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Should Health Systems Share Genetic Findings With At-Risk Relatives When the Proband Is Deceased? Interviews With Individuals Diagnosed With Lynch Syndrome

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Purpose Genetic information has health implications for patients and their biological relatives. Death of a patient before sharing a genetic diagnosis with at-risk relatives is a missed opportunity to provide important information that could guide interventions to minimize cancer-related morbidity and mortality in relatives.

Methods We performed semi-structured interviews with individuals diagnosed with Lynch syndrome at 1 of 4 health systems to explore their perspectives on whether health systems should share genetic risk information with relatives following a patient's death. An inductive, open-coding approach was used to analyze audio-recorded content, with software-generated code reports undergoing iterative comparative analysis by a qualitative research team to identify broad themes and representative participant quotes.

Results Among 23 participating interviewees, 19 supported health systems informing relatives about their Lynch syndrome risk while the remaining 4 were conflicted about patient privacy. Most (n=22) wanted their Lynch syndrome diagnosis shared with relatives if they were unable to share and to be informed of their own risk if a diagnosed relative was unable to share. The most common issues noted regarding information-sharing with relatives included patient privacy and privacy laws (n=8), potential anxiety (n=5), and lack of contact information for relatives (n=3). Interviewee perspectives on how health systems could communicate genetic findings generated a consensus: When — a few months after but within a year of the patient's death; How — explanatory letter and follow-up phone call; and Who — a knowledgeable professional.

Conclusions Interviews demonstrated strong and consistent perspectives from individuals diagnosed with Lynch syndrome that health systems have a role and responsibility to inform relatives of genetic findings following a patient's death. (*J Patient Cent Res Rev.* 2022;9:282-289.)

Keywords Lynch syndrome; medical genetics; postmortem disclosure; family communication; bioethics

Genetic information is relevant not only to patients who undergo genetic testing; it also has implications for their biological relatives. In the case of Lynch syndrome, a hereditary cancer syndrome with an increased risk of colorectal and endometrial cancers,[1-5] first-degree relatives are at 50% risk of also having Lynch syndrome. Thus, cascade screening, a process to identify additional relatives who may have Lynch syndrome, provides the opportunity for relatives to learn about their own cancer risk.

Current cascade screening approaches rely on patients to contact their at-risk relatives and inform them of their potential genetic risk and opportunity for genetic counseling and testing. However, situations where the patient dies before receiving or sharing genetic testing results represent a missed opportunity for relatives to receive important information that could guide decision-making around learning their own genetic risk and

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potentially taking medical actions to mitigate morbidity and mortality. Such a scenario is particularly relevant in the context of genetic testing initiated following a cancer diagnosis when patients are at elevated risk for cancer-related death. Without consistent practices to capture patient preferences for sharing genetic information with relatives in the event of death, health systems are faced with legal and ethical challenges on whether to contact relatives to share the genetic information. When a specific patient's preferences are unknown, perspectives of patients in general may help guide policies around disclosure to relatives.

There has been exploration of this challenge in the research setting, with support for sharing genetic findings associated with significant health outcomes for which there are actions relatives could take to ameliorate outcomes,[6-9] including specific guidance that disclosure should be active and directly disclosed to all relatives after the death of a patient.[8] Directly contacting relatives to inform them of their potential genetic risk following the death of a patient has been described as "morally justifiable" for significant and actionable genetic findings.[10] Though empirical evidence is limited, a few studies to date have administered direct assessments of patient perspectives regarding result disclosure to at-risk relatives after death.[11-13] In one study, the majority (92%) of 78 adults enrolled in a research study to receive genomic sequencing for hereditary cancer provided permission to have their results returned to a relative in the event of their death when offered this option.[11] Further, in a recent update of survey results among 464 patients in a pancreatic cancer biobank[14] (12.3% of which had received genetic counseling), only 4% indicated they would want their genetic results kept private after their death.[12] Lastly, in a survey of 555 participants of the OurGenes biobank, only 9% indicated they would not want their research results disclosed to a biological relative after their death.[13] Although these studies provide valuable insight into patient perspectives in a pre-genetic testing context, additional evidence is needed regarding preferences, concerns, and motivations, particularly among patients who have already received a genetic diagnosis that has health implications for relatives.

