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Commentary

Cancer Prevention Research

For Women, Lynch Syndrome Is About More than Colon Cancer

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Abstract

Lynch syndrome, also known as hereditary nonpolyposis colorectal cancer, has historically been characterized by a predisposition to colorectal cancer; however, for women with Lynch syndrome, the risks for gynecologic cancers pose an equal or greater risk than colorectal cancer. In addition, the gynecologic cancer is often the first cancer that presents in these patients. Also of importance to women with Lynch syndrome is the efficacy of gynecologic cancer screening being significantly lower than colorectal cancer screening, leading to inconsistency in provider recommendations for gynecologic screening and surveillance. We had the chance to listen to women with Lynch syndrome, in their own words, discuss their health care experiences as they relate to gynecologic cancer risk, and identified several important themes. They describe feeling confused about their screening and surveillance options while also being heavily reliant on their health care providers for guidance. In addition, women with Lynch syndrome discuss attempting to balance medical management of Lynch syndrome with their reproductive choices. Finally, they believe that increased awareness by women and their providers about the gynecologic cancer risks associated with Lynch syndrome should be a higher priority. We view the words of these women as a call to action for Lynch syndrome patients, clinicians, researchers, and advocates.

Cancer Risks and Screening and Surveillance Recommendations for Women with Lynch Syndrome

Lynch syndrome, also known as hereditary nonpolyposis colorectal cancer, has historically been characterized by a predisposition to colorectal cancer (1–3). However, for women with Lynch syndrome, gynecologic cancers can pose an equal or greater risk than colorectal cancer and can present as the first cancer diagnosis (4–6). While individuals with Lynch syndrome face an increased risk for multiple cancers, women specifically face an increased risk for endometrial and ovarian cancers (see Table 1; refs. 1–3, 6, 7). Women with Lynch syndrome have a 16%–71% estimated lifetime risk for endometrial cancer and a 6%–12% risk for ovarian cancer, with variations reported on the basis of gene mutation (6, 8–12). In comparison, women in the general population have a 2.6% lifetime risk of endometrial cancer and a 1.4% lifetime risk of ovarian cancer (6, 13). The average age at onset for both types of cancer is less than 50 for women with Lynch syndrome, with mutation possibly impacting age at diagnosis (6, 8, 9, 13, 14). In addition to these gynecologic cancers, there has been a debate about whether breast cancer risk also is increased in this population (15). Currently, complex screening and surveillance recommendations are the best way to increase survivorship for individuals with Lynch syndrome (3, 6). For colorectal cancer, there is evidence to support the recommendation of a colonoscopy every 1–2 years starting between the ages of 20–25 years old, or 5 years before the youngest case of colorectal cancer in the family (6, 16–18).

In contrast to colorectal cancer risk management, there has been debate about the evidence for the screening and surveillance recommendations for Lynch syndrome–associated gynecologic cancers (see Table 2). To increase efficacy, the literature supports a transvaginal ultrasound in conjunction with an endometrial biopsy that should begin annually at the age of 30–35 years old (3, 6, 19, 20). However, the strength of evidence for this recommendation, including in the current guidelines by the National Comprehensive Cancer Network (NCCN), is considered "insufficient" to recommend for or against screening because the majority of data are observational, lack a comparator group, and lack information on compliance rates (3, 6, 19–22). In addition to screening and surveillance recommendations, there has been limited data to suggest that birth control, including oral contraceptives

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Table 1. Cancer risk by gene mutation compared with general population (6)

	Population	*MLH1* or *MSH2*		*MSH6*		*PMS2*	
Cancer	**risk**	**Risk**	**Mean age of onset**	**Risk**	**Mean age of onset**	**Risk**	**Mean age of onset**
Colon	4.5%	52%–82%	44–61 years	10%–22%	54 years	15%–20%	61–66 years
Endometrium	2.7%	25%–60%	48–62 years	16%–26%	55 years	15%	49 years
Ovary	1.3%	*MLH1* – 11%–20% by age 70 years	45 years – *MLH1*	*MSH6*: There are limited data on ovarian cancer risk, with some studies suggesting average risk and some suggesting increased risk.			
		MSH2 – 15%–24% by age 70 years	43 years – *MSH1*	*PMS2*: There are limited data on ovarian cancer risk.			

and depomedroxyprogesterone acetate, may potentially decrease the risk of endometrial cancer, however further data is needed (4, 6, 23–25). Women with Lynch syndrome are recommended to consider a prophylactic total hysterectomy and bilateral salpingoophorectomcy (THBSO) after childbearing is complete to decrease their risk of endometrial and ovarian cancers (3, 4, 6, 26).

