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ORIGINAL ARTICLE

Disclosure of genetic risk to dating partners among young adults with von Hippel-Lindau disease

Elysa Bond[1,2] · Beverly Yashar[1] · Tobias Else[3] · Jenae Osborne[4] · Monica Marvin[1,4]

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Abstract

Individuals with genetic disease face unique challenges related to navigating dating relationships. While previous studies have explored the impact of hereditary breast and ovarian cancer syndrome on dating, research investigating psychosocial implications for young adults with early-onset multi-organ tumor predisposition syndromes such as von Hippel-Lindau disease (VHL) is scarce. This study assessed young adults' attitudes towards dating and decisions related to disclosing a diagnosis of VHL to a dating partner. Twenty-six young adults with VHL participated in semi-structured interviews exploring this issue, using a guide informed by the literature in consultation with providers and an individual with VHL. Interviews were coded with a primarily deductive approach using codes derived from the literature, with inductive coding employed for perspectives unique to VHL. Our results support previous findings that genetic disease contributes to fear of rejection due to decreased desirability. However, participants report that partners' reactions to VHL uniquely exacerbate this concern due to unfamiliarity with VHL and a perception that it is exceptionally serious, leading to different strategies in disclosure. While many cited negative reactions from partners, participants also described how disclosure can strengthen relationships by deepening trust. Participants discussed a desire for healthcare providers to offer support in this context and described the benefit of speaking with peers about their dating experiences and approaches to disclosure. Our findings provide insight into the diverse needs of young adults with VHL as they approach romantic relationships and decision-making regarding disclosure and highlight the importance of patient-centered support from providers and patient organizations.

Keywords Von Hippel-Lindau · *VHL* · Dating · Disclosure · Young adulthood · Psychosocial support · Genetic

Introduction

Von Hippel-Lindau disease (VHL) is an autosomal dominant hereditary tumor susceptibility syndrome associated with increased risk for the development of a broad range of benign and malignant tumors, with an incidence of approximately 1 in 36,000 across all ethnic groups. Compared to other inherited cancer predisposition syndromes, VHL is highly penetrant and characterized by high multiorgan tumor risk with variable age of onset from early childhood to late adulthood, complex multidisciplinary surveillance, and limited preventive options. VHL is caused by heterozygous germline pathogenic variants in the *VHL* tumor suppressor gene, approximately 20% of which are de novo. Characteristic manifestations include hemangioblastomas of the brain, spinal cord, and retina; pheochromocytoma and paraganglioma; renal cysts and clear cell renal cell carcinoma; pancreatic cysts and neuroendocrine tumors; and endolymphatic sac tumors [1, 2]. Genetic testing is recommended for at-risk individuals as early as birth in order to initiate surveillance in childhood. Tumors frequently start appearing during young adulthood, with a mean age of onset of approximately 26 years and penetrance of over 90% by age 60 [1]. While tumors are often treated surgically, the drug belzutifan has been recently been demonstrated to be an

✉ Elysa Bond
elysa_bond@rush.edu

1 Department of Human Genetics, University of Michigan, Ann Arbor, MI, USA

2 Department of Medicine, Division of Hematology, Oncology, and Cell Therapy, Rush University Medical Center, Chicago, IL, USA

3 Department of Internal Medicine, Division of Metabolism, Endocrinology and Diabetes, University of Michigan, Ann Arbor, MI, USA

4 Department of Internal Medicine, Division of Genetic Medicine, University of Michigan, Ann Arbor, MI, USA

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effective intervention for several VHL-associated tumors [3]. Individuals diagnosed with VHL face many psychosocial challenges that may interfere with their ability to cope with and adapt to their risk for tumors during young adulthood, although few studies have investigated the psychosocial impact of this rare disease on young people [4, 5].

Dating and developing intimacy in romantic relationships are considered important developmental tasks of emerging and young adulthood. The typical challenges of this milestone are exacerbated by genetic risk for disease, which presents unique barriers to the establishment of a long-term couple relationship [6, 7]. Genetic risk is unique from other health information or disability due to the additional heritable implications for biological children, potentially increasing the gravity and importance of disclosure to romantic partners and influencing attitudes towards family planning [7]. It has been shown that many young adults with a genetic diagnosis, including VHL, face complex decisions regarding childbearing and may decide to not have biological children in order to avoid the 50% chance of passing on the pathogenic variant to offspring [4].

Individuals at-risk for genetic disease grapple with decisions pertaining to disclosure to dating partners that are different from decisions to communicate risk to relatives, in part because the risk of rejection is higher in nascent romantic relationships than with established familial relationships [7]. Individuals may be motivated to disclose by a need for social support or due to a sense of ethical obligation, but may avoid sharing due to fear of rejection [7, 8]. Genetic disease or risk for disease is frequently perceived as a deficit that makes one less desirable as a romantic partner [7]. The possibility of rejection is especially significant due to the documented benefits of partner support for individuals with VHL [4]. Considering the threat of rejection, current literature demonstrates that individuals with or at-risk for genetic disease often feel distressed by the uncertainty of if, when, what, and how to disclose their diagnosis to dating partners [6–10].

