

ABSTRACT

In many families, there are obstacles to support and collaborate with one another around positive health outcomes. One obstacle in providing support to one another occurs when family members are unaware of the need. In this study, we examine aspects of family conversations about health that affect family members' decision to share (or not to share) information within the family, specifically information about sleep behaviors and medication intake. We conducted an interview study with independent living elderly parents ($n = 11$) and adult children ($n = 14$). We present factors that motivate and discourage family members from talking about sleep and medication within the family. We identified that some family members *shift* sharing behaviors following life changes that we characterize as “inciting incidents.” We elaborate the concept of inciting incidents as resource for design ideas and contribute with a synthesis of design insights for developing family-centered health technologies.

KEYWORDS

Intergenerational Families; Health; Family Informatics; Information Sharing; Sleep Behaviors; Medication Intake

1. Introduction

An increasing number of healthcare professionals and researchers have recognized the crucial role families play in managing individuals' health (Baghaei et al., 2011; Colineau, Paris, Marendy, Bhandari, & Shu, 2009; Katule, Rivett, & Densmore, 2016). In intergenerational family relationships, specifically between elderly parents and adult children, there is a desire to help each other and contribute to the whole family's common good, which allows favorable circumstances to promote engagement on family-oriented health interventions (Lindley, Harper, & Sellen, 2009; Stuifbergen, Van Delden, & Dykstra, 2008; Sun, 2016). Yet, some intergenerational families face obstacles in supporting each other because members may decide *not* to share health information. How can family members provide or receive support if they are unaware that it is needed? Health information sharing could thus be seen to play an important role in support provision. This insight has motivated HCI researchers to explore the effect of supporting and strengthening the family's role in health promotion and managing diseases (Grimes, Tan, & Morris, 2009; Pina et al., 2017).

In the context of the family's role in health promotion, previous studies have explored strategies to improve the family's overall diet and nutrition (Baghaei et al., 2011; Colineau et al., 2009; Schaeffbauer, Khan, Le, Sczechowski, & Siek, 2015) and physical activity practices (Knaving & Wóznia, 2016; Saksono & Parker, 2017). In addition to maintaining a balanced diet and practicing regular physical activity, quality sleep is crucial to overall health and well-being (Altevogt & Colten, 2006). However, poor sleep is a prevalent health problem among adults. In the United States, for example, 25% of the adult population reported insufficient sleep or rest at least 15 out of every 30 days (Centers & Prevention, 2008). Sleep loss and untreated sleep disorders influence basic patterns of behavior, which in turn, can undermine family health and interpersonal relationships (Altevogt & Colten, 2006; Dahl & El-Sheikh, 2007). Our work is based on the premise that sharing sleep experiences among family members may enhance awareness of sleep and cultivate good sleep health.

Administering medication is another important health context where family support may play an important role in care management. Researchers have examined

different ways to strengthen family support for chronic illness management and self-care in non-clinical settings. For example, poor medication intake management can lead to complications and higher health care costs, so one approach considers supporting individuals on how to select an appropriate OCT (over-the-counter) medication based on their health history (Martin, Jones, & Gilbert, 2013). Others have considered how to turn medication intake into a shared activity (Dalgaard, Grönvall, & Verdezoto, 2013a) and how to use remembering strategies to support medication adherence (Stawarz, Rodríguez, Cox, & Blandford, 2016). Furthermore, previous work has proposed technological solutions to support medication intake management. For instance, Dasgupta and colleagues (2016) presented a tablet-based application called *eSenior-Care* to facilitate medication tracking. This work reaffirms the important role families can play in cultivating good health. However, not all families actively cultivate good health together. With the long-term goal of promoting the culture of family health, we examine the factors and contexts that prompt health information sharing in families where it does not already happen.

In this paper, we describe an interview study that investigated health information sharing practices, specifically focusing on sharing between non-located elderly parents and adult children. We operationalize “health information” as: *“any information relevant to an individual’s mental or physical health.”* For example, family members share with one another information about healthy eating, exercise or physical activity, sleep behaviors, and medication intake. Furthermore, we chose to focus on family discussions about sleep behaviors and medication intake because (a) sleep is one of the health issues that most impact families (Altevogt & Colten, 2006; Dahl & El-Sheikh, 2007), (b) medication intake management can be challenging in non-clinical settings (Dalgaard et al., 2013a), and (c) family discussions about sleep and medication intake seem to be less common than other health-related topics (Binda et al., 2017; Binda, Yuan, et al., 2018).

We contribute to the family informatics research (Pina et al., 2017) by unveiling factors that motivate and discourage family members from sharing information about sleep and medication. In addition, we present that individuals tended to talk about health, specifically sleep and medication, with their family members following a change

which we call as “inciting incident” (Hart, 2012). “Inciting incidents” are events that move an individual out of the status quo (Hart, 2012). Introducing and applying the concept of “inciting incidents” in the context of family conversations on health information is novel and valuable because this concept can be used as an evocative resource for design ideas that enable sharing of health information related to sleep and medication. More broadly, this concept could be a useful means for HCI researchers trying to promote health information sharing and collaboration in the family context. We, thus, elaborate on the concept of inciting incidents and discuss design considerations for HCI in terms of the family informatics framework (Pina et al., 2017). Also, we complement existing design guidelines for systems that support families on sharing health information (Grimes et al., 2009) by considering the inciting incident concept which may lead to more opportunities for family-centered health informatics.

Our specific contributions to the HCI research community are:

- (1) providing knowledge of intergenerational families’ current health information sharing practices, specifically sleep and medication information;
- (2) introducing the inciting incident concept as an innovative design resource when building family-centered health technologies; and
- (3) a synthesis of design insights that consider the inciting incidents concept on family informatics framework and on design guidelines for systems that support families on sharing health information.

2. Background and Related Work

In this section, we summarize HCI research into technological support for families in general and examine studies on different family relationships. Then, we focus on technological support for health management and health information sharing within families. Finally, we emphasize that sleep behavior and medication intake are important health topics to be explored in a family context .

