Sharing Women's Health Experiences Influenced by Genetic Factors: Practices, Challenges, and Opportunities

Ziqi Yang
University of California, Irvine
Irvine, CA, USA
ziqiy30@uci.edu

Daniel A. Epstein
Informatics
University of California, Irvine
Irvine, CA, USA
epstein@ics.uci.edu

Yunan Chen
Informatics
University of California, Irvine
Irvine, CA, USA
yunanc@ics.uci.edu

Abstract

Genetics play a significant role in women's health, with family members often experiencing shared symptoms or hereditary risks. HCI has explored how digital tools like medical records, tracking apps, and online communities can support documenting and sharing of health information and management of health conditions. However, little is known about what and how these health experiences are communicated within families, especially when influenced by genetic factors. We therefore conducted a survey with 249 adult women in the U.S. to understand how they share genetic factors relating to women's health with family members. Our findings show that participants value health history and lived experiences, but gaps in time and space, stigma, and family tensions hinder the sharing of details and sensitive topics across generations and larger families. We discuss opportunities for designing tools that promote genetic health sharing, address stigma, and enable intergenerational sharing and tracking.

CCS Concepts

• **Human-centered computing → Empirical studies in HCI**; • **Applied computing → Health informatics**.

Keywords

Genetic Health, Women's Health, Family Communication

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1 Introduction

Genetics contribute significantly to people's health through genetic inheritance from parents to child, covering health aspects from illnesses to everyday wellbeing [54, 124]. Therefore, biological family members across multiple generations often share similar health experiences. Women's health experiences, including both health conditions specific to women and those impacting men and women differently [50], are deeply influenced by genetic factors. For instance, genetic resemblance results in similar timing of menarche and menopause, as well as menstrual symptoms, between sisters [36, 67, 73]. Breast cancer or cardiovascular diseases are also associated with specific genes that are passed down families [41, 106]. Thus, information about these genetic health experiences from families could greatly support women in understanding and managing their own health.

HCI has long focused on how technology can be designed to support understanding and sharing health information. However, these design approaches have largely ignored the influence of genetics. For example, self-tracking tools have supported women in understanding and managing their personal health information around menstruation, pregnancy, or menopause [30, 39, 43, 77, 78]. Online communities have focused on generalized peer support or crowdsourced advice, including sensitive topics such as reproductive health or miscarriage [3, 4, 34]. While some HCI research has studied how family members collaborate in using health technology, the communication has centered around one member's condition (e.g., a member with an acute condition)[20, 80, 98], overlooking potentially similar experiences of other members. A few recent studies have examined how technology and design artifacts can support people passing down women's health experiences across generations [24, 93], yet they have primarily focused on general health education and information. There is therefore a gap in understanding how technology can support people, especially women, in developing an understanding of their family health history, where genetics plays a significant role.

Thus, we aim to examine families' sharing of women's health experiences impacted by genetic factors to understand the underlying needs and challenges. Rather than treating genetics as a purely biomedical construct, we focus on how genetic influences are interpreted and acted upon in everyday family contexts when making sense of and managing personal health. Unpacking the practices, challenges, and opportunities enables us to offer suggestions to future technologies to better support families in sharing and passing down genetic health information. Through this study, we answer the research questions:

- RQ1: What do families currently learn and share about their genetic health experiences related to women's health, and what information would they like to learn and share more?
- RQ2: When and how do families learn about and share their genetic health experiences related to women's health, and how do those differ from other regular family communication?

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- RQ3: What challenges do families encounter when sharing and passing down their genetic health experiences related to women's health?

We conducted a mixed-method survey with 249 adult women in the United States, stratifying age based on the US population distribution. After offering some background on women's health and genetics, we asked participants to describe their past experiences sharing and the challenges they encountered. Our results identified that families shared everyday experiences including symptoms and practices, and clinical health conditions including diagnosis and treatments (RQ1), typically through conversations during family gatherings and events, occasionally with the support of documentation (RQ2). We found that many shared limited details due to a lack of awareness of genetic health, while gaps in time and space, tensions in family relationships, and cultural, generational, and gendered stigma impacted sharing opportunities (RQ3). These insights reveal the opportunities for health technologies to highlight genetic health during health documentation, address stigma to facilitate conversations, and support families in collaboratively tracking their health conditions to be shared and passed down generations. We also discuss sociotechnical considerations and risks in designing such technologies for genetic health.

This paper makes the following contributions: First, it offers an empirical account of what and how families share genetic health experiences related to women's health. In doing so, this work shows how a genetic focus reframes health information as a shared and intergenerational resource, rather than solely personal data, with implications for how HCI understands and designs for health information. We highlight topics, details, and types of genetic health information people would like to learn more about, and factors influencing the information needs. Second, it summarizes the needs and challenges for designing health technologies to be used across generations, and how such technologies can be used to support family health. Third, it highlights opportunities for future technology to support families' collaborative sharing, documentation, and preservation of genetic health experiences to pass down generations.

2 Background: Health, Family, and Genetics

Genetics, the inheritance of biological traits through DNA, is a key factor shaping people's health [54]. Genetic factors contribute not only to complex diseases such as diabetes and cardiovascular disease, but also to everyday aspects of health such as aging or weight [49, 54, 124]. Research revealed that family communication is a crucial source of information for people to learn about genetic health and promote health literacy [29, 109, 134]. In clinical practice, family health history is often collected as a proxy for genetic risk to support clinical diagnosis and decision-making [88, 99]; Recent technology has also leveraged computational and biomedical methods to assess people's health risks impacted by genetics [49, 133]. Direct-to-consumer genetic testing services offer increasingly precise assessments to highlight genetic health risks [8, 32, 56]. A few HCI studies have examined public perceptions of polygenic risk scores, and people's practices looking for genetic testing resources, revealing both interest and concerns about genetic health [115, 132]. While biomedical and computational approaches emphasize risk prediction and diagnosis based on genetic factors, much less is known about how technology may support families to understand, communicate, and pass down information related to genetic health in their everyday social contexts.

In this paper, we focus on women's health as a domain where genetics strongly shapes health experiences. Women's health encompasses both conditions specific to women (e.g., menstruation, pregnancy, menopause) and conditions that affect women differently than men (e.g., breast cancer, cardiovascular disease) [50]. These experiences vary widely across individuals, but often recur within families, creating intergenerational patterns shaped in part by genetics. Research shows that genetic factors account for up to 50% of variation in the timing of menarche and menopause[36, 73], and 35–40% for premenstrual and menstrual symptoms [67], while genes like BRCA1 and BRCA2 have been linked to elevated risks of breast and ovarian cancer [41, 132]. These findings highlight how women's health is not only individual but also genetic and familial, making family communication particularly valuable.

3 Related Work

Our study builds on past HCI work related to documenting and preserving health data, family communication around health, and women's health.

3.1 Documenting, Sharing, and Preserving Health Data

Technology has supported the documentation of people's health data in a wide range of forms, from formal clinical records to informal personal journals and tracking tools. On one end of this spectrum, clinical documentation such as Electronic Health Records (EHRs) provides a reliable record for communication, diagnosis, and treatment [23]. Emerging technologies, such as digital scribes and natural language processing methods for extracting family history from clinical notes, have further enhanced the efficiency and scope of such records [2]. However, clinical documents typically prioritize medical details over lived experiences, and their highly technical language can be difficult for non-professionals to interpret [12, 127].

On the other end of the spectrum, personal health informatics tools enable individuals to document and reflect on their personal health data in everyday contexts [43, 69, 107, 120], such as menstrual and fertility tracking apps [31, 40]. These systems capture more contextual and experiential detail than clinical records, helping people understand their own health patterns and track changes over time, yet are typically designed for individual use rather than sharing with other stakeholders such as families [57]. Together, these two forms of documentation illustrate the trade-off between technical precision and contextual richness. Although health documentation could be helpful for patient-provider communication or boundary negotiation [26, 27, 112, 131], they typically focus on short-term decision-making and needs of a single primary patient, rather than preserving information for broader family use or future generations.

Beyond immediate clinical or personal use, a growing thread of research explores how digital information can be preserved and revisited over the long term. Work on digital legacies has examined how artifacts, such as memorial social media pages or written stories, gain meaning across years or generations [35, 117], while slow technology emphasizes designing for much later use or infrequent interaction [51, 91]. Recent work in health explores how long-term tracking of women's health (e.g., polycystic ovary syndrome (PCOS)), yield deeper insights [65]; other studies have proposed creating digital legacies to pass on health experiences across generations [24, 94] and self-tracking to navigate memory loss [105] However, this work has largely focused on legacies that pass down general experiences to broad audiences, leaving a gap in understanding how technologies might support sharing genetic experiences within families.

3.2 Family Communication and Health Management

As communication between family members helps families support each other in daily life, HCI has aimed to design technology that facilitates family communication. For family members at a distance, technologies from phone calls to telepresence robots can support their communication and make them feel more connected [104]. Family storytelling can help illustrate a family's cultural background to the next generations [6, 63], enhances the children's learning or physical activity [102, 136], and promotes family closeness across generations [22, 75, 123]. Health and wellbeing are among the crucial topics of conversation [92, 125], with shared journaling apps promoting in-depth discussion [64]. While prior studies address challenges of distance, generational gaps, and cultural context in family communication, they largely focus on emotional or cultural goals. Studies have revealed that families may share genetic health information with younger generations, particularly in the contexts of family health history or populations with limited health literacy populations [29, 109, 134]; however, how technology may support families' communication about long-term health management, especially genetically shaped risks, remains understudied.

Family informatics has examined collaborative health tracking and management among family members [55, 71, 98], such as multiple caregivers [130]. These technologies typically center on the needs of one family member, often someone managing a chronic or genetic condition, such as children with long-term health needs [20], pregnant family members [79], or older adults [22], while other members act as supporters. In other cases, end-user apps enable one key member to review multiple family health records [53]. Such health technologies support collaborative care practices, but they remain centered on a single primary user and offer limited support for making sense of genetic risks that span multiple family members. Our study, thus, focuses on shared genetic health experiences among families through an understanding of family communication practices.

