
Building a Family Health Heirloom

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Abstract

Cross-generational health information can lead families to recognize and diagnose early health problems, to provide emotional support for suffering family members, and to make crucial lifestyle changes before genetic health issues arise. Our research investigates if and how families currently share health issues, what barriers make this difficult, and how technology might help families spread health stories across generations. For this workshop, we will present preliminary data from twelve interviews conducted with participants in the Pittsburgh area. We found that both across and within families, individuals have very different attitudes towards talking about health issues. Emotional barriers — such as not wanting family members to worry or feeling ashamed about certain health stigmas — can prevent families from sharing effectively. We argue that through value-centered design, technology can motivate families to actively maintain *health heirlooms* that preserve medical histories and pass along healthy practices and lifestyle choices.

Author Keywords

Health heritage; health narrative; folk health literacy; family history

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

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Introduction

Health care today is moving away from a focus on curing the sick patient and becoming more proactive in prevention, working to keep healthy patients healthy [1]. Technology is poised to play a primary role in helping individuals manage their personal health information, review trends and notice changes in their health, and to improve patient-doctor communication. In addition to personal health tracking applications, patients have access to a wealth of health information through a variety of medical Web sites, forums, and disease-specific social networks.

While many technologies exist for helping individuals manage health personal information, there is little technological support to assist family members in sharing health histories. Knowing that certain diseases, like heart disease or diabetes, run in the family can help family members at high risk make crucial lifestyle changes before the disease becomes a problem. As our knowledge of the human genome and the relationships between genetics and disease grows, knowledge of one's family health history will become ever more valuable.

Our research investigates the challenges of sharing family health information. Family health information not only includes the history of health issues, which can provide value for diagnosing and treating disease, but also health *heritage*. Rather than something static and in-the-past, we understand heritage as a fluid concept, more closely aligned with Giaccardi & Palen's notion of heritage in which "aspects of physicality, interpretation and ascribed value combine to produce and evolve the meaning of heritage" [3]. We see health heritage as having broader implications going beyond the family

medical history to include behavior and personality traits that may affect health. Families share more than genes; they also tend to share health practices and attitudes toward healthcare, as well as environment and lifestyle. Health heritage therefore includes family stories about behavior, personality, health and lifestyle practices, environment, and symptoms that may seem unrelated to medical diagnoses in addition to stories about diagnosed diseases and death.

In our initial study, we broadly examine how various factors affect the way in which family members share health events and pass on their health heritage. From these preliminary results, we hope to design new technology that will help families build and maintain their health heritage. We see the concept of an heirloom as a design opportunity to understand how to bring to digital the carry and accrue value over time.

An heirloom is something that had value for previous generations, has meaning for the current generation, and has perceived value for future generations. As with physical family heirlooms, the heritage value of digital heirlooms could grow as they are cared for by future generations. We aim to bring an heirloom quality to digital family health information in order to help families grow and share their health heritage. By focusing on heritage, we hope to assist families in improving and maintaining their collective family health.

Related Work

Existing personal health record solutions have yet to capture the richness of family health. Tools such as Microsoft Health Vault [4] allow individuals to take control of managing their own digital health records,

but encouraging communication between family members is not the primary focus. The Surgeon General's "My Family Health Portrait" [6] does focus on building a collaborative family history, but the goal seems to be a final end product that family members can take to their doctors. It may spark discussion and story sharing during the building process, but its focus on death and diagnosed diseases may overlook more subtle aspects of family health heritage such as lifestyle or symptoms of undiagnosed illnesses. Our design interventions will focus on collaborative building and sharing of a dynamic and rich health heritage. Heritage is not a utilitarian snapshot that created and then preserved. Heritage value is something that elicits a deeper meaning and transcends generations, emerging and growing with care and over time.

Study Description

To understand how people share their health with family members, we conducted twelve interviews with participants ranging in age from 24 to 91. Interviews typically lasted from sixty to ninety minutes, and were conducted in the homes of participants.

As this is the first stage of our study we asked a broad range of questions about the participants' health, what they knew about their family health history, and how they shared health information. We asked participants to tell us about the health practices of their grandparents, what they remember their parents doing for them when they were sick as children, and the extent to which carry on these practices for themselves or for their children. In discussions about how participants maintain their own health, we gathered stories that shed light on how families view the role of their professional healthcare providers and learned

when they might use alternative sources of health information. Participants told us what they knew about their family health history, and speculated about what they didn't know. We also asked participants to define what they think it means to be healthy. If they kept any health records, we asked where they were stored and for what purpose.

Initial Findings

Our preliminary analysis begins to reveal how people learn about health information, attitudinal differences towards sharing, and how families maintain health heritage. Participants understand health information somewhat differently depending on their attitudes toward healthcare. While participants generally described themselves and their families as open in sharing information about their health with each other, there are frequently situations in which such information is withheld. In addition, there seem to be societal norms surrounding who receives family health stories, as well as generational differences regarding attitudes toward healthcare and sharing health information. We touch on these findings below.