2.1. Technological Support on Families

Researchers in the HCI community have explored different forms to support families, including examining members' needs to maintain regular conversations. For example, Lindley et al. (2009) examined older adults' view on family communication and their desire to be in touch. Others have explored ways to support how families connect with one another (Neustaedter, Harrison, & Sellen, 2013; Romero et al., 2007) and have proposed technological solutions to facilitate familial conversations when members live across geographical distance (Evjemo, Svendsen, Rinde, & Johnsen, 2004; Forghani & Neustaedter, 2014; Inkpen, Taylor, Junuzovic, Tang, & Venolia, 2013; Sas et al., 2017; Vutborg, Kjeldskov, Pedell, & Vetere, 2010) and across time zones (Cao et al., 2010; Nawahdah & Inoue, 2013; Vutborg, Kjeldskov, Paay, Pedell, & Vetere, 2011). Furthermore, some systems were developed to display information about the current state of an extended family member (e.g., Digital Family Portrait (Mynatt, Rowan, Craighill, & Jacobs, 2001) and The Family Window (Judge, Neustaedter, & Kurtz, 2010)) as a way to help families to feel more connected and increase their level of awareness on each other everyday life. All these foregoing studies presented important findings which reinforced the importance of cultivating regular conversations for families members (Lindley et al., 2009) and explored the various ways in which family members connect (Judge et al., 2010; Neustaedter et al., 2013) and emphasized their desire to communicate with each other often (Evjemo et al., 2004; Vutborg et al., 2011). Yet, more research investigation is needed because it is important to understand the impact of technological solutions across a variety of family relationships, including parents and children, and grandparents and grandchildren.

Some HCI researchers have sought to support different family relationship's necessities. For example, when considering the relationship between grandparents and grandchildren, researchers have investigated their conversations needs (Forghani & Neustaedter, 2014) and proposed solutions that involves sharing the grandchildren' activities with remote family members (Inkpen et al., 2013) and storytelling (Procyk & Neustaedter, 2013; Vetere, Davis, Gibbs, & Howard, 2009; Vutborg et al., 2010). When considering the relationship between parents with minor children, some research has focused on learning more about parent-child intimacy aspects to inform future design

(Dalsgaard, Skov, Stougaard, & Thomassen, 2006). Others proposed design solutions such as Kientz et al. (2009) developed a system to support parents on keeping record of their child’s milestones and Ferdous et al. (2016) developed a system which leverages personal devices to promote sharing of experiences during family dinner table. Finally, researchers have investigated the family relationship between elderly parents and adult children/relatives to better understand how to support elders aging in place while their relatives are living apart (Santana, Rodríguez, González, Castro, & Andrade, 2005). Also, design ideas were presented such as a family stories system to strengthen the family relationship (Bentley, Basapur, & Chowdhury, 2011) and a social cloud-based tool to support family communication when there is a media mismatch (Muñoz et al., 2015).

Our study also focuses on information sharing between elderly parents and adult children. We chose to study this family relationship because (a) it is an under-leveraged resource in families’ studies, and (b) we aim to expand beyond supporting general intergenerational family communication to support intergenerational family members on health management. We claim that the family context has the means and potential to foster positive collaborations leading toward a family’s health-related goals (Colineau & Paris, 2011; Colineau et al., 2009; Grimes et al., 2009; Pina et al., 2017; Saksono et al., 2019; Schaeffbauer et al., 2015). Previous HCI studies have considered the family relationship between elderly parents and adult children in the context of informal care-giving (Gutierrez & Ochoa, 2017; Gutierrez, Ochoa, & Vassileva, 2016) and in the context of tracking health information (Binda, Georgiva, et al., 2018; Binda et al., 2017). We, therefore, propose to complement previous research by expanding the knowledge of intergenerational family members’ (elderly parents and adult children) conversational practices on health, by focusing on sleep behaviors and medication intake.

2.2. Technological Support on Family Care/Health

Many individuals consider family as a source of encouragement in which the members reciprocate and help one another at times of necessity, such as during a chronic disease treatment (Barbarin, Veinot, & Klasnja, 2015; Pang, Neustaedter, Riecke, Oduor, &

Hillman, 2013), and moreover to engage in behavioral changes for a healthy lifestyle (Baghaei et al., 2011; Colineau et al., 2009). In the context of families managing chronic diseases, Pang et al., (2013) investigated the technology preferences of individuals with a chronic illness and their challenges with sharing health information with distributed family members. Additionally, Eschler et al., (2015) investigated the use of shared calendars for families managing chronic diseases (i.e., diabetes and asthma) to support daily schedule/task management and health care activities at home. Likewise, Barbarin et al., (2015) investigated the use of time-based information objects (e.g., medication containers and calendars systems) among patients and their families to support them while managing chronic diseases.

Other researchers have proposed designs to inspire family members to share health information with each other and to collaborate with one another in order to achieve positive health outcomes. For example, Colineau et al., (2009) investigated the requirements for a collaborative family weight management site to promote lifestyle changes by engaging family members to support one another in weight management. Similarly, Knaving and Wóznia (2016) developed an interactive artifact called “Tick-TockRun” to track running training and daily activities. The artifact aimed to facilitate families’ discussion and reflection about running at home. Schaeffbauer et al., (2015) explored the use of a sociotechnical mobile app designed to promote healthy snacking called “Snack Buddy”. Snack Buddy encourages healthy eating behaviors and promotes positive support within the family. Finally, Baghaei et al., (2011) proposed an online social network, called SOFA (SOcial FAMily) aimed to engage and motivate families to adopt healthy lifestyles by presenting educational information about diet, exercise, and other healthy living information.

This body of literature contributes with important observations into how families share health information and collaborate with one another to achieve positive health outcomes. Furthermore, this literature contains interesting design solutions aiming to engage families around health goals. However, most of the HCI community has primarily focused on family member’s sharing health information related to food, diet and nutrition, or daily schedule/task management. A possible consequence is that other relevant health-related topics (e.g., sleep behaviors and medication intake) remain

under-explored. Researchers continue to develop an interest in health collaboration and its application in the family context to promote healthy behaviors (Grimes et al., 2009; Pina et al., 2017). As this interest develops, we identify an opportunity to expand the scope of health-related topics that HCI researchers might consider in the family context.

