopause symptoms even worse and that's how my ADHD was diagnosed because menopause can actually make your ADHD become even worse. So I gained 12 lb in 2 months and I totally lost my mind" (023)
	"Night sweats and things like that, I suppose, you know, or maybe related to menopause, but I'm not really super sure" (071)
Hormone Replacement Therapy	*"She explained to me that for other cancers, I think it was breast cancer… it's recommended that you do get the hormone replacement until like the age of 50. Just because it reduces the risk for that type of cancer as well" (077)*
	"[with estradiol] within 2 weeks all of my side effects were gone" (023)
	"It's been great. I use a topical gel once a day and when I first had the surgery, I had a little bit of like hot flashes and things like that and trouble sleeping, but since being on the hormone replacement.. I'm a normal person's temperature now" (067)
	"For hormone replacement therapy with Lynch, you can't take it past 50 and you can only take it for a maximum of 5 years" (023)
	"I spoke to my doctor, my GP, about hormone replacement therapy but he said just because of my history, he didn't think it was a good idea because of the breast cancer, the high chance of getting breast cancer, so I haven't gone on any sort of hormone replacement therapy" (025)

3.14. Hormone replacement therapy

The majority of participants (n = 13) from our sample had TH-BSO, and they considered the use of HRT. Only two participants had not yet undergone BSO, but planned to in the future. Most participants who were <50 years old and who had not yet experienced natural menopause, described conversations with HCPs about the use of estrogen replacement therapy to manage the symptoms associated with surgical menopause (discussed above). Other reasons for HCPs to recommend use of estrogen to participants <50 years of age were to reduce the risk of breast cancer, and to maintain bone density. Many participants were grateful for the intervention and experienced relief.

The most common reason for deciding against HRT even for participants who had their ovaries removed was being past the age of menopause and therefore, not experiencing menopausal symptoms as intensely. For three participants with previous breast cancer diagnoses, HRT was not advised by their HCPs.

Theme 4: Unmet Informational Needs.

Participants discussed their unmet informational needs pre- and post-surgery, detailed in Table 5.

Table 5
Theme 4 Demonstrative Quotes: Unmet informational needs.

Sub-theme	Demonstrative Quotes
Pre-RRS: Managing expectations	*"There's this Lynch support group for young survivors and there's a lot of healthy, fruitful discussions on there that was really great but again, I found that on my own. No one told me about that and I think those pieces would be really helpful"* (076) *"It was just that I didn't have enough information about how I'm going to feel afterwards. What's it going to do to my body?"* (050) "*Getting it done for me was not as big of a factor as when to get it done.. that is, the hardest part as a mother of four is how do you manage that? Right? Like, okay, I'm going to have a hysterectomy but with my previous scarring and surgeries and all of that, like what kind of surgery will it be? Will it take me six weeks or recover? Will it be less than that? Will I be able to do anything? Or will I not be able to? So that, I think, was the biggest factor for me.. was how am I going to manage taking care of my kids?*" (030)
Post-RRS: Heightened risk of other ailments	*"It's not good to have it too young I don't think right because you will end up with a whole bunch of unnecessary symptoms like osteoporosis and you know, it's a difficult thing to measure against and every person is different. So you know, lose one set of worries and you gain another so it's a tricky one, yeah" (056)* *"Having ovaries removed at a young age actually shortens life expectancy because it can cause heart disease"* (014) *"I do worry about bones breaking so I should be taking a calcium pill and I did start taking one but I've kind of fallen off the wagon with that but that is a concern in terms of like bone density and stuff"* (076) *"There seems to be this unclear knowledge out there, medically, I don't know if it has not been enough research done whether or not MSH2 actually does increase your risk for breast cancer.. so here I am on hormone replacement therapy, it does increase your risk for breast cancer but if you have MSH2, currently, they're saying that that's not a concern, versus if you had if you're, you know, had the BRCA gene or whatever. Anyway, so that's kind of not a drawback, but I would say, an ongoing, lingering, question… Should I be on hormone replacement therapy? So that's one sort of drawback that nobody seems to have the answer to"* (076)
Post-RRS: Ongoing need for gynecologic cancer surveillance	*"I asked, I was like, so should I still be doing pap smears even though I don't have a cervix? I've heard people with Lynch syndrome, do get pap smears because there could still be some kind of cancers that are out there and she's like oh, no, you don't need to do that. You don't have a cervix. And I was like, no, I know, I don't have a cervix but I've heard that other people in the past… And I was like, I understand that. But the tissue around cuff could still have cells on it or whatever. She's like, no, no, you don't need that"* (030) *"I have no idea what kind of screening is recommended for me at this point. I don't have a uterus and I have no idea. I've actually been planning on calling my gynecologist to say like hey, what is our next step? Are we screening for my ovaries? Do I have to get paps done? What are my next steps in terms of screening and care?"* (014) *"Now I have to go back and have my pap done because I guess the lining of my uterus can still have cancer or I can still develop cancer there even though I have no plumbing"* (023)