Learning About Family Health History

When asked how they learned about diseases that run in their families, participants primarily reported firsthand observation of relatives and their symptoms. For older relatives this observation would have been made at a young age, and participants were often unsure of diagnoses or knew only general information about the disease. Participants also talked about learning through conversation with other family members, sometimes prompted by a photo, a life event, or a recent diagnosis.

Asking about family health information can be difficult. Concern for the wellbeing of older family members may prevent younger generations from asking sensitive or difficult questions about health. For example, in an effort to understand her father's drug abuse later in life participant 2 turned to her aunt for more information about her grandmother's mental illness. She and her aunt could only speculate about how his mother's illness might have affected her father in his youth, but the two of them decided not to bring the questions to her grandfather for fear the topic or memories could negatively affect his health.

Attitudes Toward Health Can Influence Sharing

When asked what they think it means to be healthy, participants generally described physical ability first, and sometimes added mental or social health later in their description.

Participants' values influence their attitudes about health. One well-educated participant described interest in learning as part of being healthy. *"Age is irrelevant. It's your activity level and your mind and your interest in learning that is much more important than even the state of your health"* [P08]. A young participant who did not have health insurance took an even more proactive view of health. *"Health is a right. Health is something you gotta fight for. If you don't try to be healthy, then you won't be healthy at all. It's a struggle, something you have to obtain..."* [P01].

Participants often described their grandparents as not being concerned with their own health, or as taking the attitude that getting sick was just something that happened to a person, not something that people could take steps to prevent. In contrast with participants'

own proactive attitudes toward health, this was a powerful observation. Perhaps this is a generational difference reflecting a change in attitudes toward health as discussed in [1]; however, the ages of our participants spanned about three generations, so it is also possible that participants were observing a gap in communication between grandparents and grandchildren.

In addition to socioeconomic and generational differences in attitudes toward health, we also see evidence of gender differences. Women seem more likely to share and solicit health information from family members. When asked how his children were cared for when they were sick, P10 called for his wife to answer as he claimed he had little part in raising the children, and he continued to defer to his wife when asked about his family health history. In the interview with another couple, P05, the wife had clear authority over family health history information despite the husband's authority regarding health matters as a retired physician. In describing how his family shares health information, P04 depicts his mother as a central point of contact and responsible for sharing health information within his immediate family.

Withholding Health Information

Participants generally shared their health information openly with family members, but on an individual level we heard many stories of family members withholding health information. The nature of the relationship between family members influences what is shared, when, and how. For example, P11 mentioned that she did not share information about her sexual health with her children because she didn't think they would want to know. Another participant was concerned about

being a good role model for his children: *"I wouldn't share that I used to be an alcoholic [...] I'd rather them think I was perfect [...] I want to put perfection in their head"* [P01].

For two participants, their reluctance to share mental health information stemmed from their perceived social stigma surrounding mental illness and fear that the information would negatively affect their relationship with the friend or family member.

Participants also talked about not wanting to complain too much, bore, or burden their family. *"I talk about my depression a lot, I think probably too much [...] I try not to bore people to death with my stuff [...] I've learned the hard way not to share too much. I used to journal a lot, and getting back to that would probably help [not share so much]."* [P02]

Discussion

Technology can do more than simply tracking personal health. Heritage-focused design can support learning by encouraging the sharing and requesting of family health information. It can respect differences in attitudes about health by allowing family members to negotiate relevant information as they see fit, and it can maintain privacy in a fluid and visible manner.

Highlight Opportunities for Learning

Major life events can change the context of relationships between family members. Events such as milestone birthdays, weddings, and deaths in the family could present opportunities for sharing health heritage stories. By recognizing changing contexts, heritage-focused technology can support learning at times when a change in people's relationships may affect what they

are willing to share. Perhaps P01 will want to share his experiences dealing with alcoholism someday when his children are older, as a way to offer support as they experience difficult life events of their own.

Build Personal Meaning

By giving individuals the power to share, request, and prioritize their health heritage information according to their own attitudes and roles within their families, a heritage-focused health technology can help family members negotiate their health information in a way that is meaningful to them. Some may place trust in their physician while others may find firsthand accounts from family with similar symptoms most valuable. The personal value of such a technology will emerge over time as the individual shapes their own story, but in order to have heirloom value the personal meanings of others needs to be embedded and apparent as well.

Support for Withholding and Privacy

Privacy and security issues are of great importance for social, health-related applications, as discussed in [7]. In order to identify opportunities for sharing based on changing contexts, it is important for individuals to be able to include personal health information they may want to withhold from others. Whether temporarily or from certain people, *not* sharing can be as critical as identifying when sharing might be appropriate. Because contexts can change frequently, support for privacy in a heritage-focused technology needs to be especially visible and fluid. Static settings for what is shared and what is withheld will likely fall short.

Next Steps

Based on findings from our initial study we aim to apply HCI design methods to give form to technologies for

health sharing. In our initial interviews, we asked a broad range of questions about health. In subsequent interviews and as we begin generating design concepts,

we can focus more closely on how health stories can have heirloom qualities.

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