In this study, we explored perspectives of individuals diagnosed with Lynch syndrome as part of the Implementing Universal Lynch Syndrome Screening (IMPULSS) project.[15] We obtained patient perspectives on health systems sharing the genetic diagnosis of Lynch syndrome of a deceased patient with relatives. This study aims to find novel insights that can shape clearer guidance for developing relevant policies and procedures.

METHODS

Recruitment

Participants for this substudy were recruited as part of the larger IMPULSS study aimed at facilitating implementation of universal screening for Lynch syndrome across health systems.[15] Patients diagnosed with Lynch syndrome as part of that Lynch syndrome screening program were identified across 4 health systems: Kaiser Permanente Northwest (KPNW), Geisinger, HealthPartners, and Palo Alto Medical Foundation (PAMF). Identification of patients for this substudy included searches of electronic medical records with relevant clinical codes, institutional tumor registries, and genetic test results with chart reviews to confirm eligibility.

Research staff from each health system mailed recruitment letters to eligible patients at their site describing the study and providing the opportunity to opt in or out of participation. Contact information of patients who had opted in (patients at PAMF were required to opt in for study participation) or had not opted out (KPNW, Geisinger, HealthPartners) of participation was provided to the KPNW qualitative research team (J.L.S., A.J.F., J.V.D.) via International Organization for Standardization (ISO)-approved secure data transfer. The KPNW qualitative research team followed up with potential participants by telephone.

Data Collection

The qualitative team worked closely with research staff from participating health systems to develop an in-depth semi-structured interview guide to capture patient perspectives of universal Lynch syndrome screening among patients with Lynch syndrome. A patient advocate with an inherited colorectal cancer syndrome also reviewed and provided feedback on the interview guide. The analyses described herein focused on responses to a set of questions around sharing Lynch syndrome diagnosis information with relatives following the death of a patient.

Interviews were conducted via telephone, lasted approximately 60 minutes, and were audio-recorded. Interviewees provided verbal consent before the interview and received a $25 gift card for participation. All interviews were conducted and analyzed by research staff trained in qualitative methods (J.L.S., A.J.F., J.V.D.). Interview procedures and materials received human subjects research approval from multiple institutional review boards (ie, Geisinger and PAMF).

Data Analysis

Interview recordings were transcribed verbatim to facilitate content analysis. An inductive, open-coding approach was employed.[16,17] First, an initial coding

scheme was developed by the qualitative team (J.L.S, A.J.F, J.V.D.) based on multiple reviews of a subsample of 6 transcripts. Then, the preliminary coding scheme was shared with the larger study team for feedback and refinement. Next, the final coding scheme was applied to the remaining transcripts. The qualitative team met regularly to discuss coding and any ongoing refinements. Coding was conducted using qualitative software (NVivo 12, QSR International).

Code reports were reviewed multiple times by the whole qualitative team utilizing a constant comparative analysis approach to interpret and summarize data and identify broad themes.[17-19] Preliminary theme reports were shared with the larger study team for feedback. The qualitative team reviewed transcripts and responded to feedback and questions regarding interpretation of data in the theme reports. This iterative process led to a final set of findings and representative participant quotes presented in this manuscript.

RESULTS

Study Participants

A total of 44 patients were recruited by the KPNW qualitative team to participate in an interview: 5 declined, 1 was ineligible (hard of hearing), 15 were never reached, and 23 interviews were completed. Participant characteristics are shown in Table 1. Although the target population was individuals diagnosed with Lynch syndrome through a Lynch syndrome screening program, during interviews we discovered 6 participants were diagnosed during cascade screening following the diagnosis of a relative. Given their perspectives still inform sharing of genetic information among relatives, interview responses from these participants were included in this analysis.