3.15. *Pre-RRS: Managing expectations*

Some participants expressed how it would have been helpful to have more information ahead of RRS about the impact of surgery on their bodies. Participants described how having a better understanding of what to expect in the weeks following RRS (e.g., bedrest time estimate, impact on their sex life) beforehand, would have facilitated better planning and care. Many participants also suggested that HCPs should provide women considering RRS with other women's accounts of their recovery so that they can plan ahead. Ideas suggested were connecting women with LS support groups, giving women credible written materials to review before making decisions, and connecting women to an ongoing point person who would assist in managing their care.

3.16. *Post-RRS: Heightened risk of other ailments*

Participants described doubts, fears, and anxieties about the heightened risk of developing other conditions following RRS. There was significant uncertainty around the removal of ovaries and the role that HRT plays in elevating or mitigating risks of heart disease, stroke, osteoporosis, and other types of cancer. Participants expressed wanting more information about preventative steps that they could take. Additionally, women with previous diagnoses of cancer who were not eligible for HRT requested more information about other ways of coping with symptoms of menopause.

3.17. *Post-RRS: Ongoing need for gynecological cancer surveillance*

Another area in which participants expressed confusion was the need for ongoing gynecologic surveillance post-RRS. When participants from the study asked their practitioners about this, they were often times dismissed. Participants wondered about the need for screening in the vaginal vault area, lining of the uterus, cervix, and ovaries (if not removed in RRS). Some participants wished for a protocol of what screening tests should be completed annually before and after RRS.

4. Discussion

This study identified four major themes in LS women who had undergone RRS: 1) Facilitators of undergoing RRS, 2) Experiences of surgery, 3) Experiences of managing menopause and using HRT, and 4) Unmet informational needs.

Several factors were important for participants' decision to undergo RRS, such as a desire for peace of mind about cancer, being done with family planning, and "feeling old enough". These factors have also been documented in the literature of women with *BRCA 1/2* pathogenic variants (Alves-Nogueira et al., 2023; Polus et al., 2024). Participants in the current study described ongoing gynecologic symptoms (e.g., bleeding, cysts) that also contributed to undergoing RRS. Importantly, the burden of yearly gynecologic screening tests and accompanying doubt of efficacy of those tests were key facilitators to RRS. For example, participants were sharply aware of the lack of sensitivity of endometrial biopsy and pelvic ultrasound as screening tools. Participants also identified personal experiences with other family members with LS. Finally, trust in one's HCP strong recommendation for RRS was important to participants. Our findings fit into the small literature examining reasons for obtaining RRS among women with LS, which have also noted family histories of cancer (Moldovan et al., 2015), age >40 years, parity, and gynecological problems (Etchegary et al., 2015) as facilitators to surgery. Clearly, a number of participants in this study had positive relationships with HCPs providing LS-specific care, as they were aware of the limitations of gynecologic cancer screening and trusted their strong recommendations to obtain RRS.

In line with prior qualitative research (Etchegary et al., 2018; Moldovan et al., 2015), participants described how RRS negatively impacted their sexual and physical health. All highlighted menopause as a major impact to their quality of life, and commented on typical physical symptoms (e.g., hot flashes, vaginal dryness), but also unexpected problems much as memory, concentration, and sleep apnea. Menopausal symptoms and worsened sexual health are commonly experienced post-RRS, as reported in a systematic review of qualitative studies investigating RRS experiences of women with *BRCA1* and *BRCA2* pathogenic variants (Alves-Nogueira et al., 2023). In the current study, most participants used HRT to manage their post-RRS menopausal symptoms, unless it was contraindicated by a prior history of breast cancer. Most participants who used HRT found it made a positive impact on menopausal symptoms, but some expressed worry about the long-term effects on their health.