Young women's attitudes towards romantic relationships and disclosure of genetic risk to romantic partners have been well studied in the context of hereditary breast and ovarian cancer syndrome (HBOC). Individuals with germline pathogenic *BRCA1/2* variants often feel urgency to find a supportive partner, which is closely related to the urgency to have biological children prior to undergoing risk-reducing surgery or treatment should cancer arise [10–13]. These women often express self-doubt concerning their desirability as a romantic partner and perceive a limited dating pool, citing concerns of physical attractiveness due to surgery such as mastectomy or treatment side effects, the potential for cancer or reduced life expectancy, or reproductive challenges [6, 10, 12, 14]. A source of anxiety for this population is when and how to disclose one's genetic status and its implications for the future to a dating partner [6, 7, 11–13]. However, sharing this information often has a positive impact on a relationship, leading to partner bonding and the establishment of an important support system [6, 15]. The impact of a diagnosis of VHL is less clear and may differ from that of HBOC due to risk for a broader range of tumors in organs that are not necessary for reproduction or sexual function, unique uncertainty due to variability in presentation, younger age of genetic diagnosis and/or disease onset, similar health risks for both sexes, a lack of preventive options beyond complex screening, and less familiarity compared to *BRCA1/2* and breast cancer. A study concerning the psychosocial impact of VHL found that almost 50% of individuals with the condition report clinically relevant levels of distress, substantially higher than rates reported for more common forms of hereditary cancer such as HBOC [16]. VHL-related distress has also been identified in a significant subset of romantic partners [17]. Couples in which one partner has Li-Fraumeni syndrome, another hereditary cancer syndrome with pediatric onset, have described living with a sense of ambiguous danger due to the uncertainty of future cancer diagnoses, suggesting that the ongoing involvement of a multidisciplinary care team is essential [18].

Given the limited attention to the impact of VHL in this domain, this study explored the unique challenges in navigating dating relationships faced by young adults with VHL, with a particular focus on the psychosocial implications of disclosure and desired support related to disclosure. A qualitative approach was undertaken to investigate common themes and unique perspectives of young adults in this population.

Methods

Participants and recruitment

Eligible participants (18–35 years old) with a self-reported diagnosis of VHL who spoke English were recruited through the VHL Alliance (VHLA; www.vhl.org) and a research database of VHL patients who had been previously seen at the University of Michigan Rogel Cancer Center (UM Cancer Genetics Registry—IRBMED# 2002-0981-HUM00043430). The VHL Alliance distributed study information and a demographic screening survey to over 100 young adults with VHL via email, as well as via their community Facebook page. Review of the UM Cancer Genetics Registry identified 25 individuals who met study criteria and were invited to participate either via email (n = 15) or mail (n = 10). Of the individuals contacted through these two combined recruitment arms, 69 prospective participants completed the screening survey, 66 of whom met study criteria. Fifty-six of these eligible respondents (85%) expressed

interest in participating in a phone interview about their dating experiences, all of whom were contacted to schedule an interview. 26 of these young adults (46%) responded to the invitation and completed an interview. This qualitative study was deemed exempt by the University of Michigan Medical School Institutional Review Board (IRBMED# HUM00166307).

Data collection

A semi-structured interview guide informed by previous research investigating disclosure of other health conditions (HBOC, Mayer-Rokitansky-Küster-Hauser syndrome, Huntington disease, and Alpha-1 antitrypsin deficiency) was developed by the research team with feedback from a young adult with VHL [7, 10, 19]. The interview guide included questions regarding personal and family history of VHL; attitude towards VHL and perception of personal health risks related to their diagnosis; attitudes and expectations regarding romantic relationships and perception of impact of VHL on dating; dating history and past (or planned) disclosures of participants' genetic risk to dating partners and others; and support and resources received or desired from relatives, healthcare providers, or support groups regarding disclosure in this context (Appendix 1).

One researcher (EB) completed all interviews (n = 26) between December 2019 and January 2020 using BlueJeans conferencing (audio) software. The audio-recorded interviews were transcribed verbatim, with identifiable information omitted. Interviews ranged in length from 25 to 71 min, with an average length of 47 min.

Data analysis

The initial codebook was developed by four authors using a primarily deductive approach based on themes from research on disclosure in other genetic conditions [7, 10, 19]. Application of this code book to a subset of transcripts (3) identified the need to refine the initial codes in order to capture the novel perspectives in our interviews. To accomplish this, multiple coders (EB, MM, BMY) employed an iterative review process to inductively generate novel codes specific to the dataset through reanalysis of the initial 3 transcripts and review of an additional 3 transcripts, with a focus on what might be unique to VHL. The final codebook included groupings of codes related to the impact of VHL on the lived experience (medical, psychological, social, romantic, and reproductive), disclosure decisions (why, when, what, and how to share with dating partners), implications of disclosure (reaction, impact, and lessons learned), and support (experienced and desired) (Appendix 2). Using Dedoose software (version 8.3.19, www.dedoose.com), each transcript was independently coded by at least two of three coders and discrepancies in code application were resolved through discussion among all three coders. The three coding authors independently identified crosscutting ideas which were consolidated through discussion into themes, noting those previously shown in the literature while identifying novel themes relevant to the VHL population.