3.3 Women's Health in HCI

HCI has regularly focused on challenges in navigating women's health experiences and how technology can help women understand and manage these experiences across the life course. Apps and devices such as menstrual tracking tools [39, 76, 77] and pregnancy and fertility tracking tools [30, 79] can collect and leverage women's health data towards self-understanding. These systems often emphasize the plurality of women's lived experiences, supporting personalized tracking and reflection on cycles, symptoms, and bodily changes [7]. In this study, we use the term "women's health" to align with prior work, while we acknowledge that individuals affected by these health experiences may not all identify as women, and that the term has limitations in fully representing these experiences.

Research has uncovered that social stigma has been a significant challenge in navigating women's health. Topics such as menstruation, sexual and reproductive health, or menopause are often seen as private and a cultural taboo [81, 85, 87]. Sharing unexpected outcomes such as pregnancy loss in need of support is often hindered by social norms [3, 4]. Compared to other health topics, conversations around women's health are often more challenging, particularly in patriarchal societies, where stigma intersects with gendered expectations, family power dynamics, and the deprioritization of women's needs [89, 114]. Policy changes, cultural norms, and religious beliefs further contribute to women's concerns around societal stigma [34, 58, 77], resulting in informational, emotional, and mental struggles [4, 80, 116]. Recent HCI work has explored how technologies can help address stigma towards women's health, and thus support the sharing of those individual experiences, such as tangible materials, chatbots, and design artifacts [17, 47, 93]. However, these studies focused on sharing personal experiences with the public or the community, instead of genetic, familial experiences or with families. Therefore, in this study, we examine how families communicate women's health experiences shaped by genetics, and the challenges that arise with family dynamics and sociocultural norms.

4 Methodology

To examine the current practices, needs, and challenges around the sharing of women's health experiences among family members, we conducted a mixed-method online survey with 249 female participants from Prolific[1]. Since genetics influences various women's experiences, and prior studies have surfaced that factors like social stigma impact sharing disproportionally, we chose to conduct a survey and stratified recruitment by age, aiming to develop an understanding of the breadth of experiences sharing and learning about genetic factors related to family health across ages. The study was approved by our institution's Institutional Review Board (IRB).

4.1 Survey Structure

The survey had three sections: an introduction to genetic factors and women's health, questions about knowing and sharing, and inquiries about use and experiences of health technology. We iteratively designed the survey with input from the study team, and finalized it after a few rounds of pilot testing and revision.

4.1.1 Introduction and Participant Background.

The survey began with informed consent and a brief introduction explaining its focus on genetic factors related to women's health in families. In

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[1] https://www.prolific.com/

designing the survey, we reviewed prior medical literature for genetic factors in women's health to determine the types of health topics to be included, such as population-based and genetic testing studies [36, 41, 49, 73, 128, 129], and social science studies regarding typical family size and structure in the US [33, 100]. We collected information about demographics, reproductive history, family size, and genetic family members whose health they knew about, through multiple-choice questions. We specified "biological (genetic) family members" in these questions, while participants might mention additional family members in later free-text answers.

Aiming to explain the impact of genetics on women's health, we presented term definitions and Fig. 1. Our definition of "women's health" included both (1) health issues that only affect women, and (2) health conditions that affect both men and women, may impact women differently[2] [50] ; we define genetic factors as how inherited genes from family members can affect one's health,[3] [54]. Then, we asked participants to rate on 5-point Likert scales their knowledge of how genetic factors influence women's health, and their perceptions of their importance and impact.

4.1.2 Knowing and Sharing Families' Women's Health Experiences. In the second section, we focused on what and how participants learn about and share women's health information within their families. We first asked participants to select which topics they learned about or shared with their family among menstruation, pregnancy and fertility, menopause, chronic conditions, and body/hormonal changes, and which family members were involved in this sharing process. We asked follow-up, open-ended questions to encourage participants to describe details around those moments and stories of learning and sharing. For example, we asked, "*What* do you know about your family's experiences related to women's health, and *how* did you find out?", then added short prompting questions for (a) when, (b) what, and (c) how, they learned about them, such as "a. When: Was there a specific occasion or situation?" [4]. Lastly, aiming to unpack the needs and challenges, we invited participants to share "what you would like to learn more about" (one question), and potential reasons why they do not currently have that information (one question). We designed this section in two parallel parts: "knowing", focused on what participants know or have learned about their genetic health history, and "sharing", focused on what participants have shared with other family members. The two sections followed the same structure, and both sections together aimed to better cover the experiences of both younger and older age groups.

4.1.3 Use and Interests for Health Technology. We designed the last section to understand participants' use of health technology and thoughts around future technology for genetic health. We asked participants to share their current use of technologies for learning about and managing health, especially women's health, as well as open-ended questions for describing how technology might better support family communication about women's health, either through improving existing systems or imagining new tools.

4.2 Recruitment

We recruited participants through the online survey platform Prolific. To ensure the survey reached all age groups, we collected data in five-year age intervals starting. The number of participants recruited in each five-year age interval was proportionally aligned with the age distribution of the U.S. population [16]. We implemented 80+ as a group with no maximum, with the oldest participant reporting an age of 84. Eligibility criteria included: (1) being 18 years or older, (2) currently living in the United States, and (3) reporting "female" as their sex at registration. Participants were compensated \$4 for completing the survey, which takes around 20 minutes on average, per platform guidelines (Prolific requires reward rates at \$ 8 per hour minimum) [5].

We collected 256 responses in total. The research team manually reviewed all submissions and excluded incomplete or invalid responses, resulting in a final sample of 249 valid responses (see Table 1 for demographic information on race and education level). Three participants identified as non-binary, one identified as a transgender man, and all others identified themselves as women in the survey. Participants' reported annual household income ranged from below \$10,000 to over \$150,000, with a median of \$60,000–\$69,999. Participants reported being in contact with a median of 7-10 family members, with 100 (40.2%) reported having 1-6, 109 (43.8%) having 7-20, and 37 (14.8%) having over 20. All of the participants reported having menstruated. 176 (70.7%) reported having given birth to a child, 97 (39.0%) have a child who has menstruated, and 123 (49.4%) are going through menopause (44, 17.7%) or have gone through menopause (79, 31.7%). The survey was implemented using QuestionPro, which enabled participants to complete it on their preferred device, and optimized the survey interface for mobile compatibility. A majority of respondents (85.9%) completed the survey on a laptop, while 13.5% used a mobile device.

4.3 Data Analysis

We present descriptive analyses on the quantitative data, and qualitatively analyzed responses to the open-ended questions using an inductive and reflexive thematic analysis approach [13, 14]. We treated coding as an interpretive, collaborative process, refining the codebook and themes through rounds of team discussion and analytic memos [13, 14, 83]. First, we selected a stratified sample of 25 participant responses, proportionally drawn from all age groups, and organized the responses to each question into separate files. The first author open-coded these responses and wrote notes. The three authors then met to review the sample together, discuss the emerging codebook, and preliminary themes. We then coded additional responses in stratified batches, refining codes and candidate

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[2] Complete text provided to participants: "Women's health includes (1) health issues that only affect women, like periods, pregnancy, and fertility conditions, and (2) health conditions that affect both men and women but may impact women differently, like heart disease and diabetes." (Link to reference in footnote.)

[3] Complete text provided to participants: "Genetic factors in women's health refer to how inherited genes from family members can affect a woman's health. This can include things like the chances of getting certain illnesses or how the body handles changes like pregnancy or menopause." (Link to reference in footnote.).

[4] One example question provided to participants in 2A: "***What* do you know about your family's experiences related to women's health, and *how* did you find out?** You can share examples like stories, including: a. When: Was there a specific occasion or situation? b. What: Whose experience was it? What was the topic, and how did it relate to your experiences? Could you share some details? c. How: Who did you know it from? Did you learn through conversations, observation, or technology (e.g., notes, health records)?" (Texts are formatted for readability.)

[5] https://researcher-help.prolific.com/en/article/56b197

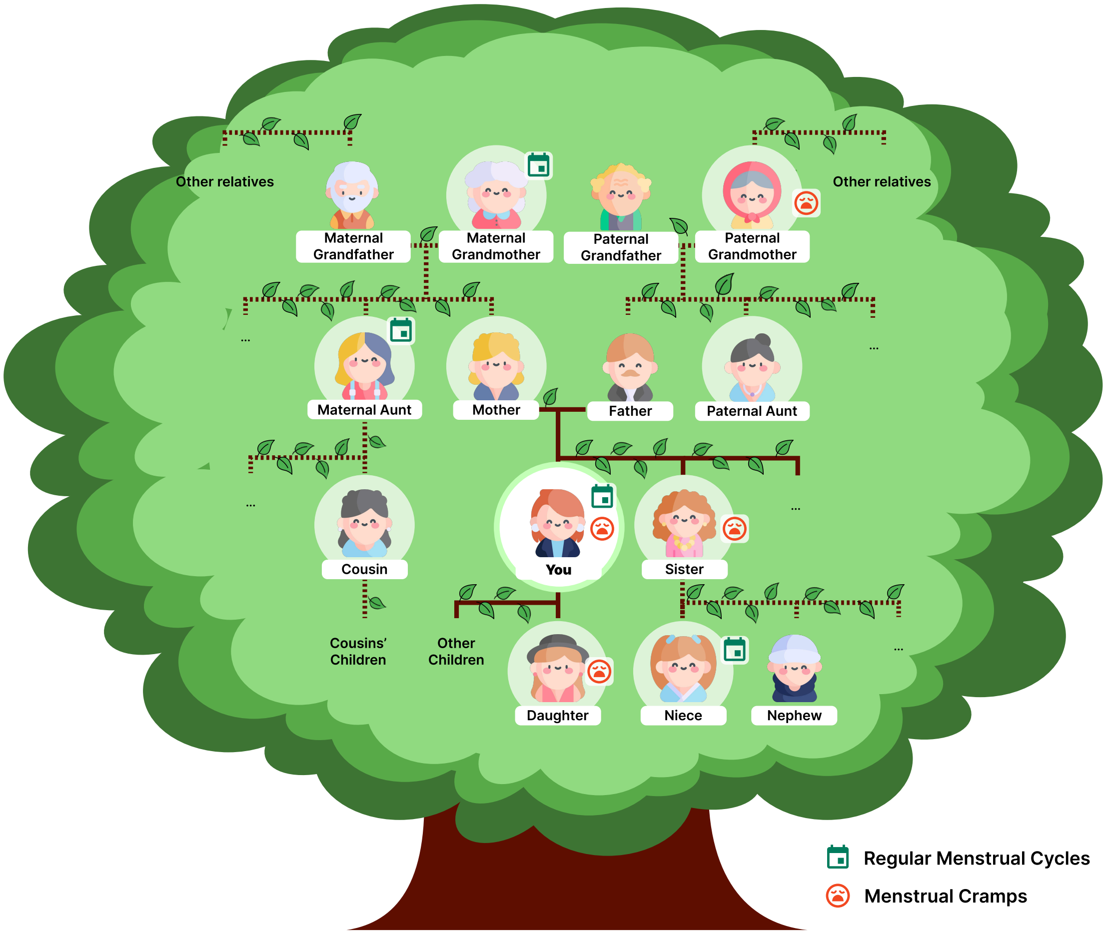

Figure 1: We showed participants a theoretical family tree annotated with how genetic health conditions might surface in a family, informed by population-level studies [33, 61, 67]. The annotations show that one may inherit women's health conditions from the parents and grandparents of both sides, and pass on those conditions to the next generations through genetic inheritance.

