
Intergenerational Sharing of Health Data among Family Members

Jomara Binda

Penn State University
University Park, PA 16802, USA
jmb89@ist.psu.edu

Natalie Cope

Penn State University
University Park, PA 16802, USA
ntc5037@psu.edu

Hyehyun Park

Penn State University
University Park, PA 16802, USA
hwp5131@psu.edu

Chien Wen (Tina) Yuan

Penn State University
University Park, PA 16802, USA
tuy11@psu.edu

John M. Carroll

Penn State University
University Park, PA 16802, USA
jcarroll@ist.psu.edu

Eun Kyong Choe

Penn State University
University Park, PA 16802, USA
echoe@ist.psu.edu

Abstract

An explosion of affordable commercial wearable sensing devices and mobile health applications has opened up new possibilities to practice self-tracking and enjoy its benefits. However, elders often do not engage with health tracking technologies because they do not see much benefits. Leveraging the inherent reciprocal relationship among family members is one potential approach to promote the practice of health tracking. In this paper, we aim to understand and support intergenerational sharing of health data as a collective and collaborative family project of mutual support. Based on interviews and scenario-based focus group discussions, we report on family members' understanding of one another's health and well-being, their current health-related practices, and issues around health management as a means to facilitate intergenerational health collaboration.

Author Keywords

Health; family; intergenerational; collaboration; self-tracking; data sharing.

ACM Classification Keywords

H.5.m. [Information Interfaces and Presentation (e.g. HCI)]: Miscellaneous

Permission to make digital or hard copies of all or part of this work for personal or classroom use is granted without fee provided that copies are not made or distributed for profit or commercial advantage and that copies bear this notice and the full citation on the first page. Copyrights for components of this work owned by others than ACM must be honored. Abstracting with credit is permitted. To copy otherwise, or republish, to post on servers or to redistribute to lists, requires prior specific permission and/or a fee. Request permissions from permissions@acm.org.
PervasiveHealth '17, May 23–26, 2017, Barcelona, Spain
© 2017 Association for Computing Machinery.
ACM ISBN 978-1-4503-6363-1/17/05...\$15.00
<https://doi.org/10.1145/3154862.3154895>

Introduction

Self-tracking (or self-monitoring) is the practice of collecting and reflecting on personal data [5]. Prior research has mentioned that the general public—especially the younger generation—has practiced self-tracking and enjoyed its benefits including increased health awareness, improved self-management behaviors, reduced negative behaviors, and more informed decision-making [2]. In contrast to the younger generation, elders do not often use health technologies for self-tracking. In a recent study on elders' perceptions toward self-tracking tools, researchers found that elders did not see the benefits of using such tools and showed passiveness in controlling their own wellness information [4].

Because elders often experience challenges in managing their health, self-tracking technologies could provide opportunities to educate elders and caregivers [4]. Using technologies can also help people reduce tracking burden, gain insights, and share data easily [2]. We apply a proactive framing of family health as a collective and collaborative family project of mutual support: each member is helping one another to be more active and engaged for health. Specifically, we want to utilize the inherent reciprocity of aiding among family members to shift what appears to be a burden into caring for one another. As a first step to identify opportunities in this design space, we examine how an intergenerational sharing of health data among family members mediated by technology could help family members be more aware of one another's and their own health, and create a culture of health within family.

Related Work

In designing sensing and monitoring applications, self-tracking component is often included due to its effectiveness on increased awareness and behavior change. These

applications include tracking physical fitness [3], sleep [1], diet [6], and stress [7]. Despite the value of self-tracking technology, researchers also reported many barriers toward the adoption of self-tracking technologies such as lack of time, insufficient motivation, unsuitable visualization and analytics tools, poor skills for analyzing data, and fragmented data scattered across multiple platforms [2].

In our study, we took into consideration these previous studies particularly relevant for elders. Besides, we also want to understand the challenges that can arise when two or more people start to share data. In light of this, we investigated and learned our target group's concerns, needs, hopes, and visions for the intergenerational collaborative health tracking system.

Methods

As part of our ongoing project, we have conducted two particular studies to understand the barriers of sharing personal data among family members, including elderly parents and adult children. We have also investigated the types of self-tracking data that could increase elderly parents' and adult children's awareness and emotional comfort. First, we conducted semi-structured interviews with adult children ($n = 14$) and elderly parents ($n = 10$) to understand their health-related practices and level of awareness. Next, based on these interviews, we designed 3 scenarios and used them as discussion probes to further investigate adult children's and elderly parents' health sharing practices and experiences. We had 10 focus group sessions with 18 adult child group / sandwich generation (i.e., they were an adult child to their parents and a parent to their adult child.) and 3 focus group sessions with 12 elderly parents participants. Using the scenarios with different self-tracking apps and visualizations of devices, we prompted the participants to envision and reflect upon challenges, opportunities, bar-

riers, and enablers of such systems. We also asked their communication routines, awareness of how the other party is doing, specific informational and emotional needs, and contexts when data sharing might be desirable.