Results

Demographic information of the participants can be found in Table 1. Of the 26 interviewees, 17 (65%) were female and 9 (35%) were male. The mean age of participants at the time of recruitment was 27.4 (range, 21–35) and the mean age at diagnosis was 15.8 (range, 6–29). Current relationship status was defined as single (27% of participants, including one participant who had never been in a romantic relationship), in a relationship (46% of participants) or married/engaged (27% of participants). Our study included 23 individuals who had only had partners of the opposite sex (88%), two men who identified as gay, and one woman who identified as bisexual.

Impact of VHL on attitudes about romantic relationships and disclosure experiences

The majority of participants believed that having a diagnosis of VHL negatively impacted their ability to develop a romantic relationship. The perception that VHL makes one less desirable as a prospective romantic partner was a major contributing factor. Many described expecting potential partners to be less interested in a relationship due to their diagnosis and shared that they often feared or anticipated rejection following disclosure. Participants described a general sense that they were "damaged" or had "baggage", specifically citing worries that potential partners might not want to deal with the health risks related to VHL. One woman described how worried she was to talk to her boyfriend about her diagnosis:

> I think part of me was very scared that he [would be] like, "this is too much. This is too serious, and I don't want to commit myself to a person who potentially could have all these bad things happen to their health." (28yo F, in a relationship).

Participants' fears concerning desirability were heightened following experienced rejection, which caused distress related to future romantic prospects and future disclosure. The majority of participants described at least one negative or unwanted reaction from a dating partner in response to their disclosure. Participants frequently felt shocked, disappointed, hurt, and devastated by these negative responses, causing them to feel less optimistic

Table 1 Demographics. Interviewed n = 26

Age (years)	
Range	21–35
Mean	27.4
Age at diagnosis (years)	
Range	6–29
Mean	15.8
Gender identity	
Male	9 (35%)
Female	17 (65%)
VHL inheritance	
De novo	10 (38%)
Inherited	16 (62%)
Ethnicity	
White	22 (84%)
Hispanic/Latino	2 (8%)
Native American	2 (8%)
Black	0 (0%)
Asian or Pacific Islander	0 (0%)
Highest education	
Some college	6 (23%)
2-year college degree	1 (4%)
4-year college degree	11 (42%)
Graduate degree	8 (31%)
Had been in a romantic relationship	
Yes	25 (96%)
No	1 (4%)
Current relationship status	
Single	7 (27%)
In a relationship	12 (46%)
Married or engaged	7 (27%)
Sexual orientation	
Partners of opposite sex	23 (88%)
Partners of same sex	2 (8%)
Partners of either sex	1 (4%)
Had biological children	
Yes	3 (12%)
No	23 (88%)
Personal history of VHL	
Benign tumor(s)	26 (100%)
Malignant tumor(s)	3 (12%)
Physical, neurological, or visual disability[a]	8 (31%)

[a]Including vision loss, hearing loss, epilepsy, use of assistive walking aid, paralysis, large scars

about dating and more hesitant to disclose their diagnosis in the future. These feelings were described by the following women who experienced rejection, one of whom was reluctant to have biological children due to the dominant inheritance of VHL and the possible impact of pregnancy on her own health, which led to the end of a long-term relationship.

> I was very disappointed and I was hurt… I was very scared that this would be what it would be like to date anyone. Like, is anyone going to want to date someone who's broken and can't have kids? I mean, any guy who wants to get married and have kids is going to look at me and go, "Well, she can't do that, so I'm not even going to try." So, I almost wanted to stop telling people and just say, "I'm not going to share this information with anyone because it makes me seem broken." (23yo F, in a relationship).

> I feel unlovable because of [VHL], because if I was with someone for that long and they couldn't love and support me with it, then how could I expect anyone else to?… it really made me wonder if people could deal with someone who had this sickness… (30yo F, single).

Some participants considered reproductive risks or their decision to not have biological children to be a deterrent in dating, something that was often cited as particularly difficult to share with a partner. However, participants did not describe a sense of urgency to find a life partner and to have children.

A subset of participants' dating concerns focused on the longitudinal impact of VHL on a relationship. These participants were less concerned about a romantic partner's initial reaction to disclosure, but anticipated that VHL would negatively impact a relationship over time and eventually lead to its termination. In a few cases, participants described how the impact of VHL on a relationship was not felt until the participant experienced health issues or needed to have surgery and relied on their partner for tangible support in novel ways. Relatedly, a few participants were also concerned that entering a romantic relationship would be selfish due to the emotional, physical, and possible financial burden of their illness on a partner, making them hesitant to enter a long-term partnership. This sentiment was particularly endorsed by individuals who had a parent with VHL and witnessed the impact of the condition upon their parents' marriage across multiple decades.

> I've always expected and have never been let down by my assumption that people will say that it's okay, whatever happens, we'll work through it. But my feeling in that area is that every relationship and every person has a breaking point. …for example, if they were driving me to the hospital for a hundredth time in 20 years time or something like that and they'd just say they're fed up, they've had enough stress worrying about me. (21yo M, single).

> …my mother has been the biggest impact on me and seeing how it has impacted her. I have a really hard time putting anyone through that. When you're mar-

> ried, that's what it is, through sickness and health. So that just kind of scares me that at some point someone will have to probably take care of me, like she takes care of [my father]. …I don't want someone else to have to go through all that because of me… (30yo F, single).