Table 1. Participant Descriptive Characteristics

Characteristic	N=23
Age in years, mean (range)	60 (33–84)
Gender, n	
Female	14
Male	9
Patient-reported race/ethnicity, n	
White	19
White and American Indian	1
White and Jewish	1
Hispanic	1
Asian	1
Household income, n	
<$15,000	3
$15,000–$30,000	4
$30,000–$50,000	4
$50,000–$75,000	3
$75,000–$100,000	4
$100,000–$150,000	2
$150,000–$200,000	2
Prefer not to answer	1
Highest level of education, n	
High school	6
Trade school	5
Some college	3
College graduate	9
Married or living with partner, n	
No	10
Yes	13
Family members receiving care from same health system, n	
None	15
Child(ren)	5
Sibling(s)	1
Child(ren) and Sibling(s)	1
Child(ren) and Grandchild(ren)	1
Health system, n	
Kaiser Permanente Northwest	3
Geisinger	8
HealthPartners	9
Palo Alto Medical Foundation	3

Perspectives on the Health System's Role in Sharing Lynch Syndrome Diagnosis Information With Relatives Following the Death of a Patient

Participants were asked what a health system should do if a person with a genetic diagnosis of Lynch syndrome dies prior to relatives being informed about the diagnosis and their subsequent risk of also having Lynch syndrome (Table 2). Most (19 of 23) had the initial reaction that the health system had a responsibility to inform relatives. The remaining participants (4 of 23) did not clearly endorse informing the family in their initial reaction; they felt conflicted and could see that although it was important to share the information, it was also important to protect the patient's privacy.

During interviews, it became clear how the interviewees' personal experiences shaped their perspectives. Some participants expressed that their own diagnoses of cancer made them wish they had known their diagnosis of Lynch syndrome earlier, potentially shaping their perspectives supporting relatives' access to genetic cancer risk information. One participant noted that being adopted and not having any family health history made them feel strongly about learning about family genetic risk information.

Table 2. Participant Perspectives on the Health System's Role in Sharing Lynch Syndrome Diagnosis Information With Relatives Following the Death of a Patient

Interview prompt: Because family members of an individual with Lynch syndrome are at risk and can benefit from early prevention and screening options, we'd like your thoughts on a sensitive topic about what to do if the person confirmed with Lynch syndrome has died and their family members have not been told about the possibility that they may also have Lynch syndrome. This is a challenging question because federal laws and regulations protect the privacy of a person's health information, even after that person has died. Yet others believe that health information like this should be shared if it could benefit others, including relatives. We've been talking [earlier in interview] about the value in learning about Lynch syndrome in terms of the knowledge for yourself and for your relatives. But there are ongoing questions about whether a health system should protect a person's privacy and health information after death versus the responsibility to tell that person's family members about the Lynch syndrome diagnosis since it can impact their health. Based on what I just explained, what is your reaction to this challenge and the information I just shared?	
Key findings	**Example quotes**
Most participants (19 of 23) had the initial reaction that family should be informed, and it is OK to share the Lynch syndrome diagnosis with family members after a patient's death. After their initial reaction, some (4 of 19) believed that the family should be informed, reflecting that the situation is complicated and that although it is important to inform the family, they also see concerns about patient privacy.	*"I know that there are all these privacy issues, but if the person passes away and there is [sic] family members that should know that they may be at risk, I think after the passing away that the family members should be informed."* *"I just believe that the doctor/patient privilege should be waived in situations like that."* *"I think that information should be made available to the family so they could keep an eye on it [cancer] so it doesn't get anybody else in the family."* *"It's a hard thing. … You want them to have the best options moving forward. But it's also a privacy thing."*
4 of 23 participants did not clearly endorse informing the family in their initial reaction because they felt like they could "see it both ways" regarding sharing the result with family members versus patient privacy.	*"It's not hurting the person who died. And that information would almost certainly benefit any of their survivors. … But I don't know. It's a tough call. You want to respect peoples' privacy and things like that."*

Health System Sharing of a Lynch Syndrome Diagnosis From the Perspective of a Patient With Lynch Syndrome and of a Relative

When asked if they would want the health system to inform their relatives about their diagnosis of Lynch syndrome if they became deceased before being able to share this information, most (22 of 23) responded that they would want the health system to inform their relatives. General reasons included that it would give their relatives important information they could act on to avoid cancer or catch it at an early stage and that sharing the information would not "hurt" the person who is deceased.