In this study, we highlight two health-related topics often overlooked in family conversations: sleep behaviors and medication intake.

2.3. The Importance of Sleep for Families' Health

Previous studies consider eating a nutritious diet, exercising regularly, and getting adequate sleep the triad to support a healthy lifestyle (Choe, Consolvo, Watson, & Kientz, 2011). The first two have received much research attention to investigate technology solutions that would ultimately engage individuals and families in cultivating good health. Sleep, on the other hand, has received less attention when considering the family context in the HCI community despite being a common discussion topic among medical researchers (Altevogt & Colten, 2006; Bonnet & Arand, 1995).

Among young adults in the developed world, 29% reported having only 6.5 hours of sleep each night. In the United States, it is estimated that 50 million people have poor sleep quality or have a sleep disorder such as insomnia and sleep apnea (Altevogt & Colten, 2006). In light of the magnitude of sleep issues, a number of studies have investigated different individuals' sleep behaviors and proposed designs to support sleep quality. For example, Rodgers et al., (2016) investigated sleep behaviors of students at universities and how they manage stress, sleep, and technologies throughout the semester. Likewise, Choe et al. (2011) aimed at uncovering opportunities for computing to support healthy sleep. Besides research projects, many commercial products exist for the purposes of tracking personal information of sleep, including the frequency, duration, or quality. Examples include: *Fitbit*¹ and *Microsoft Band 2*². These and other recent efforts have both advanced knowledge about sleep and led to the development of interesting design artifacts (e.g., SleepTight (Choe, Lee, Kay, Pratt, & Kientz,

¹<https://www.fitbit.com/home> [accessed Mar. 28 2018].

²<https://www.microsoft.com/en-us/band> [accessed Mar. 28 2018].

2015), Lullaby (Kay et al., 2012)), which aim to support individual sleep quality. Here, we see an opportunity to expand the focus from the individual to the family.

Given existing widespread focus on individual sleep data, we see merit in studying sleep in the context of family health information sharing. A study that examines how and why individuals share health information within their families, including sleep behaviors, for example, may provide new insights for HCI researchers on how to cultivate healthier family lifestyles.

2.4. The Importance of Medication Intake Management on Family Health

In addition to research on sleep, HCI research on medication intake has increased with the trend of self-care activities in non-clinical settings. Medication intake management can be challenging due to a diverse number of factors, such as: forgetting to buy and take medication, the breakdown of routines, the lack of medication information at hand, handling substitution medication (Dalgaard et al., 2013a). These challenges can be aggravated with age and levels of illness.

Under such circumstances, researchers have examined individuals' needs (Martin et al., 2013; Stawarz et al., 2016) and proposed different strategies to support individuals' on medication intake. For example, Venkov and Ivanov (2016) study has proposed a cloud-based system for prescription and monitoring of medication intake that can be used by elderly people. Similarly, Dalgaard et al., (2013a) presented design principles for pervasive healthcare medication management systems to support individuals on daily medication intake and developed MediFrame (Dalgaard, Grönvall, & Verdezoto, 2013b) which is a personal tablet-based application to support individuals on remembering and tracking medication intake. Finally, Le et al., (2007) developed a remote monitoring system to support communication between elders aging in place and the hospital. Although enhancing the individual ability of managing medication in non-clinical settings is important, an innovative HCI research approach could explore collaboration between individuals in medication management by leveraging family members' interactions with one another to engage in medication intake care.

In this paper, we provide a rich description of families' health-related sharing practices and argue for inciting incidents as an innovative approach for HCI researchers

focusing on the design of family-centered health technologies. We argue that our work could be broadly applicable to HCI researchers interested in how families collaborate to achieve health goals, specially focusing on sharing information about sleep behaviors and medication intake.

3. Method

Given our interest in understanding how intergenerational families talk with each other about health – especially sleep behaviors and medication intake – we conducted semi - structured interviews. Although interviews do have some drawbacks, including reliance on participants’ accurate recall of events and details, we believe that interviews are suitable for understanding participants’ current practices and experiences as well as learning about existing obstacles with respect to family health information sharing (Creswell & Inquiry, 2007).

3.1. Participants

We identified elderly parents and adult children as our target participants. We were interested to gain knowledge about intergenerational family members’ current practices, needs, concerns, and challenges in the context of health conversations, including sleep and medication. We were not considering aspects of sleep disorders in our investigation. In fact, we had no preconceived notions about health information sharing with regard to sleep and medication. We, therefore, established the following inclusion criteria and limited our participant eligibility based on age and independent living, not on health conditions:

- For elderly participants, individuals should be 65 yrs old (or older) and living *independently* of their adult children.
- For adult participants, individuals should be non-student, working adults (18+ yrs old) living independently of their parents and financially self-reliant.

We used several different recruitment strategies. We sent emails to the university research labs mail-lists, distributed fliers in public spaces (e.g., public library, YMCA,

local churches, university boards), and posted recruitment requests at our local university research website and on Facebook. Participants received financial compensation in the form of a \$ 20 USD gift card. Recruitment continued until data saturation was reached, defined as the point at which no new themes emerged during the data analysis. Although our sample size may seem small, it was considered appropriate because of the exploratory nature of this research and the focus on identifying underlying ideas about the topic (Braun & Clarke, 2006).

25 people participated in our study, including: 14 Adult Children (eight females and six males) and 11 Elderly Parents (five females and six males). All participants lived in a small college town in the eastern United States. The age range for elderly parents was 68 - 85 years old (See Participants Information in Appendix A, see Table A1) and adult children participants was from 23 - 64 years old (See Participants Information in Appendix B, see Table B1). None of the participants came from the same family. Elderly participants had different living arrangements, including assisted living community or independent housing. In terms of geographic distance from immediate and extended family, both adult children and elderly parents ranged from living near their family (e.g., in the same neighborhood) to living far away (e.g., on different continents).