Relationships with and trust in HCPs were important themes in this study. A study of RRS in women with *BRCA* 1 and *BRCA 2* pathogenic variants showed participants had varying experiences with HCPs, for example, some described being able to engage in shared decision making, while others felt their HCPs were so unsupportive about RRS that they had to switch clinicians (Polus et al., 2024). Our data reflect these findings, with several women reporting having their autonomy and decision-making about RRS respected, while a minority had to argue with HCPs about RRS. Importantly, several, although not all, participants in the current study had been referred to an HCP with LS expertise at a centre of excellence. Other research from the *BRCA 1/2* literature documents challenges in patients navigating cancer risk-reduction strategies and feeling confused when HCPs gave conflicting information (Caiata-Zufferey et al., 2015). Our data showed women felt their post-RRS care was either very helpful, or that it lacked in the information they needed to take care of their bodies after surgery (discharge, numbness) or in approach (e.g., being rushed). These findings are consonant with studies documenting the desire for more information prior to RRS (sexuality, menopausal symptoms, coronary heart disease, osteoporosis) as well as how to manage post-operative symptoms (e.g, Campfield Bonadies et al., 2011; Brotto et al., 2012; Hallowell, 2000; Philp et al., 2022).

Participants noted generally positive impacts on anxiety and fear of cancer post-RRS, which has been reported in both LS and *BRCA* studies (Etchegary et al., 2018; Moldovan et al., 2015; Polus et al., 2024; Hickey et al., 2021; Philp et al., 2022; Altman et al., 2018). While the fear of gynecologic cancer was reduced after RRS, many participants described worrying about the negative impact of HRT on other organ systems and physical functioning. Concerns about HRT risks have also been found in other studies of those with inherited cancer syndromes (Alves-Nogueira et al., 2023). Importantly, participants had questions and expressed confusion about any further LS-related gynecologic cancer surveillance. Some participants did not possess accurate information about gynecologic cancer screening. Participants clearly described what kinds of information they would have needed both pre- and post-RRS. To plan for aftercare, they wanted more information about expectations for symptom management, work, and resuming sexual activities. Several commented that hearing other patient recovery stories would have been helpful.

5. Limitations

This is a small sample recruited from a registry and many of the participants had been referred to a gyncecologic oncology surgeon with LS-related expertise at a centre of excellence. Moreover, those who participated were largely Caucasian, educated, and comfortable talking about gynecologic surgery. Therefore, these findings may not be generalizable to other groups of patients or those in other types of healthcare settings. In addition, participants were on average 4 years from RRS, which may bias their recollection of the experience. Future research should replicate this work with women who recently had surgery and may wish to examine RRS decision-making processes prior to surgery.

6. Conclusions

Our study adds to a small literature on the experiences of LS women post-RRS. Novel aspects of our findings are the unmet informational needs with regards to the immediate and long-term post-surgical phases, worry about heightened risk of other physical problems, such as osteoporosis, heart disease, and breast cancer, and confusion around need for gynecologic cancer surveillance. This study is also novel with regard to examining a sample of participants who all had access to health care in Ontario; unmet needs may be even greater for patients in a privatized healthcare setting. These data suggest a number of targets for intervention from HCPs who are involved in the pre-surgery phase, as well as HCPs involved at later phase of care for women with LS. HCPs can consider having these discussions at point-of-care and developing electronic materials for patient use.

7. Ethical approval and consent to participate

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. This study was approved by the Toronto Metropolitan University Research Ethics Board (REB# 2019-466-2), the Mount Sinai Hospital Research Ethics Board (REB #19-0225-E) and University Health Network Research Ethics Board (REB# 19-6329). All participants provided informed consent.

CRediT authorship contribution statement

Helen Huband: Writing – review & editing, Writing – original draft, Visualization, Validation, Project administration, Investigation, Funding acquisition, Formal analysis, Data curation. **Kaitlin M McGarragle:** Writing – review & editing, Writing – original draft, Visualization, Validation, Investigation, Formal analysis. **Crystal J Hare:** Writing – review & editing, Methodology, Conceptualization. **Melyssa Aronson:** Writing – review & editing, Resources, Methodology, Conceptualization. **Thomas Ward:** Writing – review & editing, Writing – original draft, Resources, Methodology, Data curation, Conceptualization. **Kara Semotiuk:** Writing – review & editing, Resources, Methodology, Conceptualization. **Sarah E Ferguson:** Writing – review & editing, Resources, Methodology, Conceptualization. **Zane Cohen:** Writing – review & editing, Resources, Methodology, Conceptualization. **Tae L Hart:** Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization.

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Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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