How Information Sharing about Care Recipients by Family Caregivers Impacts Family Communication

Naomi Yamashita[1], Hideaki Kuzuoka[2], Takashi Kudo[3], Keiji Hirata[4], Eiji Aramaki[5], Kazuki Hattori[2]

[1] NTT Communication Science Labs.
[2] University of Tsukuba.
[3] Osaka University Department of Psychiatry.
[4] Future University Hakodate.
[5] Nara Institute of Science and Technology.

ABSTRACT

Previous research has shown that tracking technologies have the potential to help family caregivers optimize their coping strategies and improve their relationships with care recipients. In this paper, we explore how sharing the tracked data (i.e., caregiving journals and patient's conditions) with other family caregivers affects home care and family communication. Although previous works suggested that family caregivers may benefit from reading the records of others, sharing patients' private information might fuel negative feelings of surveillance and violation of trust for care recipients. To address this research question, we added a sharing feature to the previously developed tracking tool and deployed it for six weeks in the homes of 15 family caregivers who were caring for a depressed family member. Our findings show how the sharing feature attracted the attention of care recipients and helped the family caregivers discuss sensitive issues with care recipients.

Author Keywords

Caregiving; informal caregiver; depression; family communication; healthcare technology; tracking technology

ACM Classification Keywords

J.3. Life and Medical Sciences, Health, Medical Information Systems

INTRODUCTION

Recent changes in the demographics is placing excessive demand on the healthcare systems, causing a shift from clinician-centered professional service to informal home-centered care [12]. Such changes are increasing societal awareness of the importance of informal home care.

Under such circumstances, the role of computer technologies to support informal care (including self-care) is becoming increasingly important [12]. For example, self-tracking technologies allow individuals to take a proactive role in caring for themselves [28,31]. Health-related online support groups provide a place for individuals to learn from others and receive emotional support [9,13]. While research shows promising results suggesting these technologies compensate for the scarcity of professional care, most design efforts have so far focused on supporting either the patient or the caregiver [5,15,46]. Although recent works have emphasized the need to consider caregiving in "relational terms" [2,18,41], little work has focused on designing technology that supports the relationship between caregivers and care recipients in the context of homecare.

Our goal is to design a tool that helps family caregivers improve their care and communication with their care recipients at home. We specifically focus on helping family caregivers cope better with a depressed family member. We are particularly interested in studying this population because depressed sufferers typically seclude themselves at home during depressive episodes [1,25], which makes informal care by family caregivers particularly critical [26,27]. Research associates patients who receive compassionate care from family caregivers with lower hospital readmission rates [42].

To reach our goal, we developed a tracking tool that allows family caregivers to record patient's conditions such as mood and behavior based on their observations as well as their own caregiving activities. The tracking tool helps family caregivers experiment and optimize their coping strategies with care recipients, especially when they manifest unexpected behaviors, including extreme negative, agitated, or lethargic attitudes. The tool was deployed for six weeks in the homes of 14 family caregivers who were caring for a depressed family member [51]. The findings showed that the tool helped the family caregivers better cope with depressed family members. Furthermore, although previous works have warned that family caregivers' use of tracking technologies to monitor patient's health may create patient-caregiver conflicts, this work's findings showed that family communication was actually

CHI 2018, April 21–26, 2018, Montreal, QC, Canada

ACM 978-1-4503-5620-6/18/04…$15.00
https://doi.org/10.1145/3173574.3173796

improved. This previous study differed from other previous works in that family caregivers in [51] recorded patient conditions to promote their *own* behavioral changes while family caregivers (mostly parents) in previous works monitored the health condition of the patient (child) to promote the *patient's* behavioral changes.

Building on this previous work, our current study investigates whether (how) family caregivers *sharing* tracked data with other family caregivers affect the caring and patient-caregiver relationships. A number of health-tracking apps allow the users to share data with others who are working on the same health goals [3,38,44]. Research argues that sharing experience facilitates learning, provides emotional support, and bolsters competition [7,28,31]. Individuals are also more willing to reveal personal or upsetting topics online, matching the needs of caregivers looking after a depressed family member [4,40]. Our family caregivers may also receive the same benefits by sharing their data with other family caregivers. However, note the data shared by family caregivers are not solely about themselves; they also include private information about the care recipients. Thus, sharing such data may fuel negative feelings in care recipients about surveillance or breeches of trust. Put it all together, it remains unclear how family caregivers' information sharing affects home care and patient-caregiver relationships.

To answer this research question, in the current study, we added a sharing feature to the previously developed tracking tool and deployed it in the homes of 15 family caregivers who participated in [51]. In both studies, family caregivers recorded their own caregiving activities and their care recipient's behaviors/moods for six weeks. By comparing their log data before and after introducing the sharing function, we analyzed how the sharing feature affected their tool usage. We also interviewed ten randomly selected family caregivers to ask about the changes they noticed after sharing their data, emphasizing the patient-caregiver relationships. Our findings show how information sharing by family caregivers drew the attention of care recipients and influenced family communication. The findings will contribute to the field of HCI by suggesting new ways for using health-tracking technologies and information sharing.

BACKGROUND

Caregiving for a Depressed Family Member

Research shows that depression causes a variety of behavioral changes in its sufferers. For example, the reactions of depressed sufferers tend to be negative, lethargic, and offensive [19,34]. Since sufferers typically withdraw from social activities and seclude themselves at home during depressive episodes [1,25], family caregivers who live with depression sufferers are generally exposed to these behaviors.