3.2. Data Collection

We conducted semi-structured, one-on-one interviews using different mediums such as phone, Skype, and face-to-face. At least two members of our research group were present to moderate and to take notes on each interview. During each interview, which lasted approximately one hour, the moderator asked 8-12 open ended questions to guide the participants through an in-depth exploration of the topic. All interview sessions were audio-recorded and transcribed.

We gathered some demographic information such as age and gender. Also, we asked participants' information about their current health management practices (e.g., medication management), their family relationship, and current family health conversations practices.

3.3. Study Procedure

First, the interviewer presented introductory comments with a brief explanation about the study and asked for verbal consent. After getting the consent, the interviewer started to ask questions from the interview guide. Some examples of the questions are:

- “How well do you sleep (i.e., sleep quality)?”; “Do you take any medication or supplements?”
- “Do you talk about your sleep behavior or medication intake with your elderly parents/ adult children?”
 - “(If yes,) What do you talk about sleep/medication?”; “How often do you talk about it?”; “How do you communicate?”
 - “(If no,) Why don’t you talk about it?”
- “Is there anything about the other party’s sleep behaviors/medication intake that you’d like to know about?”
 - “(If yes,) What do you want to know about?”
 - “(If no,) Why not?”
- “Is there anything about your sleep behaviors/medication intake that you’d like to share with the other party?”
 - “(If yes,) What do you want to share?”
 - “(If no,) Why not?”

In the end, the interviewer presented closing comments, thanked the participants for their contribution, and, for in-person interviews, gave compensation.

3.4. Data Analysis

We used thematic analysis to develop “themes” within the data as proposed by Braun and Clark (2006). Although this study’s resulting sample size was at the lower end of the range of sample sizes employed in thematic analysis (Braun & Clarke, 2013), this decision was made in order to enable significant reflection, dialogue, and time on each transcript and was in line with the more latent level of analysis employed, to identify underlying ideas, rather than a superficial descriptive analysis (Braun & Clarke, 2006).

As we gathered data from the interviews, our research team met regularly to

become familiar with the data. We used open-coding to generate initial codes. As we worked through the coding process, we developed some preliminary ideas about codes. Then, each team member independently reviewed the same transcript. When each member finished the review, we would compare our codes.

We thus examined the codes and piece them together into themes. To ensure the quality and consistency of our data, we applied peer-debriefing and had discussions on main findings. After reviewing the emergent themes, we defined the final set of themes for our data set. The final themes include how the strength of relationships between the children and their parents influence their health information sharing, family members' willingness to share, issues around health information sharing related to sleep patterns and medication intake.

4. Results

We present in this section factors that motivate and dissuade families to share information with each other; specifically about sleep and medication. These include: perceived value and interest, and the nature of the relationship. Then, we present the main motivating factor for discussing them: change.

We refer to our participants using the following scheme: a letter to indicate the generation (EP for Elderly Parent and AC for Adult Children), and the participant number.

4.1. Current Narrative of Family Conversations about Health

Going into our interviews, we had no preconceived notions about health information sharing with regard to sleep and medication. We learned that in some cases, sleep and medication *are* part of the overall narrative of families' conversations.

4.1.1. Families that do talk about sleep or medication

Some participants (four out of 14 adult children and one out of 11 elderly parent) *routinely* talk about sleep with their family members. For example, participant AC-10 reported that she talks about sleep four times a week with her mother: "...whether it's

my quality or her quality.”(AC-10)

Participant EP-8 explained that he talks about sleep with his adult children “...because we see each other quite a bit that we talk quite a bit. So here and there, we talk about sleep and how we’re sleeping and so they kind of let me know that they’re sleeping okay.” Consequently, participant EP-8 knows about his adult children’s sleep patterns: “So, I have a pretty good idea that in general, they sleep pretty well.” (EP-8)

Similarly to family conversations about sleep, some participants (four out of 14 adult children and two out of 11 elderly parents) described routine conversations about medication with family members. Participant AC-14, for instance, said his family often discusses about medication by asking questions back and forth: “I’ll call and ask if he [father] took his medicine. And he is in the healthcare field so if I have questions about mine, I ask him about it.” (AC-14) In this case, there does seem to be perceived value in discussing the topic. On the one hand, participant AC-14 knows that his father is keeping up with medication, which might be a crucial component of managing an illness or aging, and, on the other hand, participant AC-14 can get answers to important questions about *his own* medication.

In participant AC-13’s case, she monitors her parents’ daily medication because she is their primary caregiver: “I talk about it with my dad because I’m more so his caregiver than – I’m still my mom’s caregiver, but my dad is more sick than my mom. I monitor his medication like daily.” (AC-13) Due to a known illness and the importance of taking medication to manage it, the topic is ipso facto valuable to participant AC-13.

According to participant EP-8, in his family, conversations about medication happens regularly: “We will talk about that because the subject comes up. We talk about it all the time.” (EP-8). It comes up because participant EP-8’s son suffers from chronic migraines: “...like my one son takes certain medications because he gets migraine headaches. So, we’ll just talk about it and he’ll say, ‘Boy, you know I had a migraine.’ And I’ll ask him, ‘Well, what did you take?’ And he’ll say, ‘I have this certain medication that’s been prescribed for me,’ or whatever.” (EP-8) Participant EP-8 also shares his medication practices with his children: “And then, on the other hand and with my case, I take supplements, but they’re more like vitamins and things like that. I’ll mention things about that to my sons.”(EP-8)

Based on our data, we assume that in most of these cases, there is greater perceived value and interest in sleep and medication as topics of discussion. In some cases, this seems due to chronic conditions (e.g., migraines) or illness and the use of medication to manage those conditions. So, we were intrigued to notice that conversations about sleep and medication were atypical and unique cases since most of our participants did *not* talk about these topics (i.e., sleep and medication) with family members. We then raised the question as to why this is the case. What dissuades people from raising these topics in regular conversations? From our analysis, we identify three factors that dissuade people from discussing sleep and medication, including: lack of time, lack of interest, and lack of value. We elaborate on these factors more in depth below.