While most participants described at least one unwanted reaction, participants also described positive impacts on their relationships after disclosure. A few participants said that sharing information about their diagnosis had strengthened relationships because disclosure of something very personal was seen as a gesture of vulnerability and trust. Others added that being open about their diagnosis with a partner positively impacted communication. Some participants also noted that disclosure had a positive personal impact as well; sharing information about VHL provided a sense of relief and boosted self-esteem and hope for the future when the response was positive, increasing interest in future disclosure.

> I think it's definitely deepened my relationships. I think I have to be more genuine and I think I'm a lot more emotionally healthier now because I discuss it. I think when you're appropriately vulnerable, it can have a positive impact on the relationship. (23yo F, in a relationship).

> I think being very upfront about what was happening… gave [my partner] the opportunity to step up and be that sort of emotional support partner that I was asking for…I think it was one of the things that happened early on that really set the balance of trust and communication that has defined the rest of the relationship, that obviously I'm still in… (28yo F, in a relationship).

Attitudes towards disclosure of a rare and complex diagnosis

A significant factor complicating disclosure for many participants was the way in which VHL is often characterized by individuals who do not have VHL as particularly scary or serious, which uniquely exacerbated the fear of rejection. Many participants said that other people have never heard of VHL and tend to greatly exaggerate the seriousness of the condition when they first learn about it. Because of this perception, many participants expressed difficulty in deciding what information to share with dating partners about VHL. A few participants said that they wanted help in deciding what to share in order to avoid rejection.

> …from my experience of telling it to people, most people get completely freaked out. Like "Oh my God. How do you like, live with that?" And, "Aren't you worried about this, this and this? …What is your quality of life even? How do you even go on living with that?" And "How are you happy?", and whatever. And I'm like "Oh well, thanks."…going from never even hearing of it, to learning that, okay, it's like, ten areas of your body. That's insane and hard for people to grasp, and it sounds super scary. (22yo M, single).

> I guess [I'd like to learn] how to make it less scary. I know it hasn't like scared off anybody that I know, but it is a lot and I would want to be able to present it the right way, not to make it sound like it's the end of the world, you know? (27yo F, single).

Disclosure also led to other unwanted reactions that caused apprehension or distress for individuals with VHL. Some participants described how difficult it was to bear the emotional burden of the other person's unwanted over-the-top reaction. Unwelcome pity or exaggerated reactions of concern were seen as frustrating and emotionally taxing.

> I've gotten to a good place with it or I try to get to a good place with it, but it scares people. And it's hard because I've worked really hard and I do see a therapist to like, try to be healthy, but other people haven't… If you have an inappropriate response, I don't want to have to be the recipient of that. …I don't want to be your counselor… (23yo F, in a relationship).

> …there have been instances of crying and sadness and stuff and I always have to spend hours giving somebody a pep talk for something that's not even affecting them. It makes me feel that, I'm like, oh, crap, I have to fix this now. … I appreciate their support but it also becomes a burden. Like, oh, God, now I've got to talk them off the cliff. It's just something tough. (25yo M, in a relationship).

Approaches to disclosure of a rare and complex diagnosis

Many participants discussed downplaying the impact of VHL in order to combat this threat of rejection and other unwanted reactions, employing strategies such as emphasizing the word benign and avoiding the word cancer, or omitting key details such as inheritance, life expectancy, or where tumors could arise.

> I'm very independent and I'm very proud of how strong I am. So the last thing I want people to do is pity me or feel like I'm weak or treat me like I'm sick. And I think that that's part of that inappropriate response. If I downplay it, you won't think these things. And then I don't have to deal with you treating me differently or inappropriately. (23yo F, in a relationship).

In contrast to minimizing risk, other participants valued complete disclosure of their diagnosis of VHL and associated risks. Many cited a perception that it is dishonest and unfair to withhold information that could impact a partner's decision to be in the relationship, especially the implications for potential children, and wanted to give dating partners an opportunity to end the relationship if they did not want to accept the risks. Some participants described that it was especially important to be transparent about the realities of what living with VHL could look like now and in the future.

> …I laid it out to him that I would completely understand if he wanted to break up basically, because I was going to have this disease forever….I felt like it wasn't fair to let him continue in our relationship with not giving him all of the details of what it would mean. I feel like honesty is pretty important to me, very important to me in a relationship. (31yo F, in a relationship).

> I shared some of the scary sounding statistics… in an attempt to kind of get the severity to land. … I didn't want to continue in a relationship with someone who didn't understand how potentially serious this could be, what the long-term implications were. You know, he was making a choice for being in a relationship, and I didn't want that choice to be, you know, sugar coated in any sort of way. (28yo F, in a relationship).

> I think it is important because if you want to have a marriage with someone and you want to grow old with someone, they have to be willing to understand that they might outlive you. (23yo F, in a relationship).

For others, total disclosure was intentionally used as a litmus test early on in a relationship to discern if a partner would be supportive and able to handle future health trials. This vetting process otherwise allowed participants to get rejection out of the way before investing too much time or emotional energy into the relationship. Participants expressed that while it can be difficult to experience negative reactions, it's okay if disclosure functions as a filtering mechanism for potential partners, because having VHL is not something you can change and you want to be with someone who loves you for who you are.