Participants were then asked about a hypothetical scenario: one of their relatives had been diagnosed with Lynch syndrome but had died before sharing the diagnosis with the participant and other relatives (Table 3). Most (22 of 23) stated they would want the health system to inform them of their Lynch syndrome risk. General reactions included the belief that they "have a right to know" so they could act on the information and learn about their own diagnosis of Lynch syndrome. They felt this information was important for early cancer detection and general family health history knowledge.

One participant did not want the health system to share any diagnosis information or be informed of the diagnosis of Lynch syndrome of a relative, while generally agreeing that sharing this information with relatives is important (Table 3). However, the participant worried about the "slippery slope" of this potential breach in privacy and how it could facilitate additional privacy breaches in the future that the participant may not be so comfortable with. The participant also expressed concern about how the disclosure may impact insurance and employment of those relatives.

Concerns About Health Systems Informing Relatives of a Diagnosis of Lynch Syndrome in a Patient Who Is Deceased

During interviews, 9 of 23 expressed they had "no concerns" around health systems sharing genetic information with relatives (Table 4). The remaining participants (14 of 23) expressed 1 or more concerns. Eight participants noted 1 or more issues or concerns around protecting privacy or changing the current privacy laws; 3 participants clearly felt the benefit of sharing genetic information was more important than privacy but that health systems or lawmakers need to generate clear

Table 3. Patient Perspectives on the Health System Sharing a Lynch Syndrome Diagnosis From the Perspective of a Patient With Lynch Syndrome and of a Relative

Interview prompt: If you were confirmed to have Lynch syndrome but were deceased before being able to inform family members, would you want your health system to inform them of the possible hereditary risk? Why or why not?	
Key findings	**Example quotes**
22 of 23 participants endorsed that the health system should share their own personal Lynch syndrome diagnosis with relatives.	*"Share away. Who cares, I'm dead. It doesn't matter."* *"For me it's a no brainer to tell my family."* *"My personal view is that if doctors are aware of this particular syndrome, whether I'm alive or not should not affect them that they pass the information on, at least to my wife or to my next of kin so that they can share it with whoever they think appropriate."*
1 of 23 participants agreed in general that sharing this information is important but had concerns about privacy issues, particularly around it being a "slippery slope" in sharing private information.	*"But where does it stop, right? So today it's the hospitals, the government, the insurance companies, whoever have the right to tell and then the obligation to tell the children about Lynch syndrome. Tomorrow, what else will they want to tell the children that maybe I wouldn't agree with? ... It's an ethical dilemma, and by the same token, it's a slippery slope."*
Interview prompt: If a blood relative, such as a sibling, was confirmed to have Lynch syndrome but became deceased before being able to share with you and other family members, would you want the health system to inform you of this possible hereditary risk? Why or why not?	
Key findings	**Example quotes**
22 of 23 participants noted that the health system should share the Lynch syndrome diagnosis so that family members would learn their own potential risk.	*"I think it is our right to know. And then that would be our decision [to take action]. But we should be advised whether we are at risk or we are not."* *"Of course, I would want to know that, and I would be mad that I didn't know it!"* *"Yes – being adopted like I am, and knowing no medical history in the family, I think all medical history should be available to the family, period"*
1 of 23 participants agreed in general that sharing the information is important but worried about patient privacy and potential insurance or employment issues of the relatives.	*"Not because of the Lynch syndrome but because of what the next step and the next step and the next step are… I don't think they [health system] should do it, I don't want to tell them how to do it. I guess my big concerns with something like that is twofold – is telling insurance companies if we ever got into a climate where you could raise rates on somebody who was more likely to get sick. So that would be the first concern that I would have. The second concern that I would have would be employers … so the company I work for … has a company-funded health care program. So if they know that I'm likely to have cancer, is that going to color their actions whether it be for hiring or if there's layoffs, who goes?"*

guidelines around exactly who the information could be shared with (eg, first-degree relatives); and 3 participants specifically noted that changes in privacy laws would be needed for health systems to share genetic information. Three participants stated that they recognized the tension between sharing genetic information and protecting patient privacy and the need for more thought, but had no clear guidance on a solution.

