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Family Health Heritage: Sharing and Withholding Across Generations

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Healthcare is moving beyond a focus on curing the sick patient toward taking a more proactive role in keeping healthy patients healthy [1]. Today patients are more aware of what constitutes a healthy lifestyle and are more likely to take notice and act when health issues arise. This shift in focus places more responsibility on individuals to play an active part in their own care and well-being, and technology is beginning to play a more supportive role in empowering them to do so. An increasing number of tools such as websites and smartphone apps have been designed to help individuals manage their health. These personal health records and tools can highlight trends and subtle changes in health, and in this way empower patients and 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 websites, forums, and disease-specific social networks.

Patients also rely on support from friends and family outside of the healthcare system to assist in making health decisions. Typically, family caregivers help each other interpret and decide how to act on medical information such as test results. This information can sometimes be difficult for caregivers to access, primarily due to legislation intended to protect the privacy of patients that limits how healthcare professionals can share a patient's information [2]. As a result of these privacy concerns, there are few technologies designed around sharing health information within a patient's social support system.

Family Health Heritage

In addition to social support, family members also provide

information about family health history. Many illnesses have a genetic component. For example, a family history of heart disease or diabetes can increase the risk factor for other family members. Knowing such an illness runs in the family can help individuals make crucial lifestyle changes to mitigate some of the risk before the disease becomes a problem. As knowledge of the human genome grows and information about the relationships between genetics and disease becomes available, knowledge of one's family health history will likely prove even more valuable for diagnosis and prevention in the future.

While knowledge of family health history can provide clues about an individual's genetic potential, there is a lot more that people learn about health from their families. Families share more than genes; they also share a physical environ-



ment and general lifestyle practices. They also tend to share health practices and attitudes toward healthcare. Growing up, children learn from their parents what to do when they get sick, how to keep from getting sick, and when to go to the doctor. Though various media sources may stress the importance of diet and exercise in maintaining a healthy lifestyle, the specifics of why and how often are heavily influenced by family. Family health information therefore includes not only the history of health issues, but also health *heritage*: family stories about symptoms, healthy behaviors, personality traits, and lifestyle practices, in addition to recalled histories about diagnosed diseases and death.

Families preserve and share information among family members over generations. Health information is a part of this heritage, handed down through obser-

vation and conversation. Rather than seeing it as something static and in the past, we understand heritage as a fluid concept, something that grows and changes over time. Each point of interaction with heritage adds to its meaning. Giaccardi introduces the concepts of *pause* and *duration* to distinguish between a single point of interaction with heritage and the creation of heritage over time. Her description of heritage as “constructed across time and not just over time, through repeated and multiple experiences” [3] applies equally to family heritage as it does to cultural heritage. Family health heritage is formed from the observations, conversations, and experiences with health that family members share over time across generations.

With each pause individuals take to reflect on their family health heritage, the meaning and value of that heritage changes. We imagine

that such points of interaction with family health heritage might take on qualities similar to interactions with family heirlooms. An heirloom is an object of value worthy of being shared with future generations, and can serve as catalysts for communication and repositories of family stories. While inherent value and durability of attachment are important aspects of the design of heirloom objects [4], heritage-centered designs can look to heirlooms as objects that have the ability to create heritage meaning as they are shared with others. Heirlooms offer a design opportunity to understand how to help families build and maintain their health heritage across generations. In order for an heirloom to cross generations, the object must be meaningful to both the older and the younger generations. Likewise, the sharing of health heritage between generations will depend greatly on what

the prior generation deems worthy of passing on to future generations. Because of the changing health climate, the value of health information today is quite different from what was considered important in the past. When casting health information as an heirloom, it becomes clear that sharing family health heritage can be disrupted when there are conflicting values between generations.

Health Can Be a Difficult Subject

Understanding how people share their health information can provide a glimpse into how family health heritage grows and changes over time. In support of this goal, we conducted interviews with 15 participants ranging in age from 23 to 91. We found that, historically, families do not tend to talk about health, and this pattern continues today, despite better awareness. For example, thinking back to her childhood, one young participant observed, “I’ve never really engaged in a health conversation with any of my family members.” Likewise, when our oldest participant tried to recall a health conversation with his children, his wife explained his difficulty: “It’s hard to know what to share when you’re healthy.” For most people health is simply not a concern of daily life, and there are few prompts outside of an illness or death in the family that makes the subject relevant.

Even when relevant to the symptoms or situation at hand, some health topics can be difficult to broach. Topics such as mental health, behavioral health, and sexual health are impolite for casual conversation and seem especially difficult for families to discuss. For example, Ms. C, a young college student, shared a

story about how she chose a new birth control pill when her insurance stopped covering her prescription. She talked to her pharmacist and searched the Internet, then took the information she found to her doctor, who helped her decide between those options. While her parents typically help her manage health information in other ways, they were not part of her decision process in this case. “My parents know I’m on birth control and that I see my gynecologist regularly, but we don’t talk about it. They’re pretty conservative.” Similarly, Dr. and Mrs. F, a retired physician and his wife, find it difficult to discuss behavioral health with their son. They have observed what might be symptoms of a developmental problem in the behavior of their granddaughter, but their son refuses to acknowledge that his child might have a behavioral problem. “We’d like to get [the child’s parents] to take her to see a professional. We can’t discuss it with them. Either one of them. It’s not acknowledged; it doesn’t exist.” These are not common topics of conversation, and it’s hard to know how to talk about them.

