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Patients educating health care providers on Lynch syndrome

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Cover Page Footnote

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Abstract

Objective: Lynch syndrome (LS) patients are at an elevated risk for early-onset cancers, including endometrial and colorectal (CRC). Prior research has shown a deficit in provider knowledge of LS, which may affect patient satisfaction and adherence to recommended screening and surveillance regimens. Studies suggest patients with LS may educate providers perceived as lacking LS knowledge; however, little is known about these interactions. The goal of this study is to assess patient-reported outcomes from clinical interactions where LS patients educate their providers.

Methods: Participants (n=55) were asked to complete an in-depth telephone interview.

Results: Out of 55 participants, approximately two-thirds (n=37) reported engaging in educational interactions.

Participants reported feeling satisfied with the provider response in over half of the reported educational interactions (n=24). Participants reported changes in their patient-provider relationship ranging from improvements in their relationship to termination of services. **Conclusion:** Patients with LS report educating providers on their diagnosis as well as their screening and surveillance requirements. Patient-reported outcomes of these educational interactions vary based on the provider's response to the interaction. Providers should be open and receptive to these educational interactions and follow-up on the discussion to improve patient satisfaction.

Keywords

Lynch syndrome, colorectal cancer, patient-provider communication, shared decision making, patient-centered care

Introduction

Due to an increased risk for multiple cancers, it is recommended that patients with Lynch syndrome (LS) follow a complex screening and surveillance regimen.^{1,2} This recommendation is crucial for the early detection of malignancies; however, patient adherence to this regimen may be influenced by their physician's knowledge of LS.³⁻⁵ Current literature describes gaps in the knowledge of providers on LS.⁶⁻⁸ In a study on the barriers and facilitators to the management of patients with LS, Watkins et al. briefly reported that patients with LS were willing to educate providers who demonstrate limited knowledge of LS.⁸ Outcomes and descriptions of these educational interactions remain unclear. The authors could not identify any further literature in this area. This study aims to further explore how patients with LS engage in educational interactions with their providers about their diagnosis as well as their screening and surveillance requirements

What is LS?

LS, also known as hereditary non-polyposis colorectal cancer (HNPCC), is characterized by a predisposition to several early adult-onset cancers, most predominately colorectal, endometrial, ovarian, and gastric cancers.^{1,8-15} Other associated cancers include, but are not limited to, liver, pancreatic, urinary tract, and small bowel.^{1,8,15} Approximately 3% of colorectal cancers can be attributed to LS.¹⁰ The increased risk in cancer is due to an autosomal dominant inheritance pattern caused by germline mutations in mismatch repair genes, specifically *MLH1*, *MSH2*, *MSH6*, *PMS2*, or a deletion in the *EPCAM* gene.¹⁴⁻¹⁹ These alterations are identified through clinical genetic counseling and testing, initially identified in individuals with the related cancers.¹

In order to mitigate the risk for these cancers, individuals with LS are advised to follow a complex medical management regimen.^{1,2} The medical management for LS includes a colonoscopy every 1-2 years starting between the ages of 20-25 years old, or 5 years before the youngest case of LS in the family for colon and rectal cancer screening.^{15,17} Gynecological examinations, including pelvic examination with endometrial sampling and

transvaginal ultrasounds, should begin annually at the age of 30-35 years old.^{1,2,15,17} It is recommended that women with LS should consider prophylactic hysterectomy and salpingo-oophorectomy after childbearing is completed if desired.^{1,2,15,17}

Providers' Gaps in Knowledge

Prior studies have identified gaps in LS knowledge among primary care providers (PCPs), gastroenterologists, and obstetricians/gynecologist (OBGYNs).⁶⁻⁸ Schroy and colleagues reported that PCPs could identify the proper age to begin screening LS patients about half of the time and gastroenterologists identified the appropriate age about 75% of the time.⁶ This inability to identify the correct ages for the initiation of screening could potentially have an impact on a provider's ability to identify cancers in earlier stages. Similarly, Domanska et al. found physicians (specifically surgeons, gynecologists, and oncologists) identified the correct age to begin colonoscopies about half of the time.⁷ Additionally, this study noted that physicians correctly identified the age of screening initiation for gynecological cancer only a little more than one-third of the time.⁷ The endometrial cancer risk for patients with LS also was underestimated by physicians.⁷ Both physicians and patients were evaluated on knowledge regarding diagnosis, screening, surveillance, and inheritance of LS. Patients and physicians demonstrated a similar understanding of LS based on correctly answering a series of knowledge-based questions.⁷ One of the areas that patients have reported encountering gaps in provider knowledge is in regard to extracolonic cancers.⁸