> I think a lot of that conversation was motivated by my own fear of rejection, and need to do it then on my own terms, and set it out in my own way, sooner rather than later. … I think I felt kind of better to know now if this is going to scare him off, than invest more time in this, and kind of see if it scares him off later when he really understands how serious it is, you know? (28yo F, in a relationship).

> You don't want a relationship where you can't feel like you can tell them, or you do and it's weird. That's not sustainable… I just hope that people, like love themselves enough to wait for someone that can love you through all the health stuff, you know? (26yo F, in a relationship).

Support for disclosure

Participants described a lack of support in the context of dating and disclosure. Despite evidence that approaching dating relationships and disclosing a diagnosis of VHL to dating partners is something that can be challenging, many indicated that this research interview was the first significant conversation they had had with anyone about it. Some participants said that it was difficult to find someone who both understands VHL and with whom they feel comfortable talking about dating; they expressed that there are not many contexts where this topic comes up, and it was difficult to imagine what form a helpful resource would take. Others described the value (or anticipated value) of meeting other young adults with VHL, which provided the rare opportunity to gain helpful insight into others' experiences with dating and disclosure and engage with a community of peers who have dealt with similar challenges. One woman highlighted the benefit of peer support for this age group in particular, describing how her father could not offer the same guidance despite also having VHL.

> …the [only] guy I knew [with VHL] was my dad and he's the stodgy old professor. I was a teenage girl, we had zero in common. We're supposed to talk about this thing and he was supposed to be my support. But we were processing things so differently… And then to actually be in the same room with people who'd experienced the exact same things that I did. … [talking to dating partners] was actually one of our conversations, which was really easy. And the whole thing was so weird because everyone was so open about this stuff. I'm like, it's just like my own bullshit. …you forget that it's like, oh yeah, there are people just like me who are facing these exact same issues. (26yo F, in a relationship).

> That [VHLA] conference was really helpful for me. Just because it was people that were my age that were actually going through [dating] and dealing with it and having that perspective was huge for me…. The human connection to other people that are dealing with the same thing has been really helpful. (30yo F, single).

> I think when you have VHL it's kind of hard when you don't know either people that have that diagnosis in general, and then to have to go up to a person who doesn't have VHL and tell them what that is, it's hard to decide like, "How am I even going to bring

that subject up? How am I going to tell them, 'This is what I'm going through?'" I think to have another person with VHL who has experienced that and has had a good experience with that and say, "Well, this is how you need to bring it up," and should you bring it up… I think knowing that ahead of time instead of just going into it blindly would help. (23yo F, in a relationship).

The majority of participants said that their healthcare providers have not talked about this issue at all; conversations in the medical setting were limited to reproductive risks and inheritance, and additional resources or referrals to address the psychosocial impact of VHL on dating and romantic relationships were not routinely offered. One woman reflected on the challenges of adjusting to her diagnosis as a young teenager and discussed her frustration that medical providers never broached the topic of how VHL might impact her life as an adolescent or young adult.

I only saw a genetic counselor once. And one of the things is like, well kid, like I'm 13, what am I going to tell my boyfriend? It's always about these really big serious life things. But what about just dating? You know, casually? There's no way to navigate that. No one was talking about that. So then you just kind of muddle through, and heartbreak after heartbreak, you finally figure it out. (26yo F, in a relationship).

Some participants thought that healthcare providers should address the topic of dating and disclosure directly, potentially regarding what information to share with a partner or how to initiate a conversation. A couple of participants described doctors offering to help talk to partners if the participant brought them in for a separate appointment, which was seen by some as helpful. One participant pursued additional appointments with a genetic counselor specifically to talk about difficulties with dating. She expressed disappointment that she could not have an ongoing relationship with that provider because she saw value in the unique understanding of both the genetic and psychological aspects of VHL.

I actually went back a couple of months ago to another genetic counselor just because I was having trouble dealing with it… I think just reiterating some of the stuff that I kind of already knew… that it's not a death sentence. That people date people that have these things all the time and you know, just because I have a diagnosis doesn't mean I'm not worthy of the love and the support that I so desire. …I feel like a friend is always going to tell you that kind of thing. But I think I needed to hear it from an impartial person. (30yo F, single).

Conversely, some participants said that doctors and similar medical providers should focus on your physical health because a conversation about dating is outside of their scope of practice and may be uncomfortable. However, many maintained that it would be valuable for doctors to broach the topic to determine a patient's interest in talking to someone else about it, with the ability to direct patients towards other resources to have those conversations. Beneficial referrals included therapists, preferably those with experience with chronic illness, although these referrals were not made consistently. Some participants were frustrated that they had not known that such counseling was an option sooner.

I think just being actively encouraged to seek out, not just "go to your scans" but actually talk to someone about this… Like somebody who has therapeutic experience with chronic illness. Even if it's nothing like VHL but just the mental weight of having something, seeking out a therapist or genetic counselor or group therapy with people actually understand this and can help guide you. That would have saved me so much grief over the years. (26yo F, in a relationship).