Another overarching finding is that the nature of relationships between family members greatly influences how health information is intentionally shared or withheld. Most people have at least one close person who helps to manage health information and assists in making health-related decisions. This confidant could be a parent, spouse, friend, child, doctor, neighbor, or social worker, and the person who plays this role changes throughout people’s lives. Parents typically manage their children’s care completely. As adults, children transition to become fully responsible for their own care and may turn

to a spouse or friend to help when needed, giving parents a much less active role. In their later years, parents may begin to rely on their children to assist with their care, bringing full circle a transition from being cared for to caring for others, and back.

Why People Withhold Health Information

Health information plays a surprising role in these transitions through life stages. Children may withhold health information from their parents to assert their independence. Parents sometimes withhold health information to protect their children from worry. When designing technologies to encourage the sharing of personal stories, such as those that are an integral part of family heritage, it is important to support rather than subvert these natural transitions in family dynamics. In order to allow for health heritage technologies to grow and change with the family over time, support for withholding is imperative.

While patterns of withholding health information surrounding life-stage changes are unlikely to alter from generation to generation, other life events may cause these patterns to change. There are some occasions when family members may not want to share at all for fear of embarrassment or judgment, but more often withholding is a matter of timing. Some may choose to withhold health information to share later because they are reluctant to deal with a health issue, or because it seems unimportant. In other cases, the factors that influence sharing are more a matter of context. For example, a daughter of Dr. and Mrs. F withheld news of her cancer diagnosis from her family because

she didn't want her bad news to put a damper on important family celebrations. This was especially difficult for Mrs. F, who explained, "I was upset because she wasn't emotionally sharing something that was so significant. Usually if something is happening to you, you would call your mother!" Other participants shared that they did not want to burden or trouble family by volunteering information they had not been asked to share, or that they were just waiting until it came up in conversation.

Withholding health information is an integral part of the natural transitions in family roles, but it can also create gaps in knowledge. Most health information is learned through direct observation, so face-to-face interactions are important for creating opportunities for sharing health information. The most common prompt for sharing is a *health event*, such as the emergence of symptoms, hospitalization, illness, or the death of a family member. When symptoms of illness surface, families can more easily observe and discuss the issues when they are together in person. From our interviews, we also found that conversations about health don't generally happen without a prompt such as a health event, but when these conversations do take place, young children are frequently excluded. Mrs. J shared that when she was hospitalized with stomach pains, three generations visited her hospital room. She and her husband sent their grandchildren out of the room before they told their children that Mrs. J had been diagnosed with colon cancer and would have surgery the next day. In such situations, young children are often spared the details of the health event to protect them from worry. Missing health infor-

mation typically doesn't come up again after a health event passes.

With the passing of older generations, health information is often lost by the time it would be relevant or useful to younger family members. Mrs. K is in her 40s and finds she is now trying to gather information from her aunts in an effort to explain symptoms she observed in her father, who passed away a few years ago. She is concerned about whether mental illness may run in her family, and thinks that her father protected her from certain information about his childhood. Now facing challenges with her own mental health, she is at a loss to find information her father could have provided. The stories shared by Mrs. K and Mrs. J illustrate some of the ways that withholding affects the transfer of health heritage information across generations, and suggest that heritage-centered design may have very different concerns about the privacy of health information than technologies that focus on the individual.

Implications for Heritage Interactions

Our findings illustrate that a focus on family *health heritage* can improve the family care experience and exceed the technologies designed to track information about an individual. Based on the patterns of withholding information revealed in our interviews, heritage technologies cannot assume that all individuals who engage with their family heritage will want to contribute in the same manner. What people choose to share may depend on relationships, life stage, content, and the context in which they are sharing. Heritage technologies could aid in the transfer of health information across

generations by showing respect for withholding practices, providing for changes in these practices, highlighting benefits to future generations, and creating opportunities for sharing. Heritage-centered design can help families better understand their health and engage with it in a meaningful way.

ENDNOTES:

1. Dubberly, H., Mehta, R., Evenson, S., and Pangaro, P. Reframing health to embrace design of our own well-being. *interactions* 17, 3 (May 2010), 56-63.
2. U.S. Department of Health & Human Services. Health Information Privacy; <http://www.hhs.gov/ocr/privacy/>
3. Giaccardi, E. On pause and duration, or: the design of heritage experience. *Proc. of the 25th BCS Conference on Human-Computer Interaction*. British Computer Society, Swindon, UK, 2011, 35-40.
4. Jung, H., Bardzell, S., Blevins, E., Pierce, J., and Stolterman, E. How deep is your love: Deep narratives of ensoulment and heirloom status. *International Journal of Design* 5, 1 (2011).



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