Age Group	Count (%)	Race & Ethnicity	Count (%)	Education Level	Count (%)
18-19	9 (3.61%)	White	172 (69.1%)	Secondary or below	5 (2.0%)
20-29	44 (17.67%)	Black / African American	55 (22.1%)	High school	38 (15.3%)
30-39	45 (18.07%)	Asian	13 (5.2%)	College / Technical	35 (14.1%)
40-49	42 (16.87%)	Hispanic / Latino	12 (4.8%)	Undergraduate	92 (36.9%)
50-59	38 (15.26%)	American Indian /Alaska Native	7 (2.8%)	Graduate	60 (24.1%)
60-69	37 (14.86%)	Native Hawaiian / Pacific Islander	1 (0.4%)	Doctorate	18 (7.2%)
70-79	27 (10.84%)	Prefer not to answer/Other	3 (1.1%)	Prefer not to answer/other	1 (0.4%)
80-84	7 (2.81%)				

Table 1: Distribution of Age Groups and Race & Ethnicity

themes through team discussion until no substantially new patterns appeared. For example, in the first version of the codebook, we coded "menstrual cramps" and "irregular periods" separately, but later merged them into a broader code of "menstrual experience". Next, as many questions in the "sharing women's health experiences" section were parallel to the "knowing" section or future expectation questions, we compared and reconciled the codebooks across those questions to create a consolidated codebook. For example, experience-related codes, such as "menstrual experience", were used for questions about knowing and sharing, and formed two themes for RQ1. The first author then reviewed the remaining responses. The research team reviewed the codebook, notes, and memos together to identify five final themes. These qualitative findings deepen the interpretation of quantitative results on current practices and highlight information needs and communication challenges within families regarding women's health experiences.

4.4 Limitations

Given the importance of age in understanding how people across generations communicate with their family around genetics, we recruited participants proportional to the U.S. age distribution. However, the platform limitations of Prolific prevented us from further controlling for other demographic factors. While our sample reflected a broad range of demographic backgrounds, some groups were disproportionately represented. For example, although the overall ethnicity distribution was generally aligned with the U.S. population, participants who identified as white made up the majority. Educational attainment was also higher than the national average, with over 68% holding an undergraduate degree or above compared to about 37% in the U.S. population [15]. In addition, most participants were cisgender women, with only four identifying as gender minorities. As a result, our findings may underrepresent the communication of genetic health information and related challenges faced by minority ethnic groups, those with lower educational backgrounds, or gender minorities. Lastly, we conducted the study on the US population and primarily referred to US-based literature when surveying participants' backgrounds, while families in other countries may have different patterns of family structures, sizes, and norms in sharing health experiences. Thus, future work could address the gaps in our study by specifically recruiting from these populations, who may experience additional disparities in understanding genetic health and unique cultural barriers in family health communication.

5 Findings

We find that participants learned and shared various women's health experiences related to genetic factors with their families, spanning multiple life stages and types of information, from personal experiences and struggles to diagnosis and treatments. Participants overall perceived sharing genetic women's health experiences as a helpful practice, understanding their own health conditions, and supporting other members of the family. These conversations often took place around the time when a member reached a new life stage or event, or during family gatherings. The information was primarily communicated through in-person conversations, though women sometimes resorted to remote communication or showing documentation when they could not meet in person.

5.1 RQ1: What do People Share about Genetic Women's Health Experiences

Our participants described learning and sharing both *everyday health experiences* and *clinical health conditions* influenced by genetic factors with their families (see Fig. 2). Everyday experiences included menstruation, pregnancy, childbirth, and menopause, while clinical conditions involved illnesses and chronic diseases that required diagnosis or treatment.

5.1.1 Everyday Experiences of Women's Health. Participants most commonly described talking about personal experiences of menstruation patterns and symptoms (75.9% learned and 75.5% shared). Many participants mentioned that they know some detailed symptoms of their families, including severe menstrual cramps or irregular periods, and how those changed throughout life. A recurring scenario was when a woman reached menarche and learned about menstruation from her mother, sometimes also from her sister or her grandmother. The senior female members frequently shared how menstrual cramps are a normal symptom to expect, or a family history of severe cramps or heavy flows: *"I learned from my mother and grandmother that heavy menstrual pain runs in our family. My mother talked about her cramps when I first got my period... These conversations helped me understand that my symptoms are not unusual."* (P133, 36 yrs) The family member, usually the mother, also shared examples of these symptoms, the impact on their daily life, and how the symptoms might change over the life course. For example, P15 (32 yrs) learned how menstrual cramps improved for her mother: *"My experience was menstrual cramps when I first encountered it, and I learnt that my mother would also experience the same, but after giving birth the cramps would not be as severe as before giving birth."* Similarly, P179 (32 yrs) learned about the impact of heavy menstrual bleeding on daily life from her mother: *"She explained to me that she missed school sometimes because of the pain... I came to know all this mainly through having one-to-one conversations with my mum, especially when I was off school because of my symptoms."*

Beyond cases where one close family member shared her personal experiences, participants also described scenarios where genetic health experiences were shared indirectly through another family member.

> *I shared my mom's story about endometriosis with my younger cousin... It happened last year when she told me she was having really painful periods and didn't know if it was normal... I told her about how my mom went through something similar and wasn't diagnosed for years. I shared details about the symptoms my mom had and how important it is to speak up and see a doctor who listens. I wanted her to feel supported and not alone. She said it helped her feel better and more confident to ask questions.* (P188, 32 yrs)

P203 (61 yrs) described a similar case when she passed down others' health experiences to younger members during a family gathering: *"I shared my mother's and sister's experiences with pregnancy complications and menstrual health with my nieces and children during a family gathering when one of them started her first period.... I shared all this through honest conversations to help them feel supported and informed."* Participants frequently mentioned similar cases during family gatherings, where they could pass along what they learned to a different family member during conversations. Some indicated that these conversations made them feel comfortable having similar discussions around genetic health in the future and contributed to stronger connections within the family.

Participants also shared their health experiences around specific health stages and events, such as pregnancy, childbirth, or menopause. 62.7% of participants reported having learned from

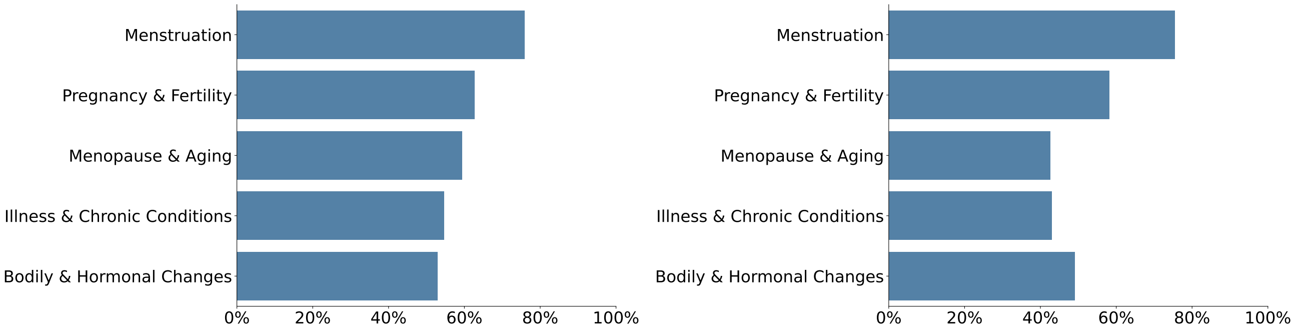

Figure 2: Distribution of women's health topics that participants learned about (left) and shared with family members (right). Participants most commonly reported learning and sharing information about menstruation, followed by pregnancy and fertility, and menopause and aging. For some topics, such as menopause and aging, the percentage of participants shared is less than those learned.

their family about pregnancy and fertility topics, including difficulty conceiving, miscarriages, and complications. For example, P242 (45 yrs) described, *"I learned about my mother's difficult pregnancies… She told me she had high blood pressure during pregnancy and had to be on bed rest for weeks."* In particular, many valued families' experiences related to childbirth, particularly about childbirth deliveries and postpartum mental health issues. For example, P212 (43 yrs) described, *"I learned about my grandmother's challenges with childbirth from my mother during a family gathering. She shared how my grandmother gave birth at home without access to proper medical care, which led to complications."*

Compared to knowing details of menstruation, pregnancy, and childbirth experiences, participants only mentioned knowing about menopause briefly, such as hot flashes and mood swings. Beyond general symptoms, some indicated that their family's time-related menopause information, such as the age at which the senior members started menopause, and the time that the stages took, could be helpful for them as a reference. For example, P199 (53 yrs) referred to her mother's menopause to understand her current stage, *"I know she [my mother] entered menopause at age 51 and I am 53 and have gone about 10 months without a cycle, so I am transitioning from perimenopause to menopause and so she also understands the hot flashes, though mine are a lot more severe than hers were."* P199 compared her symptoms and time points with her mother's, and recognized similarities that might be due to genetic factors. In addition to time points and symptoms, some highlighted learning about families' struggles during menopause, covering their emotions, reflections, and experienced stigma. P183 (34 yrs) said, *"One story that stood out was my mother discussing her struggles with menopause and how it affected her mood and sleep.... These stories helped me understand the emotional and physical challenges women face, and how health concerns were often kept private in the past."* Sharing these struggles could promote understanding of the genetic influence on their health; however, such details for menopause were rarely shared.