I'm very disappointed that my healthcare providers didn't provide a therapist or even suggest that we go discuss with a therapist specializing in chronic illnesses. I go to a clinical care center and they didn't suggest that… And I just feel like that's not appropriate… I think you would immediately send someone to a neurologist and a renal specialist. Why wouldn't you also send them to a psychologist or at least refer them to one? This is a huge part of your illness. (23yo F, in a relationship).

Some participants who had experience with dating and disclosure (regardless of current relationship status) reported that they had learned from past experiences and did not feel that they needed support in this area, but may have benefitted when they were younger and still determining how to navigate dating relationships. However, a few participants described how the impact of VHL constantly evolves through different life stages and through surgeries and health issues, and needs are not static over time. Consequently, some thought that it may be helpful to have support in the context of romantic relationships in the future.

I think that's a huge misconception… at least how I was taught how to deal with a genetic disorder is that you have this one thing and it's treated like a static thing, but it's different at every stage of your life. Like when you're a teen, you think about it totally differently, when you're in college, different. A young adult, when you have kids, when you're getting older and you have all this other health stuff come up…. So even if I

have a partner now, we're going to be working through this shit forever. (26yo F, in a relationship).

Discussion

We had the opportunity to interview 26 young adults with VHL about their diverse experiences with dating and disclosing their diagnosis to dating partners. Given the rarity of this condition, a strength of this study was the larger cohort of young adults, which enabled achievement of data saturation. We found that a diagnosis of VHL exacerbates the fear of rejection in ways that are unique from other studied hereditary cancer predisposition syndromes due to its frequent characterization by potential partners as scary, leading to differences in how our participants approached disclosure and highlighting the need for healthcare providers to offer psychosocial support in this context as part of standard care for this population.

Our data identified many challenges that young adults with VHL face in forming romantic relationships and sharing their diagnosis with dating partners, some of which are similar to those described in the literature, and others that appear to be unique to VHL. In agreement with the results of previous studies concerning other genetic conditions such as HBOC, our data suggests that a diagnosis of VHL negatively impacts formation of romantic relationships by contributing to a perception of decreased desirability and a fear of rejection, causing many participants to view disclosure conversations with apprehension. However, the perception of VHL as particularly serious by those who do not have VHL uniquely exacerbates the fear of rejection or other unwanted reactions. This perception may be due to aspects of VHL that are unique from other hereditary cancer predisposition syndromes such as HBOC: unpredictable multiorgan tumor risks including tumors of the central nervous system, misconceptions regarding benign tumors versus cancer, and unfamiliarity of the condition and its manifestations to most laypeople. Our findings suggest that this perception of decreased desirability is different from concern regarding physical desirability common in the HBOC literature, potentially due to the lack of options for risk-reducing surgery or impact on sexual organs. Additionally, although disclosing the risk to potential children was still a concern for our participants, VHL did not appear to lead to the same urgency to find a partner and have children as seen in the literature for women with HBOC, perhaps due to VHL's limited impact on sexual organs [12].

This research offers valuable insight into ways in which healthcare providers and patient organizations might better support this population. While VHL often causes distress for young adults in this context, participants cited a lack of support for navigating dating relationships. With a few exceptions, there was largely a consensus among our participants that healthcare providers do not address this topic beyond discussion of inheritance and family planning. Our results serve as an important reminder that healthcare providers caring for patients with VHL and other multi-organ tumor predisposition syndromes should be attentive to these individuals' diverse needs and the evolving psychosocial impact of a diagnosis over the lifespan, particularly considering that a diagnosis may be made at a younger age compared to other hereditary cancer predisposition syndromes. Physicians may not be best suited to speak to dating concerns, however due to their central role in continuing care, these providers should actively and routinely assess patients' needs and offer related resources, including encouraging their patients to talk to a therapist with experience in chronic illness for longitudinal psychosocial support. Clinical care centers should also prioritize ongoing availability of genetic counselors, who are uniquely poised to discuss these complex issues and aid in coordinating comprehensive follow-up care.

For some young adults with VHL, talking to peers with VHL or other chronic illnesses about their experiences and approaches to dating and disclosure is a beneficial way to decrease anxiety about these issues and increase confidence regarding disclosure, demonstrating the importance of patient support organizations catering to this population. However, there remains significant heterogeneity in desired support among different individuals and in different stages of young adulthood and romantic relationships, representing multiple opportunities for intervention. Our participants' stories demonstrate the value of a multidisciplinary team approach and may support the deliberate integration of recommendations for patient-centered longitudinal psychosocial support into VHL active surveillance guidelines.

Appendix 1: Interview Guide

1. Personal history of VHL diagnosis

*To begin I'd like to ask some questions to better understand your journey with VHL, and how VHL has impacted your life.

- I know you were __ years old when you were diagnosed. Could you tell me how you found out that you had VHL?
- Have you had genetic testing?
- Do you remember what you were first told about VHL? Who talked to you about VHL?

- VHL can be a variable condition, with some people having more medical problems than others. Overall, what impact has VHL had on your health?
- Have you been diagnosed with a VHL-related tumor(s), or had any health problems related to VHL?
- How old were you when your tumor(s) was diagnosed? Are you still being treated for this?