Patients with LS Educating their Providers

Due to these gaps in provider knowledge, patients have reported researching and educating providers on LS.⁸ As previously discussed, patients with LS have a complex medical management protocol and, therefore, provider knowledge of the diagnosis, screening, surveillance, and inheritance patterns are important to patient health. Watkins et al. provided scant data outlining the willingness of patients with LS to educate providers.⁸ To our knowledge, our study is the largest to date assessing these patient-provider interactions. We aimed to address the gap in knowledge regarding educational interactions between LS patients and their providers that was originally identified in the Watkins et al. study. Additionally, we hoped to assess the willingness of LS survivors and previvors (individuals who have a known LS mutation but have not been diagnosed with cancer) to educate providers who have a gap in LS knowledge, ascertain how patients educate their providers (including their information sources), and assess patient's perspectives on the outcomes of those interactions.

Methods

The Institutional Review Board at Albany College of Pharmacy and Health Sciences (ACPHS) approved this study. Participants (n=57) were recruited through social media methods as described in detail in Burton-Chase et al.²⁰ A Facebook post was distributed through Lynch Syndrome International's (LSI's) Facebook page to provide the eligibility criteria and basic study details. Potential participants were directed to call or email the study team. In order to ensure eligibility, a member of the study team screened participants in order of response. Patients were eligible to participate in the study if they met the following criteria: (1) 18 years or older, (2) able to read and speak English, (3) able to be contacted by phone and email, and (4) have undergone genetic testing and counseling.²⁰ When potential participants failed to answer their phones, a voicemail was left and the team member moved to the next person. Recruitment was considered completed when the study team had recruited enough participants for 55 surveys and in-depth telephone interviews.

Data Collection

Once patients met the eligibility requirements, the online survey link was sent through REDCap (<http://www.project-redcap.org/>).²¹ REDCap is a browser-based, electronic data capture software package that is HIPAA compliant.²¹ Participants were asked about providers involved in their health care, personal cancer history, and satisfaction with the provider most involved in their care. The survey did not contain questions about patients educating providers, but did provide demographic and health history information for participants who completed the in-depth telephone interview.

After participants completed the online survey, they were contacted (n=55) to schedule and complete the follow-up in-depth telephone interview. The in-depth telephone interviews ranged from 30 minutes to 1 hour and 45 minutes and were designed to elicit a better understanding of the participants' opinions and experiences regarding their health care providers. During the interview, participants were asked if they have ever educated a provider on LS, what happened during these conversations, and outcomes of the encounter. Additionally, patients were asked about what may have the greatest impact on their trust in their providers' recommendations.

Data Analysis

Once data collection was finished, the transcribed interview responses were analyzed using a grounded theory approach.²² Two authors (KH and ABC) reviewed the interview guide and randomly selected three interviews to create a preliminary codebook. Independently, KH and ABC applied the initial codebook to 5 randomly selected

transcripts (10% of the sample). KH and ABC met three times to refine the codebook and to test intercoder reliability. The first test of intercoder reliability occurred after the first transcript was coded (69% agreement), the second test occurred after two more transcripts were coded (76% and 83% agreement), and the final test occurred after another two transcripts were coded (83% and 93% agreement).

After demonstrating an intercoder reliability of greater than 80%, the coded transcripts were assessed, areas of differences were discussed, and a consensus was agreed upon for these interviews. KH independently coded the remaining transcripts, consulting ABC when uncertainties arose. ABC reviewed the transcripts coded by KH and the remaining differences were discussed and resolved.

Results

Sixty-five (65) participants met the eligibility criteria and were invited to take part in this study; 8 participants did not complete the online survey (88% response rate) and 2 participants were lost during interview follow-up (85% response rate). Participant characteristics are listed in Table 1.

Qualitative analysis of the interviews showed that two-thirds (n=37) of the participants had provided some level of education to a provider. In total, 44 educational interactions were reported. Most of the participants (n=30) reported educating one provider and a minority of participants (n=7) reported educating two providers. A slight majority (n=19) of the educational interactions involved participants educating primary care physicians (PCPs). Participants also reported educational interactions (n=17) involving gastroenterologists, obstetrician/gynecologists (OB/GYNs), and dermatologists.

Table 1. Participant Demographics

Characteristic	% (n)
Mean age (range), years	44 (21-68)
Gender, Female	76 (42)
Race, White	93 (51)
Education, Greater than high school education	93 (51)
Income, Greater than \$25,000 per year	86 (44)
Married	53 (29)
Prior cancer diagnosis*	62 (34)
Colorectal Cancer	36.8 (21)
Endometrial Cancer	19.3 (11)
Ovarian Cancer	10.5 (6)
All Other Cancers	5.3 (3)

* Participants may have had multiple cancers, so the percentages may not sum to 100.