Along with sharing typical symptoms and major events, participants also described more casually sharing bodily or hormonal changes that ran in the family. Many did not relate these experiences to a specific stage, such as having more body hair, "*I know that my family is pretty hirsute, and my mother and all of my aunts got thick, black hairs growing on their faces and other parts of the body.*"(P154, 40 yrs). Similarly, P229 (53 yrs) described her family's resemblance in thinning hair and appearance as they age, "*My grandmother and mom both had severely thinning hair and now mine is doing the same thing, which is freaking me out a bit.... As I've aged I've began looking more and more like her. I see the facial features she was bothered by happening to me.*"

5.1.2 *Clinical Health Conditions.*

Besides sharing everyday health experiences impacted by genetics, 55% of participants indicated learning about their family's genetic illness and chronic conditions related to women's health. These topics cover both women-specific illnesses, such as tumors or fibroids in the reproductive system, endometriosis, or PCOS, as well as chronic illnesses that are not specific to women but might have specific impacts on women that are different from men, such as diabetes or cardiovascular diseases.

Participants frequently mentioned knowing about a family member's health history of a women-specific genetic illness. In such cases, they usually knew about the diagnosis together with daily symptoms, impacts, treatments, or health outcomes. For example, P50 learned about her sisters' endometriosis and osteopenia and their impact: *"My oldest sister had endometriosis and never successfully carried a pregnancy to term. Another sister also has severe osteopenia, and delivered her only child three months prematurely."* Similarly, many participants mentioned their family's history of breast cancer, cervical cancer, or fibroids, and related surgery experiences. For example, P239 recalled, *"When I was a teenager, my mom told me that my grandmother had breast cancer and had to have one breast removed. My dad told me about his grandmother having breast cancer which she ignored for a long time until it was obvious."* Sometimes, participants were only able to learn indirectly through other family members, as the disease progress prevented direct sharing in family: *"My mother died from ovarian cancer at the age of 36, when I was 2 years old. I remember things about her and her passing, and have learned more through my aunts and grandma.* (P248, 63 yrs)

When people learn about a family woman's health history that is potentially genetic, the family may have further discussion about the self-care practices and implications, so younger members can become more aware. For example, when a family member had breast cancer, the younger members paid more attention to regular health check-ups, diets, and treatments since they carried higher risks.

> *My mother had breast cancer and a mastectomy in her fifties. Our family was very open about her experience, and instilled in my sisters and me a sensitivity to breast changes, conducting breast self exams, and generally being aware of breast health (for example, how diet may impact health). Finally, both of my sisters were very supportive of me when I had a biopsy of a mass discovered in my breast.* (P208, 52 yrs)

People also share with their families about chronic conditions that are not women-specific, but impact women differently than men. For example, P177 mentioned,*"I got gestational diabetes and my mum told me that our family has a history of diabetes."* Families shared tips to manage this genetic chronic condition, which could be a set of tips passed from multiple members with a similar condition.

> P212(43): *During a family dinner when my younger cousin announced her pregnancy, I shared our aunt's experience with gestational diabetes and how she managed it through diet and regular checkups. I also mentioned how my mother faced severe morning sickness and what remedies helped her. I shared this through a warm, supportive conversation, hoping it would help my cousin feel more prepared.*

Other family histories of chronic illnesses, such as cardiovascular diseases, are also sometimes shared among family members. Even when it was not discussed or directly shared, some people learned about the related daily health management practices through their own daily observation. P76 (61yrs): *"As a child we were familiar with their condition as well as what medication that they took, and other steps they took to try to control their blood pressure such as quitting smoking and reducing their salt intake. I remember the 'fake salt' my mother used, and hoped that I would never need to avoid salt."* This information, gathered through observation, also prepared them for future genetic health risks.

5.2 RQ2: How do People Share Genetic Women's Health Experiences

Through participants' descriptions, we identified two major circumstances where their communication took place, and three categories of technology and artifacts involved in their communication. We elaborate on the recurring scenarios to unpack factors that encouraged family members to share and features in technology that supported their sharing.

5.2.1 Sharing through Spontaneous Conversations. Participants described two major circumstances that led to conversations about genetic information related to women's health conditions. First, many participants mentioned having those health-related conversations during family gatherings. This often included their extended family or multiple generations together, such as aunts, uncles, grandparents, children, and cousins (see Fig. 3). Some also learn about the family's women's health experiences from their fathers, but much less than other female members of the family. Usually, the conversation starts with the sharing of one family member, and then more members share their similar experiences. For example, P10 (18 yrs) described her family dinner where her grandmother and her mother discussed menopause with the family: *"My grandmother shared with the family at our dinner table about her menopausal experience... My mother added that her experience of learning doctor advocacy skills came from supporting her mother during her menopausal challenges. Family discussions about women's health events transmitted through normal conversation across gatherings taught me to understand both the necessity of speaking openly about healthcare needs and finding proper treatment."* During family gatherings, younger family members also raised casual questions about their family's past experiences, which led to discussions about family health history. For example, P242 (40 yrs) mentioned, *"I learned about my mother's difficult pregnancies through conversations with her during a family gathering when I asked her about my birth story. She told me she had high blood pressure during pregnancy and had to be on bed rest for weeks."* Either initiated by the one who shared or the one who asked, the sharing could develop into a family health discussion containing meaningful information to the younger generation.

Secondly, participants started conversations about a genetically-related health experience when a family member is at or around the onset of a major life stage or health event. The most frequently-mentioned example is when a girl reaches menarche, and the senior female family member, usually the mother, shares information about menstruation. We see this practice quantitatively as well, where 90.8% of participants learned family health information from their mother (see Fig.3). For many participants, this is because their mother (or siblings) is the closest member to them, *"Just in general I hear family health issues via my Mother.... I'm only close to my Mother when it comes to family."* (P112, 68 yrs)

Families were also often open to sharing their experiences and tips around pregnancy and childbirth when a member first got pregnant. Participants frequently mentioned having conversations about pregnancy with their sisters, which was a common case among 51.4% of the participants sharing their women's health experiences with their siblings. For instance, P65 (52 yrs) mentioned, *"I shared stories about my pregnancy with my sister when she was expecting, including challenges during labor and recovery. We talked over the phone."* Compared to these celebratory moments where family members proactively offer past experiences, people sometimes also actively seek information and advice from their family members when they come across new health stages, like menopause: *"When I was having hot flashes and night sweats, I spoke to my mother about it. She was able to recall in detail what age she was [when] she first started experiencing the same symptoms. I wanted to know if she used any type of hormone replacement therapy, but she said she did not. With all the risk associated it helped me to decide not to...."* (P93, 61 yrs). Similarly, some also described families discussing a health issue when one member was diagnosed with a chronic condition or was hospitalized: *"When I was diagnosed with skin cancer I shared it with my Mother. We shared through conversations and she was with me when I had surgery."* (P112, 68 yrs) When the conversation is initiated after a health event, the family communication usually centered around the specific family member and one specific topic, so family members with similar experiences could provide help.

While most conversations took place in person, many participants leveraged remote communication tools as an alternative when they could not meet offline, such as phone calls, messaging

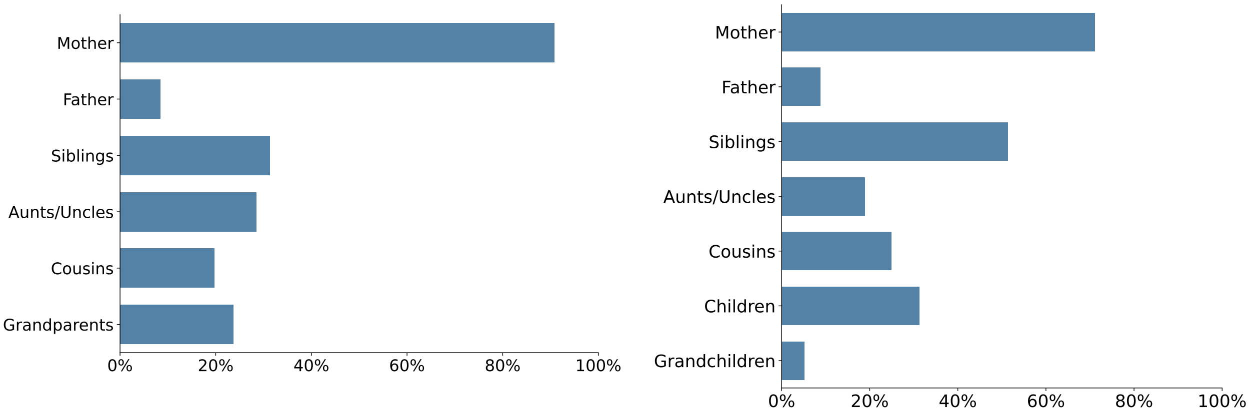

Figure 3: Distribution of family members from whom participants learned (left) and shared (right) their family women's health experiences. Participants mostly reported learning and sharing about their family's women's health experiences from their mothers, some learned and shared from their siblings or extended family, but much fewer from their fathers.

apps, and video chats. For example, P54 (70 yrs) talked with her family remotely due to distance: *"This was in the 80's when my mom was diagnosed with breast cancer. We talked about it and she told me her experiences with treatment. I lived far away, so we did this by phone calls and letters."* Similar conditions took place when one member was hospitalized: *"My endometrial cancer diagnosis and subsequent surgery and radiation is the condition that I have shared the most with two family members and four very close friends. I spoke to them frequently during the six months where this was front and center in my life. We spoke on the phone, in person, and through texts and emails."* (P106, 73 yrs) . Participants also shared resources and useful apps during the remote exchange. P10 (18 yrs) described, after chatting about her cousin's menarche, "*I provided my cousin with some useful articles after the conversation and sent her a period tracking application.*" Such remote communication served as an addition to the in-person sharing.