Awareness of Lynch syndrome by both patients and clinicians is often as a result of the colorectal cancer risk, for which the screening and surveillance guidelines are relatively straight forward. However, the reality for women with Lynch syndrome is that the gynecologic cancer risks are not nearly as well understood or managed. Information on these gynecologic cancers are far more limited, screening and surveillance recommendations can be missing or conflicting, and often the most consistent clinical advice is to remove a women's reproductive system once childbearing is complete. In addition, the information reaching women with Lynch syndrome about their gynecologic cancer risks is inconsistent, which inhibits compliance for these high-risk women.

In a recent study examining transitions in care for patients with Lynch syndrome, women shared their thoughts and experiences regarding extracolonic cancer risk, screening, and surveillance. These women were recruited through social media as described in Burton-Chase and colleagues and asked to complete both an online survey and a follow-up telephone interview (27). We completed qualitative inductive coding of the interviews of only women with Lynch syndrome. We analyzed the information they shared about risk, guidelines, and screening information, as well as how the women acted on the information shared with them by their health care providers. While this was not the primary focus of the study and participants were not directly asked about specific recommendations regarding gynecologic cancer risk, we found the insights shared by these women to be highly compelling and worthy of a commentary. Basic demographic information for our cohort can be found in Burton-Chase and colleagues (27). This is an understudied area with limited information and guidance available to both patients and clinicians and hope that sharing the experiences of these women, in their own words, can bring some additional awareness to this important women's health issue.

Table 2. Gynecologic cancer screening and surveillance guidelines for LS (6)

Endometrial cancer:

Women should be educated about the reporting of any abnormal uterine bleeding, which could include further evaluation through endometrial biopsy.

Hysterectomy is a risk-reducing option to be considered because it can reduce the incidence of endometrial cancer. Depending on whether childbearing is complete, comorbidities, family history, and LS gene mutation, the timing of a hysterectomy should be an individualized discussion.

Endometrial biopsy every 1–2 years can be considered as a diagnostic tool for women with LS.

Transvaginal ultrasound is not recommended as a screening tool for premenopausal women, but may be used for postmenopausal women at the clinician's discretion.

Ovarian cancer:

The incidence of ovarian cancer can be reduced by a bilateral salpingo-oophorectomy, but it is a an individual risk-reducing option for women who have completed childbearing, comorbidities, family history, LS gene mutation, or menopause status. There is insufficient evidence for *MSH6* and *PMS2* mutation carriers having a risk-reducing salpingo-oophorectomry.

There is currently no effective screening for ovarian cancer, but education of women on known symptoms including pelvic or abdominal pain, bloating, increased abdominal size, or urinary frequency or urgency over a period of week and/or a change necessitates a prompt evaluation by a doctor.

While screening can be helpful on an individual basis, there is no support for routine ovarian cancer screening for LS women. Transvaginal ultrasound is not sensitive or specific as a screening tool and should be used at the clinician's discretion.

Reproductive options:

For women patients of reproductive age with LS, prenatal diagnosis and assisted reproduction including preimplantation genetic diagnosis should be considered options.

Abbreviation: LS, Lynch syndrome.

In Their Own Words: What Women with Lynch Syndrome Say About Their Health Care

The women we interviewed are clear that ***Lynch syndrome is more than colon cancer.*** The most prevalent themes that we identified in these interviews include: (i) having concerns about gynecologic cancer risk not being taken seriously, (ii) their fear and anxiety about gynecologic cancer risks, (iii) confusion about what screening, surveillance, and preventive options are recommended including broader conversations about reproductive decision making, and (iv) relying heavily on health care providers, who they do not necessarily believe are as educated as they should be on gynecologic cancer risks associated with Lynch syndrome, for support, knowledge, and guidance when making difficult choices. In addition, the women discussed patient-provider communication and how they

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would like their providers to talk to them about their cancer risks, risk-reduction options, and overall reproductive choices.