2. Family history of VHL

- Regarding your family, were you the first in your family to be diagnosed with VHL?
- Who else in your family has been diagnosed with VHL? What impact has VHL had on your family?
- Have family member(s) died from a VHL-related tumor? (Who? How old were you?)

3. Attitude towards VHL and perception of health risks

*I'm curious about how you feel about your diagnosis of VHL.

- What was your personal reaction when you found out that you had VHL?
- In general, how would you describe your health?
- To what extent has your physical health related to VHL has interfered with your daily life/normal social activities (with family, friends, neighbors, or groups)?
- What is your perception of your health risks related to VHL, now and in the future?
- How do you perceive your risk of developing a(n) (additional) tumor compared to an average member of the US population?
- How do you perceive your risk of developing cancer compared to an average member of the US population?
- How concerned are you about the possibility of getting (another) tumor or cancer one day?
- How often do you worry about this? Have these thoughts affected your mood or interfered with your ability to do daily activities?
- How often do you worry about the health of family members who have VHL?
- How do you think individuals who do not have VHL perceive VHL?

4. Perception of romantic relationships and impact of diagnosis

*The goal of this research study is to understand the challenges in navigating dating relationships faced by young adults with VHL. Before we talk more specifically about dating with VHL, I'd like to learn a little bit about how you think about romantic relationships in general.

- How important do you consider a romantic relationship to be in your life, now or in the future?
- What hopes or expectations do you have regarding long-term romantic relationships/marriage? Has this changed at all since you were diagnosed with VHL?
- What do you value in a romantic relationship? Has this changed at all since you were diagnosed with VHL?
- In what ways has your diagnosis of VHL affected your views on having (more) children, if any?

5a. Dating history and disclosure to romantic partners

*I'd like to ask you about your experience with dating and talking to romantic partners about VHL, to get a sense of the challenges that might be involved with disclosure of your diagnosis to partners.

- Have you ever been in a romantic relationship? How many relationships have you been in since you found out that you have VHL?

  (If the participant has never been in a romantic relationship or has been single since learning of their VHL diagnosis, skip to Sect. 5b).
- Are you currently in a relationship?
- Have your relationships been with men, women, both?
- How would you characterize your relationships since learning of your VHL diagnosis (high school relationship, casual dating, serious relationship, etc.)?
- In how many of your relationships did you tell your partner about your diagnosis?
- Why did you choose to share this information? Or, why did you choose not to tell them?
- What did you think about when deciding if you would tell your partner(s) about VHL?
- How did you tell them (in person, over the phone, through email, in a group setting, etc.)?
- How did you decide when to tell your partner(s) about VHL?
- How long had you known this person? How long had you been dating/in a relationship when you shared that information?

- How did you determine how to initiate this conversation?
- How did you decide what to tell your partner(s) about VHL?
- What information did you share? Why did you choose to tell them what you did?
- How did you describe your personal health risks?
- How did you describe risks to possible children?
- What did you expect your partner(s)' reaction would be when you shared that information with them? What was their reaction? How did you respond to your partner's reaction?
- How did sharing this information impact your relationship(s)?
- How (if at all) did your experience(s) talking about VHL with dating partners change your perspective on sharing that information with dating partners?
- Do you consider disclosing your diagnosis of VHL to potential romantic partners to be challenging?
- In what ways? Why or why not?
- (If currently single) Are you currently seeking a romantic relationship?
- Why or why not?
- In what ways has your diagnosis of VHL impacted how you seek out potential partners, if at all?
- (if currently single) Are you as interested in entering a romantic relationship as you were prior to your diagnosis of VHL?
- Is there anything else you'd like to share about disclosure of your VHL diagnosis to (potential) romantic partners?

(skip to Sect. 6).

5b. General perception of dating and disclosure

- Are you currently seeking a romantic relationship?
- Why or why not?
- In what ways has your diagnosis of VHL impacted how you seek out potential partners, if at all?
- Are you as interested in entering a romantic relationship as you were prior to your diagnosis of VHL?
- Have you thought about whether you would share information about VHL with dating partners?
- What are the reasons you would or would not tell a romantic partner about VHL?
- Have you thought about when you would tell a romantic partner about your diagnosis?
- Have you thought about what you would tell a romantic partner about VHL? What information would you share?
- What do you anticipate that a potential partner's reaction might be? How do you think this disclosure could impact a romantic relationship?
- Is there anything else you'd like to share about disclosure of your VHL diagnosis to potential romantic partners?

6. Disclosure to others

*To help put what we were just talking about into a larger context, I'm interested in knowing how you talk to other people in your life about VHL.

- Who else have you told about your diagnosis of VHL?
- How do you decide who to tell? Are there people you choose not to tell? Why or why not?
- When and what information do you share? Is there information you don't share?
- Do you think it's easier to tell friends about VHL compared to someone you're dating? If so, in what ways?

7. Support for disclosure

*I'd also like to ask about anyone in your support network that may have helped you think about sharing information about your VHL diagnosis with dating partners.