5.2.2 Sharing Asynchronously through Technology. When asked about information beyond verbal exchanges, our participants reported various uses of technologies for their personal health information, with many using health websites (28.8%) and health apps (20.6%) (see Fig. 4). Specifically for their personal women's health, a fair percentage use manual tracking (20.6%), but we also see fairly extensive use of formal health records (29.6%) and technologies designed specifically for health settings, like dedicated apps (27.9%) (see Fig. 5). Despite these personal uses, only a small number of participants reported sharing such data with their families, and no participant mentioned a systematic way of documentation or sharing.

Participants mentioned seeing daily personal records and documents as meaningful media carrying health-related information. For example, photos, especially pieces of daily life like birthday photos, may reflect people's health conditions through their appearance: *"My maternal aunt had B cell lymphoma... My aunt was telling me how her legs were swollen from her treatment... but I didn't realize how terrible it had gotten until I saw her birthday picture."* (P48, 71yrs) People also shared with family members photos of their symptoms and treatments as part of daily life. For example, P163 (54 yrs) shared pictures of her treatment, *"I have chronic anemia and have had to receive iron infusions. I've shared this by word of mouth, text, and sent pictures of the infusion in action."* Some participants also mentioned writing out their family's experiences through a blog, which made sharing more convenient: *"I shared my grandmother's breast cancer story with my cousin by texting her a link to a blog I wrote about it. We later talked more about it over a video call."* (P60, 44 yrs) Although these remote communications delivered health information, the main sharing process still happened during synchronous conversations.

In a few cases, formal documents or resources, such as medical records and death certificates, were used to share the family's genetic health condition. Some participants valued sharing medical records since they contain an accurate description of one's health condition: *"My aunt actually showed me her blood clot one time. I asked her so many questions because I was young around 10 years old..."* (P36, 35 yrs) Meanwhile, information from death certificates was found with a time delay: *"Most of my conversations came from my mother or sister, but sadly, how I discovered women's health issues in my family came through reading death certificates while I was working on my family tree."* (P32, 65 yrs) One participant mentioned sharing genetic testing results of a family member with cancer, *"I shared her genetic testing results with my female cousins via a group chat, urging them to get screened early"* (P153, 25 yrs). However, only a few participants mentioned proactively sharing these records with family members, instead mostly sharing them upon request.

None of our participants mentioned any practice of maintaining family-centered health documentation, like collecting genetic records, diagnoses, or test results across members. However, some participants described benefiting from collaboratively learning and managing their women's health with technology. P130 (38 yrs) mentioned that she and her cousin had the same autoimmune disorder, and that "*we continue to compare notes.*" A few participants described looking for health information resources together. For example, P124's family discussed her mother's genetic women's health issues, and then "*We also watched a few videos together that*

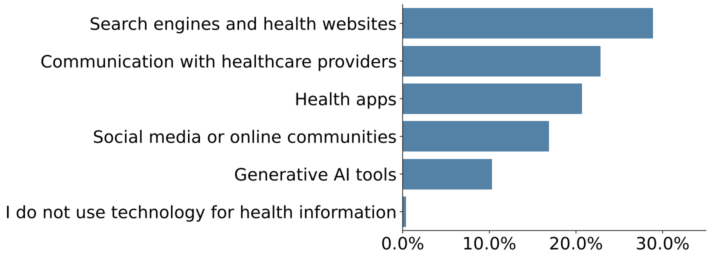

Figure 4: Types of technologies that participants used to learn and manage health information. Search engines and health websites were the most commonly used resources, followed by communication with healthcare providers and health apps.

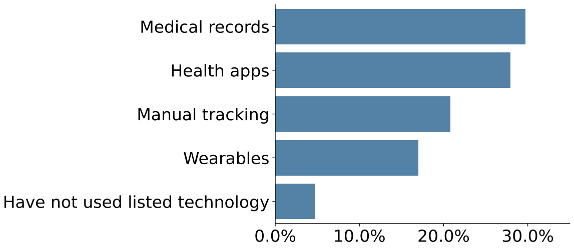

Figure 5: Types of technologies that participants used to manage their women's health information. Participants most commonly relied on medical records and health apps, followed by manual tracking and wearables.

explained what fibroids were and what a hysterectomy involved. That blend of lived experience and accessible information really stuck with me." Similarly, P137 (29 yrs) and her sister discussed their mother's menopause experience, and "*It helped my sister feel less alone, and we even looked up some articles together afterward.*" These collaborative practices supported participants in learning about their genetic health.

5.2.3 *Expectations and Concerns for Future Technologies.*

When asked about their visions of the future technologies, participants showed strong interest in technologies for sharing genetic women's health experiences with families. Many participants suggested enabling sharing features in current technology for women's health, such as period trackers and health records. For instance, participants imagined "*having a centralized electronic family record*" (P24), "*biological family members could share diagnosis on it that could be genetic*" (P37), or ‘‘*period trackers like Clue could add family-sharing features to discuss menstrual patterns across generations*" (P109). Some participants were also interested in long-term preservation of such records: "*Just keeping track of the history for an extended time. [That] way we can have a good tracking history.* " (P36, 35 yrs) In addition to sharing and keeping health data, participants also felt they would benefit from more emphasis on genetic health to raise awareness. P42 (36 yrs) thought "*finding patterns can be beneficial for my biological family*", and P75 (55 yrs) mentioned "*create a separate app that integrates with the other genealogy apps.*" Regarding family communication, several participants also imagined creative interactions to address stigma around talking about women's health, such as "*an app that shares comforting and funny memes about your period... and you can all chat and laugh*" (P21, 28 yrs), or "*virtual reality provides personal experiences of menstrual pain through virtual experiences to young males*" P130 (38 yrs).

Still, some participants raised concerns about sharing personal women's health data or using technologies for sharing. Multiple participants, especially senior ones, felt unwilling to share information online due to privacy concerns, and thus, still prefer limited in-person sharing. For example, P45 (68yrs) mentioned, "*I really don't like putting my information or that of my family online anywhere and would like to keep it private.*" While many participants felt that AI could help "*show whether something is passed down*" (P40, 38 yrs), a few raised concerns towards AI, mentioning "*medical info should not be used to train an AI*" (P206).

5.3 RQ3: Challenges in Sharing Genetic Women's Health Experiences with Family Members

Although our participants were often able to discuss genetic factors related to women's health with their families, they also reflected on the various challenges they faced. Participants often described not having a good understanding of how genetics impacts aspects of women's health. After reading the background section of our survey, although participants generally agreed that health history was important for understanding women's health (92.0% rated "agree" or "strongly agree" on a 5-item Likert scale) and genetics had a major impact (79.5%), they were less likely to agree that they had knowledge about how genetics impacts women's health (44.2%) and therefore did not have a chance to talk about it with their family members. Many participants mentioned that they or their family "*know little about genetics*" (P12, 28 yrs) or "*they don't consider the way their private information about their health can help their biological family members to be better informed of what could be genetic.*" (P158, 27 yrs).

Beyond these factors, participants described how family dynamics, physical and temporal distance, and forms of stigma introduce barriers to sharing women's health experiences and, therefore, understanding genetic health.

5.3.1 *Challenges in Sharing Women's Genetic Health Information and Experiences.*

Participants often described not communicating with different family members, and as a result, lacking information about what their experiences might say about their own genetics. As mentioned, participants responded that they communicate women's health experiences with their mother most, followed by siblings, while their extended family or relatives are comparably less involved.

Primarily, participants described not knowing about their family's women's health experiences because they do not have a close relationship with them. For P197 (60 yrs), the reason is *"Simply not having the closest relationships."* The lack of closeness is especially a barrier to discussing health conditions with extended family members or relatives. For example, P113 (36 yrs) described: *"My mom has passed away, and I am not close with many other members of my biological family.... I don't have a relationship with any female relatives who are younger than me."* Some participants explained that "*not knowing the relative well [enough] to establish rapport [could] be a reason*" (P21, 28 yrs). Even when they try to establish a close relationship, the attempt may fail, such as for P159 (46 yrs): *I am just not as close to the women in my family as I once was. I have tried to have a connection since reaching adulthood, but no one else seems interested in any kind of relationship. Therefore, no one to share experiences with.* Participants described more often lacking information about extended family members due to a lack of closeness, but desired to learn more about them. Extended family members, such as grandmothers, aunts and cousins, are frequently mentioned: *"my aunt's menopause journey, and my cousin's life with PCOS"* (P140, 23 yrs), or *"I'd want to learn more about the reproductive health experiences of women across different generations in my family—like my great-grandmothers, aunts, and cousins."* (P144, 22 yrs). The lack of closeness further made it difficult for participants to learn about genetic health conditions in the family. For example, P40 (38 yrs), knowing about her mother's cancer diagnosis, wanted to learn more about her family's genetics, but was struggling because "*I am not that close to other family members to discuss them.*"

Communicating around genetic factors became even more complicated when family relationships were strained or tense. For example, P51 (66 yrs) described not wanting to discuss her or her family's childbirth experiences with her sister: *"With my sister, we didn't have a great relationship, so she would be the last person I would have gone to to ask her about or tell her about my experience. She wouldn't have cared to have that kind of feedback... so it wouldn't have related first hand to her either. "*

Participants further described how changes in family structure, such as adoption or divorce, left them less connected to their biological relatives and thus made genetic health information unavailable. Four participants mentioned that they or their family member was adopted, and therefore did not know much about their biological family's genetic history: "*I'm adopted and don't know much about my biological family... I'd want to know what autoimmune diseases run in the family. Also, what did my recent relatives die from.*".P171 (81yrs). P70 (56), on the other hand, met her biological mother in her 30s, and highlights that they were able to discuss shared experiences, *"We discussed menopause at length because at the time she was going through menopause. On several occasions, we discussed our pregnancies and [deliveries]. We both had thinning hair after menopause."* Similarly, some participants whose parents were divorced indicated that they had less information about one side of the family: P34 (70 yrs) said about her father, *"he wasn't in my life once my parents were divorced."* These participants highlight how family structure can influence how readily a person can understand genetic factors related to their well-being.