4.1.2. Families that do not talk about sleep or medication

According to our data, 10 out of our 14 adult children participants and 10 out of 11 elderly parents reported *not* discussing sleep and medication with family members.

In certain families, conversations about sleep and/or medication are atypical. Participants mentioned talking with family members about diverse topics but not health-related topics. For example, participant EP-4 reported talking with her adult children on a regular basis. But sleep is not among their topics of conversation: *“I do talk to them a lot about their children, [or] anything but not sleep.” (EP-4)*. Other topics, such as children, may take priority over sleep. And even when conversations are frequent, there is a finite amount of time to spend on them. It is simply not possible to talk about every conceivable topic. Lack of time was one of three main reasons given for *not* raising health-related topics.

Our participants mentioned that they usually engage in family conversations with their elderly parents/adult children for a short period of time. During these limited conversations, other topics are a higher priority, such as: updates on grandchildren or other events. For example, participant AC-7 said that conversations about sleep or medication do not emerge in the restricted time he speaks with his parents: *“I speak with them maybe roughly 10 minutes a day ...there are so many other things to talk about that this [sleep] never comes up.” (AC-7)*

In addition to lack of time, participants affirmed that lack of *interest* also influences people’s decision to discuss health. According to participant AC-6, he does not talk about health because his parents are not interested in discussing it: *“I don’t think they’re interested, [therefore] I don’t mention.”* (AC-6) At this point, we do not know whether participant AC-6 tried to discuss health at some point in the past and his parents did not engage with the topic or if they assume a lack of interest for some other reasons. We wonder if it might be the case, for instance, that participant AC-6 is not interested in discussing these topics.

In participant EP-7’s case, he affirmed that his family talks about other health-related topics such as food and nutrition but not sleep: *“We have thought about food because they’re [adult children] interested in nutrition and the rest of the stuff, we’d talk about, but sleep is one thing that I don’t think we’ve talked about.”* (EP-7) Despite that, participant EP-7 considers that sleep conversations might be interesting; however, the topic has never come up during family conversations. He explained: *“We don’t have issues between my wife and I about sleep and my guess is that all the kids when growing up all slept well and as I grew older and as I grew away, I guess, we just assumed they continued to do the same thing.”* (EP-7)

We do find it intriguing that, when discussing whether a topic is interesting, the word “interesting” seems to connote *problems*. For example, sleep is only interesting when someone is having trouble sleeping. Participant AC-3 cited the appearance of good sleep behaviors as a reason for conversation avoidance: *“...they [elderly parents] seem to sleep fine and I don’t think they have a bad time and I am thinking like they function okay.”* (AC-3) Similarly, participant AC-12 said: *“I don’t usually talk about my own sleeping behavior because I don’t have any problem with it.”* (AC-12) Likewise, participant EP-10 said: *“We are having normal sleep, there is no problem. So, they [adult children] don’t discuss.”* (EP-10)

We also found similar responses with regard to medication intake since this topic would be avoided unless one is experiencing negative side effects from medication. Participant EP-2 presented her point of view for not talking about medication in her family: *“We don’t [talk about medication intake]. It’s probably because there aren’t a lot of health issues. And also that it’s not something that comes up the way food comes*

up in the conversation.”(EP-2)

Finally, participants suggested that there is no *value* in talking about sleep or medication. Participant AC-5, for instance, suggested that there is no point in talking about sleep *unless* something is wrong. Speaking about their mother, they said, “*I mean I think it’s just like as long as she’s [mother] sleeping.*” (AC-5) We infer from this comment that “*as long as she is sleeping*” then there is no reason to talk about sleep. Whether their perspective might change if their mother had trouble sleeping is an open-ended question. However, our other interview data suggests that this might be the case. As participant EP-2 stated: “*...[sleep] it’s not an issue. If I was having a problem sleeping, they [adult children] would probably know about it. But I don’t have a problem. My husband doesn’t have a problem. So it’s not something that comes up because it’s not an issue.*”(EP-2)

Participants mentioned similar responses when reflecting on conversations about medication intake. For example, participant EP-9 said about her children’s medication: “*I mean I don’t know what concern it would be. They [adult children] got too much on their plate for them to be worried about my medications and me, worried about what they take. It’s just something we don’t discuss.*”(EP-9) At this point, we note that it might be the case that participant EP-9 sees medication as a private, personal topic that she does not wish to share with her children. This situation, however, might be the case for participant EP-4, who said: “*They [adult children] don’t need to know [medication intake] that doesn’t affect them at all.*”(EP-4) In our analysis, it seems that medication in this case is framed as a personal issues whose consequences are limited to the person taking the medication. Participant AC-10 seems to echo this sentiment: “*I mean, it’s more [medication intake] supplemental too. There is nothing necessary for her [mother] health. No big concerns.*”(AC-10)

4.1.3. Summary

Overall, our participants asserted that if “*[in terms of health] nothing has changed recently, so..*”(AC-10) they do not perceive any reason to change the overall narrative of their conversations with family members. Even those participants who did not talk about sleep or medication implied (or stated directly) that a change in circumstances

might lead to more discussion about these topics within the family. This situation is interesting because it raises the question as to what kind of changes these could be.

4.2. Inciting incidents: Events that Shift the Narrative

In this section, we characterize two different kinds of changes: major and minor health changes. Major health changes include things like having a medical emergency and/or hospitalization. Minor health changes could be changes in prescription medication or a disruption in regular sleep patterns. We characterize these changes as inciting incidents since, as our results show, they have a tendency to disrupt the status quo and initiate new health information sharing behaviors.