- Have you spoken with other individuals with VHL (outside of your family)?
- Who? What have those interactions been like?
- Have you been a part of a support group for VHL?
- When did you first become involved?
- Was disclosing VHL to others discussed in the support group? Was disclosing to a romantic partner specifically discussed?
- Was that discussion helpful? In what ways was it helpful, or not? Or if you have never been involved in such a discussion, do you think that would have been helpful?
- If you were in a support group, what would you want them to discuss?
- Has anyone else (a family member, friend, etc.) helped you think about sharing information with dating partners in any way?
- Who? What was that conversation like?
- Who initiated the conversation?
- How did/do you feel about that conversation?
- Has a healthcare provider ever discussed sharing information with dating partners in any way?
- What kind of provider? At what point in your medical care? What was discussed?
- Who initiated the conversation?
- How did/do you feel about that conversation? Or if you have never had such a conversation, do you think guid-

ance from a healthcare provider or someone else would have been helpful?
- What would you want a provider to discuss with you? What kind of provider would you like to talk to about this?
- Are there resources that you wish a healthcare provider had given you? Other resources desired?
- Do you think guidance from someone other than a healthcare provider would have been helpful?
- Who? In what context?

Appendix 2: code book

Factors relevant to the impact of living with VHL

Medical/Physical.

- Perception of current health (e.g. physical impact of surgery, disability, severity compared to others).
- Perception of future health risks (e.g. risk of cancer, inevitability, life expectancy, hope for future research).

Psychological.

- Worry for self (e.g. anxiety around annual screening, worry about quality of life or reduced life expectancy).
- Uncertainty/unpredictability (e.g. stress of not knowing when/where tumors may arise).
- Worry for family (e.g. fear of relative dying).
- Negative impact on life (e.g. financial stress, guilt, feeling in a minority).
- Positive impact on life (e.g. pride in overcoming challenges, inspired vocation, bonding with relative).

Social.

- How others (outside of family) perceive VHL
    - They don't know what it is.
    - They exaggerate it.
- They minimize it.

Romantic.

- Importance of romantic relationship (in general, and change in importance due to VHL).
- Impacts desired attributes of romantic partner (e.g. selection against those who prioritize biological children, selection for certain character traits).
- Complicates dating (e.g. anxiety in disclosure, limited pool of dating partners).
- Impact perception of one's own desirability (e.g. having baggage, decreased physical desirability).
- Fear of burdening partner (e.g. partner distress with health challenges, partner as caretaker, financial burden).

Reproductive.

- Family's experience (e.g. relative's medical history, relative's attitude towards diagnosis).
- Impact of VHL on parents' relationship (e.g. parent becoming caregiver, impact on child).

Disclosure decisions

Why share or not share?

- About individual with VHL
    - Sharer/not a sharer (e.g. no reason not to share, discloses to most people, private).
    - Importance in one's life (e.g. it's not going away).
- Self-identity (e.g. it's part of what makes me who I am, pride, it doesn't define me).
- Dishonest to withhold (e.g. might impact partner's decisions, providing an out, values honesty).
- Medical necessity/opportunity (e.g. appointment, physical evidence, in case of emergency).
- Emotional necessity/opportunity (e.g. reciprocating intimacy).
- Time (e.g. don't waste time in unpromising relationships, urgency in dating).
- Fear (of impact on oneself) (e.g. rejection, being treated differently, opening healed wounds).
- Fear (of impact on partner) (e.g. burdening others, being a downer).

About relationship

- Characterization of relationship (e.g. long-term/serious, strength of relationship).
- Litmus test (e.g. disclosure as test of partner, as test of relationship's potential).

About partner

- Anticipated reaction based on attributes (e.g. partner's relevant experience with illness).

External

- Someone else forced disclosure (e.g. pressure from family, someone else shared).

When to share? (e.g. on first date, within certain time period).

What to share?

- General description of VHL.
- Past medical or family history.
- Current medical issues.
- What screening entails.
- Future health risks.
- Risk to biological children.
- Minimizing risk/impact (e.g. strategies employed, avoid unwanted reactions, avoid worrying others).
- Use of educational tools (e.g. sharing website, sharing VHLA booklet).
- Extent of disclosure (e.g. phased approach, inviting questions, censoring information).

How to share? (e.g. in person, via phone, via text).

Implications of disclosure

Reaction.

- Positive.
- Negative.
- Indifferent.

Impact.

- Impact on relationship
  - Strengthened.
  - Weakened/ended.
  - No change.
- Ongoing evolution (longitudinal impact of VHL on relationship).
- Impact on future disclosure.
- Impact on oneself.

Lessons learned.

Support/resources

Utility of support/resources (experienced).

- Interaction with VHL/other community (e.g. talking to peers with VHL, utilization of support groups).
- Interaction with family/friends (e.g. talking to affected parent, talking to unaffected parent).
- Interaction with healthcare providers (e.g. interactions with physicians, genetic counselors, therapists).

Utility of support/resources (desired).

- Interaction with VHL/other community (as above).
- Interaction with family/friends (as above).
- Interaction with healthcare providers (as above).

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Declarations

Conflict of interest The authors have no competing interests to declare that are relevant to the content of this article.

Ethical approval All procedures were in accordance with ethical standards of the University of Michigan Medical School Institutional Review Board (UM IRB) and the Helsinki Declaration of 1964 and its later amendments or comparable ethical standards. This study was deemed exempt by the UM IRB (IRBMED# HUM00166307). Verbal informed consent was obtained from all participants included in the study prior to each interview.

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