5.3.2 Gaps in Time and Space.

While some participants recognized the role of genetics in health and were open to sharing related experiences, many shared little with family members because of time and space. Here, we unpack how physical separation and time gaps led to missed opportunities and loss of details in family sharing of genetic health.

Physical Separation. Beyond challenges with family relationships, participants frequently mentioned the physical separation between family members, impacting their ability to communicate about family genetics. Participants described that when they live in the same household as other family members, they have more opportunities to both observe family members' health conditions and discuss them, and thus know more details of those experiences. For P89, sharing a space with her grandmother as a teenager allowed her to better understand her health condition: *"When I was in high school, my grandmother was living with us, I shared the bedroom with her. I watched her health decline and tried my best to help her. "* (P89, 63) However, when people grow up, they may no longer live with those family members and *"live far apart"* (P122, 36 yrs), reducing their regular communication. Or, even when families live in the same household, they may not share a physical space long enough to have meaningful conversations: *"Everyone in our household has a busy schedule"* (P46, 26 yrs) Furthermore, given the limited gathering opportunities, families prioritize important life updates over health discussions during conversations: *"The fact that I live hours away from them means that when we are together and visiting with one another, we aren't typically talking about personal health issues, but instead catching up with the events of our lives. "* (P215, 45 yrs) As a result, health topics have a lower priority in their conversations, and thus are not frequently discussed during family meetings.

Although participants mentioned remote communication when there was physical distance, many still preferred in-person conversations, perceiving the topics to be more intimate. For example, P240 (40 yrs) describes *"some of my family live far away from me and that has led to lack of enough time to bond and share some women health experiences... I had gone for a family gathering and I met my sister in the event, I shared my experience with her when I was giving birth to my first born. We had a meaningful conversation about child birth..."* Similarly, people may feel more relaxed about sharing difficult experiences when in person. *"I would like to be fully upfront with my family members about the genetic risk factors whenever possible; especially those struggling. I believe it's best discussed in person after dinner, dessert, and one and half glasses of wine"* (P139, 26 yrs) Participants also prefer in-person conversations as they may allow more interaction and depth of conversation. *"I could see myself sharing some of my experiences with my grand daughters. I would do it in person when they are a little bit older. I would love to answer any questions they might have."* (P54, 70 yrs)

Time Gaps. In general, participants primarily described sharing or discussing women's health experiences related to their current or next life stage. Comparably, they may not talk as much about their past experiences. For example, P75 (55 yrs) highlights how her desired information changed as she aged: *During my childbearing years, I would have wanted to know if any family members had fertility issues. Now, I would want to know if any family members had or have any gynecological cancers, or breast cancer... I'd also want to know how their bodies reacted during menopause and what symptoms they experienced.* Fig. 6 highlights participants' differences in what they know about women's health topics by age. Younger participants are generally more familiar with topics related to menstruation, fertility, and pregnancy, which may be more relevant to their current age, while participants in their 40s and 50s know more about topics like menopause, aging changes, and chronic conditions.

15% of participants mentioned that they may be interested in genetic information relating to a life stage further in their future, such as pregnancy, childbirth, or menopause. For example, P147 (29 yrs) described:*"I'd want to learn more about my grandmother's and mother's reproductive health experiences like pregnancy, menopause or any genetic conditions they faced. Knowing what they went through could help me prepare for the future."* Participants felt that learning about health topics related to later life stages may prepare them for future experiences. For example, P17 (19 yrs) indicated that about her older relatives, she wanted to know: *"how their health changed as they got older, especially during menopause"* (P17, 19 yrs). P8 similarly described wanting to know *"sooner rather than later"*.

Despite the participants' interest in learning about health factors that might impact them in the future, responses revealed that there was often a gap in time between when a family member had a health experience that might have a genetic component and when they considered sharing that experience. This time difference greatly limited the family's ability to learn personal information about their genetic health. For example, participants said that even though they are interested in the experience of their mother, or other senior female family members, they did not learn enough about the genetic health experiences, such as cancer, chronic disease, menopause, and aging, before the member passed away (P25, P48, P113, P160). For P160 (69), her mother passed away long before P160's menopause stage: *"I lost my mother early on in life, I think I would have learnt a lot about menopause from her if she were to be alive before I experience that stage"*. P23 (26 yrs), similarly described knowing little about her grandmother's cervical cancer: *"I would like to know more about my maternal grandmother's health experiences since I only know shallowly about everything that happened to her before she passed away."* In other cases, the older generations could not remember details due to memory loss or had difficulty communicating. For instance, for P79 (46 yrs): *"I would love to know more about my mom's fertility issues. By the time I could talk with her about them she had dementia."* When these participants sought genetic health information for their ongoing health needs, it was too late for the older generation to share.

In addition, generation gaps also prevent family members from sharing genetic health information: the younger member would be too young to understand the experiences, and it would be difficult for the older generation to remember the details when decades post their health experiences: *"I do have one granddaughter, but she just turned 8 in March. Too young now to talk about miscarriages and periods right now. She has a mother who will talk to her. I probably will some day tell her about my miscarriages."* (P191, 76 yrs) Similarly, P231 chooses to postpone sharing to the future: *"I'd like to share my menstrual health and fertility journey with younger family members, like nieces or daughters, when they reach adolescence or adulthood."* These sorts of choices often led the younger generation to feel like they did not receive a full picture of their genetic health. For example, P82 (55 yrs) was not told about her grandmother's hysterectomy: *"I may not have heard the whole story, because it was told to me later on, by my aunt and mother, so I didn't hear it direct from my maternal grandmother. I was young (pre-puberty) when she passed away so it wouldn't have been brought up."* In other cases, participants described being told about her mother's menstruation experiences when they were young, but now cannot remember: *"I was too young to know or remember when it was being talked about... I assumed they would share if it was important. I was shy talking about things like menstruation or the menopause."* (P179, 32 yrs).

Participants described how physical distance can further impact their sharing behaviors when family members are not co-located and have fewer opportunities to meet in person. As P220 (57 yrs) mentioned, *"unless you are in the same household, you may not find out about diagnoses, hospitalizations, and chronic illnesses of other family members until months or even years later... memories fade because so much happens in our lives. I've even forgotten some of the diagnoses I've received over the years (my mom too), and didn't realize then until I went through old paperwork from doctors, specialists, and ER visits!"* In general, unless families communicate regularly in a shared household, people gradually forget details about their health conditions before the opportunity to share, even with frequent family conversations.

Participants often brought up documentation, such as clinical records, as a mechanism to help with preserving these details over time. However, participants commonly described not having that information: P54 (70 yrs) wrote, *"I would definitely like to know more about my mom's experience, type of cancer, grade etc. I was diagnosed with breast cancer a few years ago, and I wish I had more information about my mom's. I have none of her medical records."* For P214 (55 yrs), she wished to have the family's clinical records, such as treatment history, *"in the case of my grandmother, records were lost... I know that my paternal grandmother and paternal aunt died of breast cancer, but I would like more details such as whether or not they had regular mammograms. "* Yet, having clinical records may still not be enough, since they may only include basic facts but not lived experiences. As P88 (45 yrs) mentioned, only knowing about diagnosis is limited: *"My family doesn't share stories, just statements and facts. My aunt says my mother had breast cancer, but she doesn't know anything more."* Participants were interested in documentation to add rich details of experiences to their knowledge of family health history beyond major diagnoses or events.

5.3.3 Stigma in Family Communication.

Many participants mentioned they or their family consider women's health as a stigmatized topic, similar to discussions in prior work [17, 85, 94]. Here, we extend these conversations to unpack how cultural, generational, and gendered stigma all impact how families communicate around genetic health.

Cultural Stigma. Aligning with prior work on the topic [3, 7, 94, 110], participants often highlighted how societal perspectives on women's health topics often caused reluctance to discuss genetic factors. P83 (49 yrs) highlighted: *"Cultural Taboos – Matters (e.g. menopause, miscarriage) have been thought not okay to focus on. "* P52 (35 yrs) similarly pointed out *"topics like menstruation, menopause and fertility struggles were often considered too private to discuss openly."* This broader stigma around the topics influenced participants' willingness to share. For example, about her menstrual pain, P118 (32yrs) recalled, *"I felt shy, embarrassed, and unsure how*