Table 2. Source of Information Used by Patients with Lynch Syndrome (n=37 participants)

Information Source	% (n)
Non-Specific Website	63.6 (35)
Social Media	32.7 (18)
National Institutes of Health	5.5 (3)
PubMed	7.3 (4)
Lynch Syndrome International	25.5 (14)
Cancer Center Website	10.9 (6)
Genetic Counseling Paperwork	10.9 (6)
Family Member or Acquaintances with Lynch Syndrome	10.9 (6)

* Percentages do not sum to 100 because there could be multiple sources of information.

Some participants reported talking with health care providers about what LS is and the associated screening or surveillance recommendations. These participants reported using varying resources to obtain their information including, but not limited to non-specific websites, social media platforms, Lynch Syndrome International (LSI), cancer center websites, genetic counseling paperwork, and family members (Table 2). Each participant could report using multiple sources of information (Table 2). A few participants (n=3) reported using the National Institute of Health's (NIH's) website to find information; one participant said, "There's information on NIH's website, and I'll check that periodically just to see if there's any new research, protocol, new this, new that to come out." Other participants reported bringing printouts of research studies, brochures, pamphlets, and other materials to help them discuss LS with their providers. Another participant talked about using pamphlets she could leave with her providers, "I got pamphlets from Lynch Syndrome International that I bring with me when I go to doctor offices so they can hand them out and...to educate them as well, tell them about it and what to look for. I mean, I don't expect every doctor to know every syndrome there is, so more than likely they're not going to know about it." Overall, a majority of participants (n=35) reported using various websites to obtain their information and when they educated providers they were educating them on the characteristic features of LS and the current screening and surveillance guidelines.

Participants reported feeling satisfied with the outcome of over half (24 of 44 interactions) of the educational interactions. One participant who was satisfied with the outcome said, "I took the article to him [PCP] and showed him the article and he kept the articles and read them. I feel like he was receptive to it. He had his own recommendations based on that." Another participant said, "And she was just like ready to listen to everything that I had to say and was excited that she could do more with the knowledge that I was giving her to be a better

doctor and educate her patients.” While both of these participants demonstrate how provider’s receptiveness lead to satisfaction, other participants were not as satisfied with the outcome of the educational interaction. During two of the educational interactions, patients reported being unsure about the outcome. In the remaining educational interactions (n=18), participants reported being dissatisfied with the outcomes. One participant who was dissatisfied said, “I was just so frustrated and so like just shocked that my provider didn’t know what it was...even after teaching them, ‘It doesn’t exist. This isn’t a real thing. Come back to me in your 40s,’ which is kind of like, ‘Oh, okay.’ I can’t think of what happens to those patients who take that advice, you know.”

Out of the 44 reported educational interactions, over three-quarters of the participants (n=34) reported a change in their relationship with their providers as a direct result of these interactions. In the interactions where participants reported no resulting provider relationship change (n=9), a majority (n=6) reported being dissatisfied with the outcome. The positive changes that participants reported included the participant feeling that their provider was more invested, learned more, had an increased respect for the patient’s knowledge, and was more thorough. However, negative changes, including the termination of the relationship and a decrease in patient trust of the provider, also were reported. Participant quotes about these outcomes can be found in Table 3. Participants also reported the factors that had the greatest impact on their

trust of provider’s recommendations. Participants (n=32) often mentioned a provider’s knowledge regarding LS. One participant mentioned she would want the following traits in her provider in order to gain their trust: “Be knowledgeable of Lynch syndrome. If they’re seeing someone who has the diagnosis, to know what it is before they see them or to also be educated to better be aware of who needs to be screened.” This quote underlines the importance of provider knowledge for patients with LS. Other participants recognized that they may continue to be an educator, but would need more respect from their providers to continue to play that role. One participant said he needed “providers who listen to me as a patient and as a person, pay attention to what I’m saying, and don’t ignore me because I don’t have a doctorate degree. To me it’s important they treat me as a person who is knowledgeable and will listen to what I’m telling them.” This participant recognized the need for a respect of patient’s knowledge for him to continue trusting his provider’s recommendations.

Discussion

Through educational interactions with their providers, our results articulate the nuanced ways in which patients with LS are engaging in the shared decision-making process. Our results confirm the anecdotal experiences of LS patients educating their providers, which thus far has not been detailed in the literature. To the best of our knowledge, this study is the first to assess patient-reported