The women we interviewed were consistent in discussing that ***they need to have their concerns about gynecologic cancer risk taken more seriously by providers***. For example, one patient explained: *"The very first oncologist I saw [said] "No, you don't need a hysterectomy. No, you don't need additional screening. No, you don't need any follow-up." Every concern I raised, he dismissed. He said, "You're only a stage I ovarian cancer patient." I understand that, but there's got to be a reason why I have this when no one else in the family has it. And his response to me. . ., "Well, somebody's got to be the first."* This concern seems to be especially true when the first cancer presenting in the family is not colorectal cancer.

Women with Lynch syndrome describe feeling ***a sense of worry about cancer that is pervasive, but also feeling like they do not know what option is best for them***. *"[I] don't want to have to think about getting a hysterectomy at the age of 35 or making the decision not to have kids, because it is overwhelming. . .. . ."* Prior studies have recognized that the decision to undergo a prophylactic THBSO is complex and involves many factors such as worry about cancer risk, understanding of the cancer experiences of other people, physician recommendations, and informed decision-making (28–30). Specifically, one of the areas of need that was identified both in our study and by Etchegary and colleagues was the need for better patient understanding of surgically induced menopause (28). One participant said: *"Endometrial cancer is almost up there with colon cancer as a risk for Lynch syndrome. . .Being placed in early menopause and just the risks and the benefits of what that means for Lynch patients. . .I think that's an area that deserves just as much attention as the colon cancer conversation."*

Women with Lynch syndrome report ***relying heavily on their providers for support and knowledge***. One woman said: *"He [the gastroenterologist] suggested that I talk to my OB about potentially getting a hysterectomy, because that was a recommendation for people with Lynch syndrome. He wanted me to start having that conversation with my OB. . .and see if that's right for me."* These provider conversations can lead to confusion by women in regards to what the gynecologic cancer risk estimates mean for them as individuals. One woman explained: *"The medical geneticist said, 'You really want to have a hysterectomy. . .the numbers are. . .60 percent of women are going to have uterine cancer by the time they're 75.' 60% is a pretty high number. 75 is a pretty old age. So in my head, I'm thinking 45 is quite a ways from 75, and 60 isn't 100."* Women also talked about the need for in-depth conversations with knowledgeable providers to understand all of their options: *"The providers down here have been telling me that I should have a total hysterectomy by 27. And that was just a scary thought. So when I went to the gynecologist up there, she. . . said, "I don't see a reason for you to have to lose anything before 35." And so having that fear alleviated, knowing that I wanted to be a mother, and also just the way she said, "Here's the guidelines we're going to take as far as treating you from a gynecological standpoint." So having that ability to see what her steps are going to be. . .I have never spent that much time with a physician in my life."*

In terms of ***how providers should discuss the options women have for treatment***, one woman stated: *"Well maybe if they present two avenues. One avenue is, "We should have the surgery right away. This is the easiest thing. You don't have to have any following screens. It completely eliminates this particular risk." And the other side is, "You have to go into your uterus every year and they sample some of the tissue and that's a really uncomfortable procedure." That's kind of how they talk about it, but they don't give you the middle of the road. They don't give you the [option], "Maybe we could ride that out for a few years and get you closer to your natural menopause age." And then the hot flashes might not be so bad, where you take someone who is so young and just take out all of their hormones and expect that it's going to be magically fine. It wasn't magically fine. It was horrible."*

Finally, many of the women we spoke to talked about the ***personal journey*** they are on and how ***imperative they think it is that providers be better educated on the*** Lynch syndrome–***associated gynecologic cancer risks***. As one woman said: *". . ..potential hysterectomy and removal of all my reproductive organs. That's a pretty personal thing to talk about, and I'm trying to make the decision that's best for me personally as well as medically. It's easy to talk to the providers about that to understand the medical risks. When you talk to family members or others about that kind of stuff it becomes much different, more from a psychological standpoint. I suppose they are valid things to think about, but what's worse, to have some hot flashes or get cancer? It's definitely a more objective and scientifically based opinion."* Another woman indicated that she needed time to process and work with her provider on her own. *"She [Physician] told us what screenings needed to be done. After the family left, I held back a little bit and I talked to her – one-on-one. . . about some concerns that I have that I just didn't want to say in front of the family, because my brother was like, "Yes. Yeah, we need to get this done." And I was like, "Wait a sec. You know, you're just – all it involves for you is to have your colonoscopy and your endoscopy. For me it was involving having a hysterectomy."*

Where Do We Go From Here?