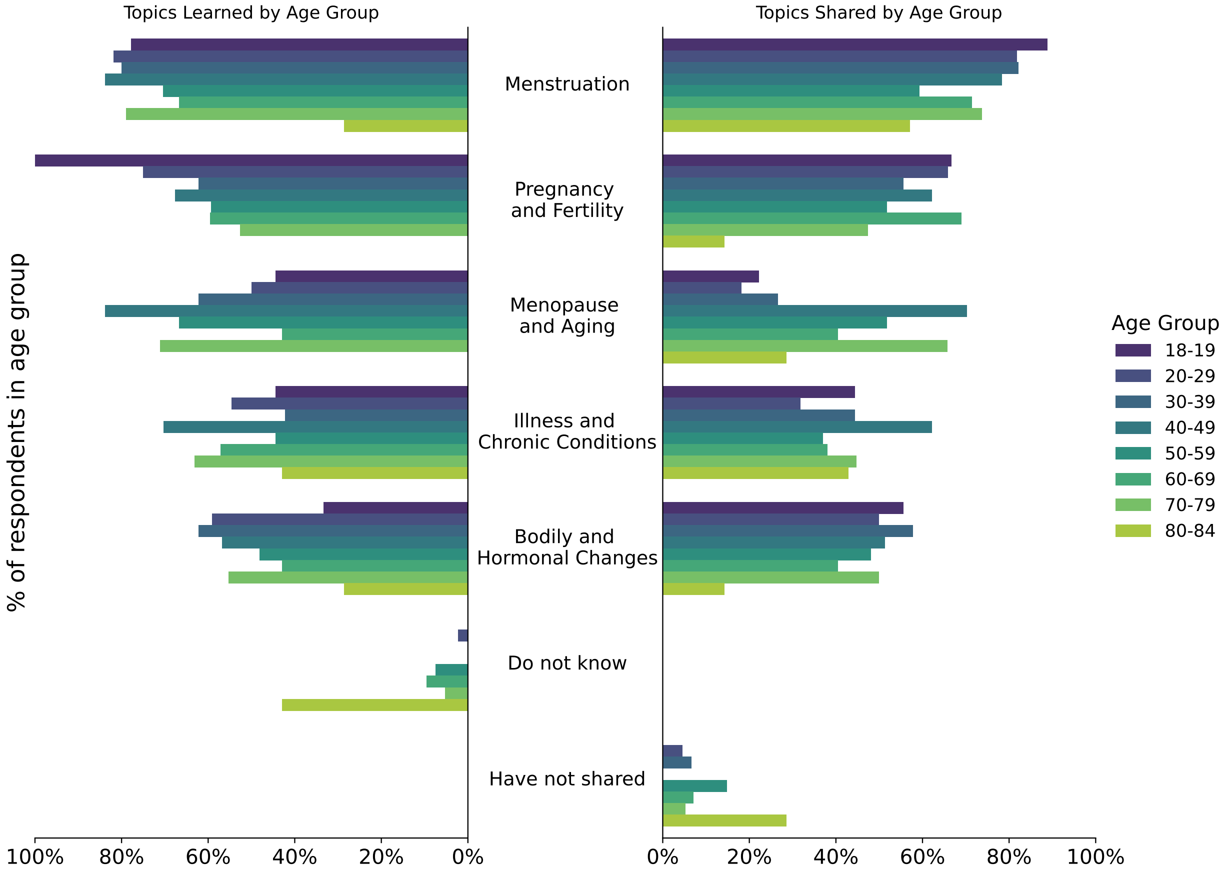

Figure 6: Topics learned and shared grouped by age. We see trends related to the life stage of the age group. Most age groups reported learning and sharing about menstruation, while a higher percentage in older age groups reported knowing and sharing about menopause and aging, or illness and chronic conditions. For most topics, older age groups (60+) reported learning less about the topic. For most topics, participants who reported sharing with families were fewer than those who learned.

they'd react." P228 (48 yrs) similarly said, "Sometimes I was embarrassed or didn't dare to share or ask."

Participants often brought up how their cultural backgrounds, such as their ethnicity or religion, further limited how willing family members would be to discuss genetic factors relating to women's health. For example, P117, 36 yrs: *"I feel like its a cultural thing. We are a very close family and see most of my family that live in state every Sunday... I feel like it's not a common thing for Hispanics to discuss... I thought it was normal for us not to talk about these things."* Participants sometimes avoided discussing specific health conditions which may be informed by genetics, but cultural practices may make it uncomfortable to discuss. For example, P127 initially avoided sharing her pregnancy with her father, because he is *"very strict catholic, so I knew it would be hard to accept, since I wasn't married."*

Participants also noted that fear of judgment from family members might affect their willingness to discuss topics around women's health. For example, P62 was uncomfortable with the idea of sharing her miscarriage with her family because she thought they would think less of her: *"Sharing would result in my mother wanting to 'fix' me."* Similarly, P24 described how she did not have frequent discussions with her mother about aging symptoms, due to the possibility of leading to emotional conversations about aging: *"I think health can also be difficult to discuss, especially emotionally. My cultural upbringing includes avoiding emotional conversations, so we do not frequently discuss these topics."*

Generational Stigma. Participants often surfaced how generational differences in what was appropriate to discuss impacted elder family members' willingness to share their experiences, or younger members' concern that the conversation not being welcomed. Participants frequently mentioned a cross-generational *"lack of open communication"* with their family members, using terms like *"generation silence"* (7 participants) and *"generational gap"* (19 participants) to indicate how older family members tended not to discuss these topics. For example, P10 (18 yrs) experienced that *"Many older family members concealed women's health matters because they considered such discussions to be forbidden or intensely private.* ". P223 (60) highlighted that her mother and sister avoided sharing menopause experiences until she experienced menopause in order to protect her: *"They didn't [want] to scare me with their experience."*

Furthermore, participants experienced generational stigma regarding how they approached women's health topics. Participants often did not discuss genetic health topics because elder generations *"neglected or trivialized"* (P137) the concern, or considered potential genetic factors as *"normal"* since the older generation also had the same experience (mother of P153, 25 yrs). P30 (70 yrs) described, *"For 3-1/2 years I told my mother I was having terrible cramps, and she just brushed it off with a standard set of replies: 'they're just growing pains,' 'stop imitating your sister,' 'stop exaggerating,' etc."* P144 had irregular periods, explained that she did not tell her family because she *"worried they would assume I was overreacting or make it into a bigger issue than it was."*

P191 (76 yrs) unpacked how these generational differences shift over time: *"When I was growing up, no one talked about health problem as much as they do today... when my mother was diagnosed with breast cancer, she did not want to tell anyone. She stated that people were still afraid of cancer, more like that it might somehow be contagious."* P130 (38 yrs) further highlighted how, *"I watched my sister dilate with nervousness so I explained how our mother endured postpartum depression in silence during those first months while crying in private and believing she was failing because 'good mothers shouldn't complain.' "* She went on to describe evolving challenges despite topics being less stigmatized: *She [my sister] endured silently until my mother stepped in after seeing her withdraw and insisted that she seek help. "*

Gendered Stigma. Although genetic risk factors can be carried by both parents, participants frequently described stigma around discussing genetic factors with the male members of their families. P56 (62 yrs) stated, *"I don't think that male members of a family want to hear a lot about female health experiences".* Some participants indicated they thought men's health concerns were different from women's, making it unhelpful to share experiences with the different gender, *"The men in our family have different concerns and not as prevalent, though theirs can be serious, too."* P217 (61 yrs) similarly said, *"The only reason or barrier that prevented me from sharing some of my women's health would be with my brothers, or males in the family that I didn't feel comfortable talking with them about."* Only 21 (8.43%) participants indicated that they had learned about their family's women's health experiences from their father, and 22 (8.84%) have shared with their father, much less than the communication with their mother, aunts, siblings, and cousins (Fig. 3).

Participants often saw the lack of communication with the male side of their family as a gap in understanding their genetic health, and sought to learn more about the health experiences of the paternal side of their family. P244, 47, wrote, *"I would want to learn more about my dad's side of the family. I think I take more after my father, but wasn't very close with that side of the family. Therefore, I would be curious to know what illness or diseases the women in his family suffered from, if any. That information would be helpful for me to know what to be vigilant or screened for. ".* Many participants specifically mentioned learning about paternal grandmothers' experiences, such as details of menstrual cramps and cancer (P88, P27, P5, P215, P131).

6 Discussion

Here, we discuss how our observations suggest directions for technology to better support genetic health, including how frequently and how much people share, address stigma, and support intergenerational tracking and sharing.

6.1 Encouraging Genetic Health Experiences Sharing in Families

We find that sharing genetic health information can help families better understand and manage their health, but it is limited in several ways. Many people do not share enough about genetic conditions due to limited awareness. Further, compared to other forms of family communication, conversations around genetic health do not happen as frequently in everyday interactions, but are often initiated by opportunities and events. Thus, the opportunistic process limits the range of information being discussed. Meanwhile, older generations focus on facts rather than details for genetic illnesses, and younger members' experiences rather than older members. There is a need for families to share more about their genetic health.

6.1.1 Promoting awareness of genetic health to encourage conversations. Given that people often undervalue the importance of genetics, a first step towards increasing conversations is to promote awareness of how genetics impacts health. In particular, the existing health technologies people use can be adapted to highlight the genetic influence.

One approach is to include more information about genetic influence in the health tracking apps that people have been using [39, 76]. People commonly use these apps to track symptoms and severity in many women's health domains, including menstruation, menopause [78], and pregnancy [80], to better understand their health conditions. These technologies could more deeply incorporate educational resources, such as highlighting types of symptoms that might have a genetic cause. These resources could either be framed generally, such as in informational widgets about genetic causes for particular symptoms, or in response to tracked data that a person includes, such as highlighting that the frequent occurrence of a symptom might be indicative of a genetic predisposition.

Beyond self-tracking, clinical technology and genetic testing could further enable communication around confirmed genetic impacts. For example, although the rise of consumer-facing DNA testing kits has enabled people to become more aware of their risk levels for certain health conditions [70, 90], these tools are often framed in terms of larger ancestry, e.g., cultural lineage and ethnicity. These technologies could prompt more conversation by highlighting that having elevated risk levels for a condition can mean that other family members may as well. Beyond consumer-facing technology, patient portals to EHRs often include details about formal diagnoses, such as care strategies [44, 119]. These technologies could further highlight genetic factors where relevant, or even encourage conversation with family members. That said, regulation and validation of scientific evidence are critical in these technologies, and may impact what guidance or encouragement can be included.

6.1.2 Promoting the depth of information being shared. Our study surfaces that there is often a lack of depth in people's sharing of conditions, such as diagnoses or lived experiences, leaving families feeling like they have not learned enough. To increase depth in sharing, one approach could be to blend the rich information that exists in medical records about a person's condition with the ways they often go about sharing around health. People often turn to technology to document life experiences related to their health journeys, such as through diaries, photos, or videos, typically for social support [37] or part of leaving a digital legacy [35]. Tools could promote these logs being useful for having deeper genetic health conversations by encouraging people to place emphasis on the specific care decisions and narrative rationales. For example, rather than supporting sharing cancer journeys in general [59, 60], tools could encourage individuals to document and share specific aspects of their diagnosis. Because this sort of documentation is often expressly for sharing, it can be a useful space for incorporating information that may assist family members in understanding their genetics.

6.2 Addressing Stigma in Family Communication about Women's Health

Prior HCI research has documented societal stigma towards women's health experiences, where women often regard these experiences as private and sensitive topics to share [25, 81, 94]. Our findings extend this work in two ways: First, we identified that such societal stigma prevented sharing in family communication, even within close-tie members. Second, we found cultural stigma, generational stigma, and gendered stigma further prevented family health communication. The stigma led to participants' fear of judgment and conflicts from family members, which echoes with the concept of anticipated stigma in mental health research [45]. Compared to general health conversations, families may experience ideological misalignments due to various cultural norms towards women's bodies, privacy, and health decisions. While family informatics research has emphasized privacy and data-sharing boundaries [11, 98], our study reveals how these boundaries are actively negotiated in everyday conversations, complicating decisions about what to disclose and to whom. We find that family sharing of women's health is also imbalanced in the family structure, as rare involvement of male members limits family engagement and results in loss of paternal information. These cultural, gendered, and intergenerational dynamics illustrate sociotechnical barriers unique to women's health, making conversations more selective and fragmented than in other health domains.