Preliminary Results

Information Awareness in Intergenerational Relationships

We learned that elderly participants routinely talked about health and well-being information that are relevant to activities and diet—such as sharing healthy recipes and daily activities (e.g., walking)—with their children. Nearly all participants were able to describe the other party’s typical routine, diet, and activity level. However, participants presented more difficulty in describing information concerning sleep and medications because these topics are not easily brought up in routine conversations; for example “*I don’t usually talk about my own sleeping behavior because I don’t have any problem with it.*”

We also learned that if one member in the family had faced a previous serious illness, the other family members presented a high level of awareness toward the one who were ill. We observed that due to the illness, family members changed their current family communication practices and increased their interaction frequency by pursuing more conversations. We also noticed that those participants presented a more positive attitude towards sharing health information with their family such as “*My father has had two strokes. So, every call we’ll talk about what we ate or what he’s been trying to do to achieve good nutrition and health.*” We identified that participants who lived distant from their family members tend to face challenges of receiving news late or even “filtered news” with only the bright side. Also, the distance barrier prevented them from closely following the family members’ daily routine.

Tensions Around Sharing Due to Family Relationship

Conflicts may occur due to changing of caregiver roles or the need to probe information. For example: “*[My father] does not want to listen to what I had to say about what he eats—and most of the time, he does not want to listen to anything I say about work. I shut up.*” Adult children participants used the term “stubborn” to describe their parents’ behavior and emphasized that they often needed to convince their parents to visit a doctor or to take a medication. We learned that family members deal with the relationship tension by using family influence to pass down a “healthy way” to other parties. For example: “*I bought them [parents] for Christmas a blender, a powered expensive blender, and I encouraged my parents to use it, especially my dad, because he has cholesterol problems, so he can eat more vegetables smoothies and stuff like that.*”

Concerns on Sharing Personal Health Data

We observed that elderly parents considered that their children might not be interested in knowing more about their health. They were also concerned about intruding their children’s lives and “burdening them with their problems.” One participant said “(I) do not want to make [my children] worry.” However, adult child participants did not seem to have the same concern about intruding into their parents’ lives. Nearly all adult child participants affirmed that if they want to know more about their parents’ health the will directly ask the parents.

Participants used the term “news worthy” to describe events that deserve to be shared among family members. They can be health related (e.g., concussion, cold) as well as non health related (e.g., vacation, family party). We identified that the importance of the news and emotional valence could influence people’s decision to share the news. Participants pointed out that they need to have a sense of control

in deciding what to share. In other words, they wanted to have the ability to withhold information if necessary. For example, a family member would not mind sharing a photo of home-cooked meals, including a failed one because it could be humorous. However, they would not share information that might show negative emotions, such as “at 11 p.m. I ate three cupcakes that were in the fridge.”

Conclusion and Future Work

This study aims at gaining insights into people’s goals, needs, preferences, current limitations, and future opportunities of intergenerational health collaboration, which serve to inform the design and development of a family health sharing platform. Based on these preliminary results, our next step is to create low-fidelity prototypes that reflect the feedback and the design requirements we learned from our participants. Then, we will implement high-fidelity prototypes to support collaborative practices, such as tracking together, setting mutual goal, and cheering one another. Meanwhile, supporting each family member’s privacy is important; we will include a feature that allows users to share their personal health data at different levels of granularity. Finally, to assess the effects of the proposed approach and the prototype, we will conduct field deployment studies of our intergenerational health collaboration system.

REFERENCES

1. Eun Kyoung Choe, Bongshin Lee, Matthew Kay, Wanda Pratt, and Julie A. Kientz. 2015. SleepTight: Low-burden, Self-monitoring Technology for Capturing and Reflecting on Sleep Behaviors. In *Proceedings of the 2015 ACM International Joint Conference on Pervasive and Ubiquitous Computing (UbiComp '15)*. ACM, New York, NY, USA, 121–132. DOI : <http://dx.doi.org/10.1145/2750858.2804266>
2. Eun Kyoung Choe, Nicole B Lee, Bongshin Lee, Wanda Pratt, and Julie A Kientz. 2014. Understanding quantified-selfers’ practices in collecting and exploring personal data. In *Proceedings of the 32nd annual ACM conference on Human factors in computing systems*. ACM, 1143–1152.
3. Sunny Consolvo, David W. McDonald, Tammy Toscos, Mike Y. Chen, Jon Froehlich, Beverly Harrison, Predrag Klasnja, Anthony LaMarca, Louis LeGrand, Ryan Libby, Ian Smith, and James A. Landay. 2008. Activity Sensing in the Wild: A Field Trial of Ubit Garden. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '08)*. ACM, New York, NY, USA, 1797–1806. DOI : <http://dx.doi.org/10.1145/1357054.1357335>
4. Jina Huh, Thai Le, Blaine Reeder, Hilaire J Thompson, and George Demiris. 2013. Perspectives on wellness self-monitoring tools for older adults. *International journal of medical informatics* 82, 11 (2013), 1092–1103.
5. Judy Kopp. 1988. Self-monitoring: A literature review of research and practice. In *Social Work Research and Abstracts*, Vol. 24. Oxford University Press, 8–20.
6. Lena Mamykina, Elizabeth Mynatt, Patricia Davidson, and Daniel Greenblatt. 2008. MAHI: investigation of social scaffolding for reflective thinking in diabetes management. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM, 477–486.
7. Margaret Morris and Farzin Guilak. 2009. Mobile heart health: project highlight. *IEEE Pervasive Computing* 8, 2 (2009).