There is a lack of strong evidence supporting the use of transvaginal ultrasound in conjunction with an endometrial biopsy for cancer screening and surveillance. While a hysterectomy with oophorectomy may present a more efficacious way to mitigate cancer risk, this choice comes with other risks. Our data show that women with Lynch syndrome face two major challenges: first, in raising awareness of the gynecologic cancer risks associated with Lynch syndrome, and second, in navigating their own personal

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journey through complex reproductive decisions. The women we spoke to did not describe a linear pathway from screening to surveillance to reproductive and health care decision-making. They did not solely focus on specific aspects of provider recommendations such as screening challenges or the impact of changing clinical guidelines on health care decision-making. Instead, the women focused on the quality of the provider relationships, the providers' expertise in Lynch syndrome, and the inherent dynamic of their conversations with their provider. For example, these women discuss weighing cancer risks against reproductive choices, while relying heavily on their providers for medical insights and less emotional advice.

While limited in its scope, this commentary is a call for action for women with Lynch syndrome and their providers. The research community needs to generate more data on the efficacy and timing of medical management of gynecologic cancer risk to inform both women with Lynch syndrome and their providers. It also is imperative that we continue to investigate the mutation-specific recommendations so that women can be counseled using the most accurate information possible. In addition, more needs to be done to educate gynecologic providers on Lynch syndrome, so that in-depth, accurate patient–provider conversations are possible. The women we spoke to discussed being confused about their screening, surveillance, and prevention options in addition to their reproductive decision-making. As a result of this confusion, women discuss fear and anxiety related to making the appropriate choices for themselves. To mitigate these issues, providers need to have access to more accurate information on surgical guidelines and the consequences of the choices women face in terms of reproductive timelines. For example, when should a woman choose to freeze eggs to preserve fertility? Or when should a woman consider a THBSO? It also is clear that researchers need to conduct additional studies on patient–provider communication to make these difficult conversations more about individual choice and less about following recommendations that are considered "insufficient" for recommendation in the entire patient population.

In terms of future research questions, we suggest starting with the following:

(i) How are the gynecologic cancer risks being interpreted by health care providers and how are these risks being discussed with patients?
(ii) What is the level of current provider awareness, particularly among providers outside of comprehensive cancer centers who may have limited interaction with women with Lynch syndrome, of these gynecologic cancer risks? Are they aware of differences by gene mutation? Do they believe there are opportunities to have access to the most up-to-date information for these high-risk patients?
(iii) Given that these women report being highly reliant on their health care providers for guidance, in what ways can we engage and inform these providers? Alternatively, what resources could be developed to increase patient knowledge and lessen the burden on providers?

As we have already stated, for women, Lynch syndrome is about more than colon cancer. The lack of clear screening, surveillance, and preventive guidelines for gynecologic cancer risks leads to additional complexities for these women in terms of decision-making and patient–provider interactions for extracolonic cancers. The initial diagnosis of Lynch syndrome and the decisions women make about their care can impact their family members. For example, first-degree relatives may base their decisions to undergo genetic counseling and testing partially on the cancer risk information probands received from their health care providers. This commentary is a call to action for clinicians and providers, and we hope that the proposal of future research questions leads to better overall care for this high-risk patient population. Women with Lynch syndrome need, and deserve, more accurate and complete information to feel empowered and less alone in making what is clearly a complex and personal set of decisions. Finally, providers for these women need more evidence-based directions on how to enact the evolving NCCN guidelines.

Disclosure of Potential Conflicts of Interest

No potential conflicts of interest were disclosed.

Authors' Contributions

Conception and design: W.M. Parker, K. Hennig, A.M. Burton-Chase
Development of methodology: W.M. Parker, A.M. Burton-Chase
Acquisition of data (provided animals, acquired and managed patients, provided facilities, etc.): W.M. Parker, K. Hennig, A.M. Burton-Chase
Analysis and interpretation of data (e.g., statistical analysis, biostatistics, computational analysis): W.M. Parker, K. Hennig, A.M. Burton-Chase
Writing, review, and/or revision of the manuscript: W.M. Parker, K. Hennig, A.M. Burton-Chase
Administrative, technical, or material support (i.e., reporting or organizing data, constructing databases): W.M. Parker, A.M. Burton-Chase
Study supervision: A.M. Burton-Chase

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