Existing family-based health applications like FemGenix, Waffle, and Healow enabled sharing of health-related information [42, 53, 64], but rarely aim for privacy or access control. To account for existing stigma, tools could support privacy needs through indirect sharing, such as private journaling features or anonymous contributions in such family health applications, which could reduce the pressure of face-to-face disclosure. The tools with sharing features may also be sensitive to boundaries with privacy control. Systems can allow individuals to control what information is shared, with whom, during what timeframe, and at what level of detail. Designs could also consider anonymizing some health data or for family members to collaboratively manage access, depending on the owner or the types of experiences.

Technological approaches could further help destigmatize the topic to enable family conversations around genetics. Design artifacts can help overcome stigma by making women feel more comfortable sharing and promoting their understanding of stigmatized experiences. For example, prior work has suggested drawing, materials, physical objects, and digital storytelling to describe personal experiences and ideas around menstruation, abortion, and menopause [5, 81, 86, 94, 110]. Family communication tools could integrate these sorts of artifacts carrying educational values, such as digital stories or illustrations explaining women's health experiences.

We also note that in the case of women's health, gendered stigma is particularly interfering with a family's ability to have conversations around genetic health. Male members contribute significantly to a person's genetic tree, but their general lack of participation increases the likelihood that a person does not learn about conditions that run on their father's side. Thus, there is a need for technology to address gendered stigma by engaging male members in the conversation, so that health information from the paternal side gets communicated. Prior work has suggested or engaged male members as partners in health practices such as collaborative pregnancy tracking or intimate technologies, yet they mostly only engage as a supporter [20, 72]. Future family tracking tools could design user profiles for men in the family, and actively encourage these users to input and reflect on their own health or the health of their relatives.

6.3 Supporting Intergenerational Long-term Collaborative Health Tracking

Beyond synchronous exchanges, we found that misalignments in time, space, interests, and family relationships made passing down health experiences more challenging. The time gaps introduce great uncertainty about whether the information could be accessible when needed, while physical distance reduces opportunities for in-person exchanges. Misalignments in interests result in conversations leaning towards common conditions and celebratory events rather than stigmatized topics or negative outcomes. For some, discussions only stay within their nuclear families, but not with older generations or the larger genetic family. To overcome these challenges, we suggest that technology aim to support long-term tracking of factors related to genetics, ideally intergenerationally.

6.3.1 Documenting and preserving health data for long-term use. Prior research explored how health documentation, like tracking data or medication schedules, can support collaborative practices in family communication, such as coordinating wellbeing activities or managing clinical diagnoses [101, 102, 108]. However, these practices are often centered around a specific period of time, such as family communication when someone is hospitalized. Our findings suggest that once the immediate health need is resolved, people tend to lose track of the documentation.

We suggest that tracking tools could adopt ideas of existing long-term technologies. For example, borrowing from slow technology [51, 91], health documentation tools, and tracking apps could resurface health observations or records every few years, in case it was forgotten but became relevant in light of the more recent experiences of a family member. For example, an EHR could be designed to email an individual or their next-of-kin a record of their diagnoses every five years. In the meantime, a combination of various forms of health data, especially preservation of multimedia records, might be useful, since some may value records of late family members, such as videos or voice recordings. Further, this technology could probe whether genetic information was up-to-date and accurate to people's own self-understanding. For example, PCOS often evolves as a condition, with many people regularly self-tracking to understand how the condition manifests for them [25, 65]. Long-term technologies could support individuals in updating their documented experiences, in order to help other family members who might have similar conditions or symptoms.

There are substantial challenges and tensions associated with this sort of digital preservation. First, many of the experiences that would need to be preserved are emotionally-laden, potentially on topics such as the death of family members or struggles with infertility. People often avoid using technology to revisit these memories [74], and unprovoked reminders could resurface the negative feelings. Second, further work is needed to identify exactly what would be beneficial to surface and how to do so. Perhaps specific diagnoses are most relevant, or what treatment strategies were effective, or simply the day-to-day experiences of a loved one. Families and individuals within families may vary greatly in what to preserve, so designing with flexibility is a challenge. Third, digital preservation is a well-known and difficult design problem, given factors like software and format obsolescence, digital hoarding to lack of motivation or management resources [38, 122, 137]. Examining genetic health experiences through the perspective of Personal Information Management (PIM) [126] could help mitigate some of these challenges.

6.3.2 Building a shared understanding of genetic health among family members. For documenting health experiences, current personal informatics literature often emphasizes tracking for one's personal benefit [21, 102]. When sharing does occur, it is primarily with the intent of receiving social support, rather than informing others of something which might affect them [3, 62, 68]. Research on family informatics has examined how tracking can help support collective understanding [96, 98]. However, these practices nearly all focus on a nuclear family or single household, and primarily center on understanding one member's health or how the one's practices impact the collective [20, 98, 113]. As we view a large genetic family as a social unit in health communication, we identified technologies involved and see family health sharing as a sociotechnical system. Personal health tools and records, such as menstrual trackers, photos, genetic testing results, and EHRs, can be viewed as individual, fragmented information sources.

We thus extend this discussion to highlight genetic health as a case where family members, both nuclear and extended, can collectively contribute to a more specialized understanding of how they experience different health conditions. This concept extends from ideas like data donation [10], scientific crowdsourcing [95], and collective sensemaking [82, 97], which seek to build up an understanding of how complex health conditions manifest at a population level. For example, families could maintain a collaborative online document and have members update their knowledge of their or their families' health conditions regularly. Further, with recent computational advancements in extracting or analyzing health data based on text or medical imaging [46, 135], technology could help analyze the collective health knowledge and recognize potential patterns or insights. We see an opportunity for family members to each contribute understanding of how a condition manifests for them, with technology assisting with organizing, aggregating, and disseminating takeaways back to the genetic tree.

Given the challenges around lack of contact and remote engagement, further work is needed to understand how to best scaffold participation in such collective sensemaking around genetic health. We suspect that the families that may benefit most from leveraging technology to collaboratively build up an understanding of genetic health are those who may have a harder time adopting the practice. Our findings suggest that individuals who are in regular, in-person contact with family members may discuss genetic health more often, and therefore may develop a shared understanding without shared tracking. Further, forms of stigma may prevent family members from engaging with the practice. We therefore see value in further exploring barriers to contribution.

6.4 Technology Boundaries and Sociotechnical Challenges

Although we suggest that there are some opportunities for technologies to support families' genetic health communication, we recognize that technological solutions alone are not sufficient to address these deeply sociotechnical challenges. For example, while technological improvements may increase people's awareness of genetic health, how individuals interpret and act on this awareness is shaped by social factors such as education, beliefs, ethnicity, and personal or family health history [52, 103, 115, 118]. Thus, technologies providing specific informational augmentation may not fundamentally address these challenges. Instead, educational programs [19, 66], easily accessible resources, or community-based interventions about genetic health [121], may be better resources for promoting public understanding of genetic health and supporting underserved populations in the long term.

Similarly, we also recognize that technologies alone will struggle to fully address societal stigma, since they are often rooted in gendered and cultural structures. In more patriarchal cultures, women often have limited agency in families, and their health needs and experiences get more downplayed and stigmatized [1, 103, 114]. These forms of stigma extend beyond misunderstanding or lack of information, and thus, the design could be more challenging or require being more culturally responsive. There are also limits to the extent to which we can expect technology alone to overcome social barriers. Technology can help connect family members who do not frequently communicate, but the communication breakdowns may be embedded in more complicated dynamics, such as tense family relationships, past conflicts, or perceptual gaps, and thus need to be approached more sociotechnically, with considerations for existing dynamics. Overall, we suggest considering how technologies can support women by addressing more informational, interactive, or technical issues, while carefully navigating contexts where discussing women's health may expose individuals to social risks or conflicts.

As we propose technologies to support people's long-term documentation and sharing of genetic health information, the digitalization of sensitive and familial data also introduces critical privacy risks. Both HCI literature and our participants have discussed reluctance to share personal data and experiences around abortion, miscarriage, or reproductive health, citing privacy concerns related to this health data being used by governments or law enforcement as part of legal proceedings or insurance policies by third parties using it to raise costs or market products [18, 48, 111]. Research has also discussed potential legal issues when sharing genetic testing results or health concerns, including genetic discrimination by employers or insurers, unclear obligations to warn at-risk relatives, and inadequate protections for familial data sharing[9, 28, 84]. Such risks could be more prominent if health data is shared across large families and generations, since one may not be able to manage indirect and future sharing of their data. Some technical approaches to genetic health sharing might address the privacy risks partly, such as providing local deployments or data anonymization, or keeping physical copies. Still, we emphasize that if we incorporate genetic data more deeply into our self-tracking apps or health records, we are simultaneously introducing these privacy, legal, and governance risks and vulnerabilities.

In summary, we envision future technologies for family genetic health as integrations and improvements to tools people already use, rather than entirely new or radical systems. Meanwhile, because many challenges in this space are deeply sociotechnical, designers must pair technical innovation with sensitivity to the cultural, relational, and structural dynamics that shape how families communicate about genetic health.

7 Conclusion

Through our survey on their families' sharing of women's health experiences impacted by genetic factors, we find that families shared various genetic experiences related to women's health, which helps members better understand and manage their genetic health. However, challenges such as the lack of awareness of genetic health, remote family relationships, time and space gaps, and types of stigma, prevented families from passing down sufficient genetic health information. To promote family exchanges of genetic health experiences, we make recommendations for health documentation tools to integrate information around genetics, emphasize narratives, and conversational mediators to integrate design artifacts and educational resources to navigate stigma. We picture future intergenerational collaborative long-term tracking systems for families to collectively share, document, and preserve their genetic health information.

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