Our interviewees elaborated *changes* like these when they explained why they *initiated* conversations about sleep and medication with others in their family: “... *a change in prescription or like going to a doctor to get something checked up on.*” (AC-12)

4.2.1. Major Health Changes

When family members experience medical crises, our participants anticipate a change in health information sharing practice. According to participant AC-3: “*if they [parents] had been in the hospital then we would be aware of what was going on. I mean we were definitely going to ask them what the diagnosis was and what the doctor said and how long do they need to be on the medicine and I will probably ask them if there’s a way that they can get off the medicine but if like diet and exercise would help with it versus being on medicine. I would follow up with them to see how they’re feeling.*” (AC-3) Similarly, participant AC-6 said: “... *if they’re unhealthy or if they had an emergency or something, went to the hospital then I would ask what happened to them, ‘What are you taking?’*” (AC-6)

In participant AC-2’s case, for example, he said that due to his father’s back pain they often talk about sleep: “*I tell him he needs to get more rest.*” (AC-2) Prior to experiencing back pain, participant AC-2’s father may not have had trouble sleeping, and so it was an atypical topic of conversation.

Interestingly, in at least one case, a participant described using his own major health changes as a way to discuss health and medication with his family members. Participant EP-1 explained that his diabetes prompts health discussions with family members: *“We’ve certainly talked about me being a diabetic.” (EP-1)* After an additional diagnosis of restless leg syndrome, participant EP-1 raises health topics with family members both as a way to inform them about his health *and* as a way to check in on their health: *“Well, it’s – people really don’t know much about restless leg syndrome even though it appears to be hereditary in my family, so I talked about it and asked if they were having troubles like that and they weren’t, and I just told them how uncomfortable it was and what medications I was taking to accommodate that.” (EP-1)*

The severity of the health event surfaces sleep and medication as a topic of conversation whereas it might otherwise be overlooked. However, hospitalization and/or medical crises are not the only events that shift the health information narrative towards sharing.

4.2.2. Minor Health Changes

Some changes might be minor yet significant enough for family members to take notice and share. Something as simple as a change in medication would incite participant EP-7 to share with his daughter: *“for an example, any changes like that in my history, my life history, if we change or we have any kind of medication changes, she [daughter] knows what we’re doing.” (EP-7)*

Participant AC-5 described a scenario where sleep irregularity might be enough of a change to motivate sharing about sleep: *“it’s probably just if something odd was to happen or if certainly not sleeping then that would be an issue.” (AC-5)*

In fact, it was common among our participants to mention sharing sleep information after experiencing changes in sleep patterns. As result, family members provided advice or guidance as a way to help improve their sleep quality. For instance, participant AC-13 explained how she discussed sleep with her father in order to help him sleep better: *“My dad, he’s been struggling with sleep. His sleep has been pretty much poor. I do discuss with my dad how he has slept because we’re trying to get him to*

sleep better, so I discuss that with him.” (AC-13)

Participant AC-9 explained that, after hearing her stepmother complain about sleep, her family engages in occasional conversations about sleep. She decided to give advice to her stepmother as a way to show care: *“When I was down there for a week, my stepmother complains about having cramps at night that would wake her up. I suggested that maybe she’d try Powerade, drinking Powerade because that works for me.” (AC-9)*

Finally, several interviewees affirmed that any changes in their current health would motivate sharing. For instance, participant AC-13 said that because she has been sick recently, she is sharing information about medication with her parents: *“I’ve been taking antibiotics, I’ve been telling both my parents just to make sure whenever you’re sick that you take a lot of vitamins just so you can get better faster.” (AC-13)* Similarly, participant EP-3 said that she would engage in health conversations if she begins to experience health problems: *“I don’t think there’s anything to talk about. Yeah, only if – yeah, that would be the only thing. If I did have a problem, then I would discuss it with them [adult children].” (EP-3)* Finally, participant EP-6 said that health changes would motivate conversations with his children: *“...only if there was some kind of change that I would need that something recurred in my health that we require something differently, then I would tell them [adult children] and talk to them about it.” (EP-6)*

5. Discussion

Our findings reveal reasons that motivate and discourage family members from engaging in conversations about sleep and medication intake. Interviewees explained that these kinds of conversations are generally atypical because they are not “interesting” or “valuable” topics for conversation unless *changes* arise.

We know it may seem obvious that if health events/changes occur, which were operationalized in our study as minor and major health changes, it is likely that people will talk about these events to each other. Indeed, health events are well-known and studied in previous literature (Barbarin et al., 2015; Pang et al., 2013). However, our

findings inform that when people experience changes in their health, such moments and events can be leveraged in the design of health technology to better facilitate sharing of the information among family members. Our study considers that just because people talk about health events/changes, or even may change their behavior because of health events/changes, it does not mean that health events/changes are regularly leveraged in design. This distinction is key to ground our study novel contribution which is: as far as we know, nobody has used these natural health events/changes as a constructive and innovative means for design.

Our study shows that changes to sleep or medication intake can facilitate health information sharing. In other words, these changes function as “inciting incidents” that motivate adult children, or their elderly parents, to share health information in casual conversations with family members. Therefore, we argue that the concept of “inciting incidents” is more important for submerged health conversation topics which do not get raised regularly such as sleep behaviors and medication intake than common health-related topics, like nutrition and physical activity.

The concept of inciting incidents has roots in narrative theory (Herman, Phelan, Rabinowitz, Richardson, & Warhol, 2012). Hart describes inciting incidents as “*events that rip the protagonist out of the status quo and initiate a journey toward the new reality that waits at the end of the narrative*” (Hart, 2012, p. 30). “Inciting incidents” does not refer to a framework or set of procedures for collecting data, such as critical incident technique (Flanagan, 1954; Hughes, Williamson, & Lloyd, 2007). Rather, it is an interpretive lens that can be used for making sense of when and why health information sharing behaviors change. Inciting incidents, in the form of changes in sleep quality or medication intake, “*set [new stories] in motion*” (Hart, 2012, p. 29); stories that in some cases involve sustained, long-term sharing of health information.

Building upon our study results, we present design considerations that leverage the inciting incidents concept on family-centered health technologies as a way to contribute with the further development of health information technologies that consider different range of users and their needs and diverse perspectives (Asan & Carayon, 2017; Valdez & Brennan, 2017).