Additional issues were noted beyond privacy. For instance, 4 participants noted negative reactions (eg, fear, not being able to "handle" the information, not wanting the information) following being informed about the diagnosis of Lynch syndrome in their relatives; 3 participants noted logistical challenges around lack of or outdated contact information for relatives; and 2 participants expressed concern that the relatives' insurance rates might increase if it was known there was a diagnosis of Lynch syndrome in the family. Lastly, 1 participant noted there might be relatives the patient was not in contact with by choice and the patient may not have chosen to share the diagnosis of Lynch syndrome with these relatives.

Perspectives on How Lynch Syndrome Diagnosis Information Should Be Provided to Relatives Following a Patient's Death

Participants were asked to provide guidance to health systems on how to inform relatives of the diagnosis of Lynch syndrome of a deceased patient (Table 5). Of the 17 participants asked about timing of contact, 16 suggested health systems should wait a few months after the patient's death to allow for mourning but should reach out within the year. One participant suggested the health system should

Table 4. Expressed Benefits and Concerns About Health Systems Sharing Lynch Syndrome Diagnosis Information Following a Patient's Death *(may have endorsed more than 1 benefit or concern)*

BENEFITS	
Key findings	**Example quotes**
Family members have a "right to know" (n=12) Important health information and potential cancer prevention (n=9) Information is knowledge (n=6)	*"For my descendants that could be affected by this, if they were prevented from getting the preventative screenings that could possibly save their life and they didn't get it because of that privacy thing, that would be wrong. That would be simply wrong."* *"Essentially that person has died. And so the risk is for all the survivors and not for the dead. So, if that information can help ease the pain, or ease the worry or eliminate the risk, I'm not sure we should avoid that responsibility, you know."* *"Give them [family] as much information as possible so that they can decide what to do next."*
CONCERNS	
Key findings	**Example quotes**
No concerns (n=9)	*"I personally have no barriers or concerns … [family members] should know and if they want to ignore the situation, then that's totally in their court."*
Concerns (n=14) regarding: ᵒ Privacy and privacy laws (n=8) ᵒ May create anxiety or upset family members (n=5) ᵒ No contact information or information not up to date (n=3) ᵒ Increase family members' insurance rates (n=2) ᵒ Family members not on speaking terms (n=1)	*"The law would have to be changed where, if somebody has had a genetic mutation, they can have the immediate family know about it or be aware of it. But I guess the laws would have to change first. I know they're not going to risk being sued and everything for release of information they can't release."* *"It could be a scary thing sometimes for someone that you might send it to. I mean, are they emotionally capable of handling it? It might be pretty hard to know."* *"The health care provider, or whoever diagnosed this, is not going to contact a family member if they don't know where to contact them."* *I guess the other dilemma is if like their insurer found out – it's possible they could raise their insurance rates or something like that."*

reach out "as soon as possible." All 22 participants who were asked about how the health system should contact relatives suggested there should be a personalized outreach and the opportunity to speak to someone knowledgeable about Lynch syndrome. The consensus was this approach could be two-pronged: a letter followed by a face-to-face appointment or phone call.

In all, 9 participants noted health systems should consider implementing protocols to obtain permission from the patient at the time of genetic testing on whether or not to communicate the genetic findings with relatives in the event of their death. Suggestions for implementing this process to capture when patients were willing for their results to be shared included signing a consent or written waiver regarding permission to share and a flag in the electronic medical record noting the patient would like their genetic findings shared with relatives.

DISCUSSION

Overall, the qualitative results in this study demonstrate strong and consistent perspectives from individuals with a diagnosis of Lynch syndrome that health systems have a role and responsibility to inform relatives of genetic findings following the death of a patient. Consensus was that this information is important for relatives to receive given it has significant implications for their future health and well-being. Importantly, roughly 35% of participants had at least one first-degree relative who also receives care from the same health system, emphasizing the potential impact that sharing this information could have on patient care.