Table 3. Participant Reported Outcome Quotes

Participant-Reported Outcome	Participant Quote
Increased provider investment	“It definitely makes your relationship a lot more personal, which I think is good in a certain way because if you have a more personal relationship then they’re not going to treat you just like a chart.”
Increased provider knowledge	“She was just like ready to listen to everything that I had to say and was excited that she could do more with the knowledge that I was giving her to be a better doctor and educate her patients.”
Increased respect for the patient’s knowledge	“I’m not an expert, but I’ve been doing my own research, and I’m knowledgeable in that area. They know I’m not going to be taking whatever they say. I’m going to ask questions and do my own research.”
Increased provider thoroughness	“My primary care physician has always been attentive, but anything that’s odd he wants to follow up on now.”
Termination of patient-provider relationship	“They can’t even hold a conversation with me about it or they show that they don’t show any interest, I usually don’t go back.”
Decreased patient-provider trust	“When I talked to him [the dermatologist] about Lynch syndrome, ... So was he receptive to it, not so much. I felt like he cut me off when I was talking about it.”

satisfaction with and outcomes from these educational interactions. In the majority of instances, the patients reported generally educating primary care physicians, OBGYNs, or gastroenterologists about LS. Watkins et al. briefly described the willingness of patients with LS to educate providers they feel lack LS knowledge.⁸ Shared decision-making has been identified as a key component of patient-centered communication and it involves the following processes: (1) information exchange, (2) deliberation, and (3) reaching a final decision.^{23,24} Through these educational interactions, patients with LS initiate the information exchange process. This process may be of more importance to patients with LS than in the general population due to their complex screening and surveillance regimens and the documented gaps in provider knowledge.^{1,2,6-8} One challenge that patients face in engaging in this process is in information gathering. As reported in this study, participants used varying resources from general internet searches to scientific research papers. The Institute of Medicine acknowledges that there needs to be more comprehensive information available for patients.²³ This information gathering process is further complicated by the broad organ system involvement and the lack of screening and surveillance recommendations with a high level of evidence, particularly for women.^{1,2,8-15,17}

From the information exchange process to reaching a final decision, participants reported that these interactions were integral to their satisfaction with these patient-provider relationships. Participants reported that the providers receptiveness during the information exchange process was important. While a majority of participants agreed that baseline provider knowledge was crucial, some participants, in recognition of the continuing educator role they may play, also mentioned that respect for their knowledge during the information exchange and deliberation processes also was important. If the goal of patient-centered care includes the concept of shared decision-making, LS patients are an appropriate clinical population to further explore and understand the nuances of the patient-provider relationship. For instance, by LS patients initiating the information exchange, they are taking on work above and beyond the normal patient role. Our interviews cannot answer whether these patients are happy to continue in this atypical role or would be happier returning to a more traditional doctor-patient sharing of this work.

There are study limitations that must be considered when interpreting these results, such as small sample size and bias that was introduced through our recruitment method. To our knowledge, this is the largest study to date that explores patients with LS educating their providers. Through recruiting via social media and through an advocacy organization we may be introducing bias into our sample. However, Burton-Chase et al. suggests that a more

geographically diverse population may be achieved through this method.²⁰ It is important to note that the majority of participants included in this study, reported self-identifying as white and having a household income greater than \$25,000 per year. Caution should be used when attempting to generalize these results to populations not well represented in the study, as persons outside of our participant population may have differences in access to resources as well as differences in approaches to these interactions. Further studies should target a larger number of patients with LS including more males and those who may not be engaged on social media platforms because this may oversample more engaged patients.

Conclusion

Patients with LS are educating health care providers that they perceive to have a gap in LS knowledge. Many patients are satisfied with these interactions; however, some patients may report dissatisfaction if they do not feel the provider is listening or is not receptive. Patients report utilizing a variety of resources and educating mainly on the characteristic features of LS and the current screening and surveillance guidelines. A majority of patients report changes in their provider relationships including an increased provider investment, knowledge of LS, thoroughness, and respect for patient's knowledge. In contrast, other patients reported termination of their provider relationships and a decreased trust in those providers when they were dissatisfied with the outcome. Further research is needed to better understand the varying levels to which patients with LS educate their providers as well as the effect of patients educating their providers on their future patient-provider relationship. Providers could encounter patients who educate them about LS. During these interactions, it is important to patients that the providers listen and be receptive to what they are saying. After an educational interaction, providers should do their own research and follow-up with their patient about current screening and surveillance recommendations. As one participant said, "I guess I feel like it's more of a give and take and that...even if they're less knowledgeable, but I feel like what I'm saying is being heard and given weight and taken into consideration, then even if they know less but put forth the effort, I'm more likely to say okay, this is someone that's going to work with me." As research rapidly evolves, the patients may benefit from an ongoing conversation where both the provider and patient contribute to the discussion of needed screening or surveillance. To increase the chances of a positive outcome for patients, physicians and patients have to be willing to commit to the higher level of engagement that is required for shared decision-making. LS patients, especially those we interviewed for this study, are uniquely qualified for and in need of this model of care. However, for shared-decision making to be possible, providers may need additional training on how to engage

effectively with patients who are well-informed regarding their health care needs.²⁵

We confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

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