5.1. Design Implications

In this section, we elaborate on the inciting incidents concept inspired by the design lens presented on the family informatics framework and on the proposed design guidelines for systems that support families on sharing health information. We look at two stages of the family informatics framework presented by Pina et al., (2017) and two design guidelines for family-centered health technologies presented by Grimes et al., (2009) to: (a) discuss how our findings complement these current processes and (b) present design ideas that leverages the inciting incidents concept on building family-centered health technologies.

5.1.1. Inciting Incidents and Family Informatics

Pina et al., (2017) developed a model for family informatics that identifies stages and challenges in the process of family-centered health tracking. First stage is **deciding**, which is when a family decides to track. Pina et al. explains that families can be motivated by a sense of curiosity or a desire to improve the family’s well-being. Inciting incidents could be seen as another motivating factor. We know, for example, that disruptions to normal sleep cycles and changes in prescription medication can facilitate families to incorporate these otherwise uninteresting topics into regular conversations. We suggest that future design explorations could consider family conversations as an analogue way of tracking health information. This design insight is interesting because it raises the question of what it would take to translate conversations into a tracking system such as wearable or mobile application. One example of design solution consists of building upon existing family storytelling tools (Bentley et al., 2011; Procyk & Neustaedter, 2013; Vetere et al., 2009; Vutborg et al., 2010) and developing a new storytelling tool version that offers narrative features that encourage members to include submerged topics into their regular story line conversations.

Furthermore, we observed that the inciting incidents concept is a broad category of life events. Therefore, a potential design direction is to generate a full list of inciting incidents and then to conduct a version of artifact analysis to understand the qualities of different inciting incidents. Another design direction could consider that major and minor health changes seem qualitatively different as shown in our study. We

suggest future work should investigate what these differences imply for the long-term sustainability of health information sharing. For example, do minor health changes yield or facilitate changes that remain? Our analysis shows that inciting incidents motivate people to decide to share.

The **action** stage in Pina et al.'s (2017) model describes actions families take in working towards their collective health, e.g., changing an evening routine to support an adult with sleep apnea. Different contexts necessitate different kinds of action. This stage in the model inspired us to think about the unique challenges our interviewees face when it comes to taking action to support each other. We also considered whether inciting incidents were effective for motivating non-collocated families to act. Non-collocated families lack the benefit of face-to-face interaction and support. However, those in our study still took action and implemented practical support strategies following an inciting incident. For instance, they may devote parts of a weekly phone call to checking in and sharing advice about how to cope with a new health problem as in the case of a daughter who advised her mother to drink a sports beverage before going to bed to ease nightly leg cramps. In addition, inciting incidents motivated some elderly parents to anticipate and preempt their adult children suffering health problems later by encouraging them to change their habits now.

In summary, our findings contribute to an ongoing research interest around the need to effectively design for family's reflection towards action in healthy behaviors. For example, Saksono et al.,(2019) discuss findings on tracking physical activity practices among collocated families and suggest that future work should *"support individuals in thinking about ways to be active and such reflections should be tailored to the user's readiness to change their behavior."* We extend upon this prior work by showing how non-collocated family members shaped the way they take action to support one another on sleep and medication intake. Problem solving strategies and adopting a long view were examples of insights we observed in our analysis on non-collocated families which is in accordance to other studies on different contexts, such as the context of patient-clinician relationship (Ozok, Wu, & Gurses, 2017). Therefore, future work could investigate different families' relationships and dynamics, and their strategies to take action on supporting collective health. Still, it seems reasonable to say that

non-located elderly parents and their adult children contend with different external constraints when it comes to taking action. They may also face different internal ones. So, designers need to consider that families are complex (Neustaedter et al., 2013) and may face competing constraints. Appropriate consideration in a family informatics perspective therefore requires examining more in depth how and why inciting incidents motivated family members to take action.

5.1.2. Inciting Incidents and Systems for Family Sharing of Health Information

Grimes et al.(2009) presented a set of design guidelines as a starting point to conceive health technologies that support families on sharing health information. In Grimes' et al., (2009) study, it was presented that families may decide to withhold health information to avoid negative consequences. Accordingly, our interviewees explained how sharing sleep and medication information with others would require a sacrifice of personal privacy. We were intrigued at how inciting incidents change this narrative. For example, following an inciting incident, several interviewees appeared not to frame personal privacy as a significant consideration. Sharing health information with family became the priority, which means that priorities can shift following an inciting incident. This does not mean inciting incidents will always outweigh perceived negative consequences. Some inciting incidents may carry more weight than others. Experiencing a medical emergency may shift priorities more effectively than a change in medication. On the other hand, a change in medication could be quite effective if it has the potential to bring new side effects, for example. The key insight here is that not all inciting incidents are created equal. Some will be more effective at initiating behavior change than others.

Given the variety of external factors that might encourage or discourage health information sharing, we suggest that it is important for HCI researchers and designers to understand which inciting incidents appear to be effective under certain conditions. We provide a design example that seeks understanding on the inciting incident effectiveness. For example, several systems exist to advance the knowledge on personal sleep information (Choe et al., 2015; Kay et al., 2012). Perhaps designers could develop a similar system that would intelligently detect an inciting incident on the

individual’s sleep patterns. Then, the system would prompt him/her to share that information within his/her family, and encourage him/her to shift priorities on sharing by giving him/her the option to get support from family. Such system would then facilitate future work to understand different types of inciting incidents and their level of effectiveness based on the user’s response and action on sharing health information with his/her family.