The most common issues noted by interviewees were centered around patient privacy, an important concern in cases where patient preferences around sharing their genetic information were not captured prior to death. Thus, health systems need to balance the privacy of the deceased patient with the opportunity to minimize health risks in relatives by providing them with important cancer risk information. This barrier could be addressed prospectively by systematically capturing preferences of patients, including who they want the information shared with and their contact information, consistent

Table 5. Perspectives on How Lynch Syndrome Diagnosis Information Should Be Provided to Relatives Following a Patient's Death

Key findings	Example quotes
When the information should be shared: A few months after, but within a year	*"Hopefully it wouldn't be too long after the person passed away – like it wouldn't be over a year but within a years' time."*
How the information should be shared: Explanatory letter and follow-up phone call with an option to meet face to face	*"A letter … give them the facts … and explain why you need to come in and speak to someone."*
Who should share the information: Health professional knowledgeable about Lynch syndrome	*"I would like to be informed by a professional or someone who had information that could answer some of my questions … I would like to have a voice to talk to."*

with current guidance in the research setting.[10,20] A single representative for the family could be chosen to disseminate findings across relatives. However, there may be limitations to this approach. First, this person may be a spouse or partner who is not biologically related to the patient and thus will not directly benefit from receiving the information. Second, this person will act as "gatekeeper" of the information and may not share with all relatives who may have similar genetic risk.

Prior studies of patient perspectives on sharing genetic findings with relatives while the patient is still living indicate that patients support disclosure of findings to relatives and that relatives want to be provided with information that may be important to their health.[12,21,22] Findings from qualitative interviews with 33 patients seen in a genetics clinic for hereditary cancers and cardiac conditions (29 of whom had received genetic testing with a positive finding, 2 a negative finding, and 2 no testing) indicated two emerging themes when participants were asked about their perspectives on confidentiality and consent around disclosure of their genetic findings to their relatives: 1) Patients viewed genetic information as familial and thus family members had a right to know their genetic risk; and 2) Participants had concerns about what implications there would be from their genetic testing information being treated as familial and wanted to ensure they would be informed about how their genetic information would be shared.[21] Shifting to the context of disclosure of a patient's genetic information with relatives after death, the empirical evidence is limited to quantitative studies of patient perspectives among research participants. Results of three studies showed the majority support such sharing; one study reported that 92% support providing permission for their research genomic sequencing results to be returned to a relative in the event of their death,[11] and two studies of surveyed biobank participants indicated that 96%[12] and 91%,[13] respectively, support having any genetic test results from their biospecimen be shared after death. The results of our study are consistent with these previous findings and provide important perspectives from patients who have a genetic finding that relatives can act on to improve their own health outcomes. Interview findings indicated that hesitancy to share may arise from concerns about how their genetic information may be used beyond this context (ie, a "slippery slope" regarding patient privacy).

Limitations

It is important to recognize that perspectives presented in this study are limited to individuals who received a genetic diagnosis of Lynch syndrome, thus, their perspectives may differ from their relatives. Future studies should focus on capturing perspectives of relatives to explore their interest in receiving information, with a focus on relatives' right to not know this information.[10] Additionally, although we took many steps to ensure our data were grounded in patient perspective (eg, consistent use of a formal interview guide, trained interviewers, formal coding/analysis) and recruited individuals from health systems in different geographic regions, it is possible we did not capture a full range of patient perspectives. Thus, future studies should aim to capture patient perspectives across a diverse range of patient populations, including patients from different racial, ethnic, and cultural backgrounds.

CONCLUSIONS

Findings provided the novel insight from patients with Lynch syndrome that health systems have a role and responsibility to share genetic information with relatives following a patient's death. These findings could be leveraged to guide future health system policies and protocols in this context. Further, patients' perspectives can be extrapolated to other genetic conditions and risk variants, with options for medical intervention that may occur in the clinical or research contexts, including in the context of the biobank setting wherein biospecimens may be analyzed and future genetic variants identified.

Patient-Friendly Recap

- Patients are diagnosed with Lynch syndrome through genetic testing, results that, if shared, could lead to earlier diagnosis in at-risk relatives.
- Because those with Lynch syndrome may die prior to contacting relatives themselves, study authors interviewed patients to learn their attitudes toward whether health systems should share this genetic information after their death.
- While most interviewees supported data sharing with relatives after the death of the patient, some expressed concerns over privacy and the possibility that their relatives might prefer not to know.
- Suggestions for engaging relatives included doing so first via letter with phone follow-up by a health professional knowledgeable in Lynch syndrome.

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Author Contributions

Study design: all authors. Data acquisition or analysis: all authors. Manuscript drafting: Hunter, Schneider. Critical revision: all authors.

Conflicts of Interest

None.

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