When inciting incidents *are* effective, they seem to make people see the world in new ways. Things that used to be important (e.g. privacy) become less important. Grimes’ et al. (2009) pointed out that the comparison of health information among family members can lead to discouragement or embarrassment. This finding is interesting because it raises the question as whether inciting incidents could cause family members to see comparing health information as an opportunity to support and encourage each other rather than as a competition. Our findings did not provide a final answer to this question, but they do suggest that, following inciting incidents, people tend to value activities and experiences differently. For example, sharing information about several nights of poor sleep might still be embarrassing, but the benefits of sharing could outweigh the cost of embarrassment. Our findings suggest that it might be beneficial for HCI researchers and designers to explore ways of reframing the act of sharing health information (e.g., poor sleep) as an opportunity to affirm the value of family members’ opinions and guidance as opposed to an admission that one “needs help”. Designers, thus, could develop mechanisms that promote the idea that sharing is an act of power and not a sign of weakness. For instance, different systems exist to support individuals on daily medication intake (Dalgaard et al., 2013b; Venkov & Ivanov, 2016). In practice, a system built around our design consideration would reframe the fact that one member needs help with managing his/her medication intake to value family members’ encouragement towards the one who has a health goal. We provide a design example for a family who is not yet sharing health information (e.g., medication intake) due to feelings of embarrassment thus requiring support to connect managing his/her medication intake and positive feelings.

Designers could develop systems that support families on sharing of health information that include features for members to set a health goal (e.g., “Take medication

timely for a week/month”) and by a simple push notification an individual would share his/her status (e.g., “I took all my medication on time today!” or “I was 5 min late to take my pill today”). The system then would allow other family members to reply with a support message (e.g., “Good Job!” or “No worries! You can try again tomorrow”) or guidance message (e.g., “Maybe you can set an alarm as a reminder”). At the end of the goal period, the system should show to the family a summary of logs to observe their interaction as a family and how it helped them to achieve their goal, even when a relapse happened. This summary should be aimed at highlighting positive and empowering interactions that arise. Then, individuals might feel more encouraged to share health information within their families than before, and it might reduce their perception of weakness.

6. Limitations and Future Work

This study used rich data provided by different intergenerational families’ dynamics and backgrounds. Although our sample size was sufficient for this study, we acknowledge that a larger and more diverse sample such as participants with lower socioeconomic status (SES) and with ethnic variation would be informative. In addition, we recruited adult children and elderly participants from different families which may have limited our data analysis on understanding the reasons and meanings behind some family health-conversations. Also, we use the term ‘elderly’ to describe the parents who ranged in age from 68-85 years old, which represents a broad range from healthy and active to less healthy and more frail population. This large range of population may limit our data on understanding the differences in the parent-child communication/relationship and cultural differences.

Furthermore, we understand that as any other methodology, there are trade offs on using interviews to collect data which relies on participants’ remembrance of events according to their perspectives on their families sharing practices which may not represent the other members’ viewpoints. In future work, we plan to recruit members of the same family as a way to know whether members from the same family would describe similar health information sharing patterns or not. Furthermore, talking to

multiple members of the same family might also help us triangulate health information sharing practices in ways individual family members might not. Finally, we plan to further investigate the concept of inciting incidents considering different nuances and context in families. We are interested in evaluating the concept as a generative tool for designers. We plan to talk with design practitioners and to conduct workshops to understand how practitioners might make use of the concept when designing tools to promote health information sharing in the family context. We believe that inciting incidents could be an effective, general concept for the design of family-centered health technologies and HCI designers.

7. Conclusion

In this paper, we report the results of an interview study aimed at understanding health information sharing on intergenerational families, by focusing on elderly parents and adult children. Our goal was to understand how intergenerational families talk with each other about health, especially sleep behaviors and medication intake. Given our interest in promoting more health-related conversations between family members, we were intrigued by the reasons that dissuade family members from discussing health topics, including lack of time, lack of interest, and lack of value. However, we observed a crucial motivating factor for discussing health topics: *change*. We examined that either major or minor changes would affect participants' current health information sharing, and we argued that these changes in circumstances incite family members to action. We refer to these changes as “inciting incidents”, and we argue that inciting incidents appear to set in motion conversations about health among family members. We claim that this concept could be a useful design resource to expand the lens of family informatics framework and family sharing systems. We contribute with design insights for HCI designers interested in promoting collaboration in health-related goals in a family context.

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Appendices

Appendix A. Elderly Participants Demographics

Table A1. Demographics Information from Elderly Parents Participants

	EP1	EP2	EP3	EP4	EP5	EP6	EP7	EP8	EP9	EP10	EP11
Gender	Male	Female	Female	Female	Female	Male	Male	Male	Female	Male	Male
Health Issues	Restless Leg Syndrome, Diabetes	Knee problems	Allergies Osteoporosis	High Cholesterol & Blood pressure	Knee problems	High Cholesterol	-	Sleep Apnea	Diabetes	High Cholesterol	High Cholesterol
Medication	Iron, Calcium, Vitamin B	Aspirin, Glucosamine	Anti-Histamines, Calcium	Simvastatin, Calcium, Vitamins B,D,C	Fish Oil, Calcium	Simvastatin, Fish Oil, Vitamins	Vitamins	Vitamins	Vitamins	Simvastatin	Simvastatin, Vitamin K
How often ?	Daily	Daily	Daily	Daily	Twice a day	Daily	Daily	Daily	Daily	Daily	Daily

Appendix B. Young Adults Participants Demographics

Table B1. Demographics Information from Adult Children Participants

	AC1	AC2	AC3	AC4	AC5	AC6	AC7	AC8	AC9	AC10	AC11	AC12	AC13	AC14
Gender	Female	Male	Female	Male	Male	Male	Male	Female	Female	Female	Female	Female	Female	Male
Health Issues	Urticaria, Allergies	-	-	-	-	Lactose Intolerance, Asthma, Nasal Polyps	-	Anemic	Female Osteopenia, Diabetes, Irritable Bowel Syndrome	-	Asthma	Insomnia	-	-
Medication	Anti-Histamines	-	Vitamins	Vitamins	-	Probiotics, Corticosteroid Inhaler	Vitamins	Iron, Vitamins	Insulin	Fish Oil	Albuterol	Sleep Supplement	Probiotics, Vitamin C	Vitamins
How Often ?	Twice a week	-	Daily	Daily	-	Daily	Daily	Daily	Twice a day	Daily	If needed	Daily	Daily	Daily

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