Family caregivers are often confused by such behavioral changes in depressed sufferers because they tend to deviate from the sufferer's original personality [25]. Due to the large variance in depressive symptoms, family caregivers often have trouble assessing their causes and do not know how to deal with them. Depression's recurrent nature also creates anxiety in family caregivers who worry about triggering relapses by their own words/behaviors [19,24]. As a result, many caregivers are confused about how to optimally cope with sufferers, not knowing whether they should criticize the sufferers or suppress their reactions to avoid exacerbating depressive symptoms when they experience the extreme behaviors of sufferers [51].

Helping family caregivers develop coping skills to deal with such sufferer attitudes/behaviors is not trivial. According to Keitner et al. [27], the course of depressive illnesses, recurrence rates, and the suicidal behaviors of depression sufferers are all affected by the family and its functioning, indicating the importance of the informal care provided by family caregivers. Thus, our work supports family caregivers and helps them optimize their coping skills to improve their interaction with care recipients at home.

Family Caregivers and Tracking Patient Health Conditions

Health-tracking technologies have the potential to help family caregivers develop and improve their coping skills with sufferers of depression. While most health-tracking tools focus on individuals managing their own health [28,31], they possess a number of features that fit the needs of family caregivers who are looking after a depressed family member. For example, tracking technologies help users identify the hidden patterns in their life/health that are often indiscernible and different among individuals [6,31,41]. Since depression has a large variance in symptoms and family situations, the flexibility of tracking technologies is welcomed for this population [10,33]. Furthermore, tracking tools allow users to try out new experiences as part of experimentation, leading to opportunistic engagement in desired behaviors [8,29]. This implies that tracking technologies may help family caregivers optimize their coping strategies by experimenting with various coping strategies.

Even though many reasons exist to assert why tracking technology might help family caregivers improve their coping skills, family caregivers who monitor the health condition of care recipients introduces new challenges concerning privacy issues. Some studies warned that patient-caregiver conflicts might increase when family caregivers monitor patient conditions [16,21,47]. In these studies, family caregivers are typically parents who monitor the health condition of their child. The parents' goals are to improve the health control of their child and train him/her in self-care. Toscos et al.'s work on children with type I diabetes showed how tracking technologies might exacerbate parent-child conflicts, especially with teenagers [47]. Although a parent might just be checking a child's blood glucose level, which is understandable and even desirable parent behavior for managing their child's health, the parent's perspective might clash with the child's perspective, which might place considerable value on the freedom to make his/her own health decisions. Other studies have shown that parents with access to their children's geographical location traces can cause family tension [32,36]. Other work, which explored the implications of collecting and sharing health information within family members, revealed conflicting values of family members to information sharing: parents value the openness of sharing information among family members while children express privacy concerns [20].

In contrast, some studies report that when family caregivers track patient conditions, family communication increased [22,51]. For example, Huber et al. studied the impact of in-home monitoring technologies on family relationships and described how they enhanced communication between independently-living older adults and their informal caregivers [22]. [51] showed that family caregivers who track patient condition (i.e., mood and behavior) and their own caregiving activities improved patient-caregiver relationships. During deployment, asking the care recipients about their health conditions became a daily routine for the caregivers when they record with a tracking tool. Interestingly, contrary to Toscos's findings [47], care recipients in [51] seemed pleased when family caregivers asked about their health conditions.

One factor, which may contribute to such contradictory results, is the difference in the goals of caregivers for using tracking technology. In the former case that led to tension between patients and caregivers, the family caregivers monitored the health condition (or location) of patients to promote *patient's* behavioral changes. In other words, parents' ideal healthy behavior of their children often deviated from their children's actual healthy behavior. Such mismatched values in them often caused caregiver-recipient tension [2]. On the other hand, for the latter case that led to increased and healthier family communication, family caregivers monitored the health condition of their patients for *their own* sake. For example, Huber et al. reported that a tracking tool reduced the anxiety of family caregivers by allowing them to confirm that their parents were doing fine [22]. In [51], family caregivers used the tracking tool to promote their *own* behavioral changes: to develop their own skills to better cope with depressed family members.

In the current study, we extend [51] by adding a sharing feature to the tracking tool and examine whether/how caregivers sharing the care recipients' personal information affects the relationship between caregivers and care recipients. Although [51] showed that tracking technology helped family caregivers improve their coping skills and family communication, they were only allowed to track data individually; they could not share data with other family caregivers.

Social Features of Tracking Tools

Online support groups allow people to receive information and social support to cope with a wide range of difficult situations [23,50]. For family caregivers who lack the time/energy to attend physical meetings or feel barriers related to face management, a dedicated online group may serve as a place to ask for guidance and encouragement [41].

A number of tracking tools leverage the social influence of online support groups by forming or linking to online communities [3,38,44]. For example, UP Health allows users to share information about their efforts to stop smoking and ask about the smoking habits of others [44]. Such social networking sites as PatientsLikeMe allow patients to self-track their health conditions as well as share their experiences with patients who are working toward the same health goals [3]. Furthermore, social media platforms and sites like the Quantified Self website provide places for self-trackers who use different tracking tools to share their personal data and learn from others [31].

Research shows that health-tracking apps that leverage social influence promote user engagement in desired behaviors to accomplish their health goals [7,17,28]. For example, Consolvo et al. examined the impact of social support on self-trackers by comparing two user groups [7]: mobile fitness journal groups with and without a sharing feature. The sharing feature allowed users to see the data of others and exchange messages with them. Results revealed that participants who used the social version were significantly more likely to reach their daily step goals than participants whose version did not support sharing. Social support from others was helpful and spurred competition that was also often seen as motivational.

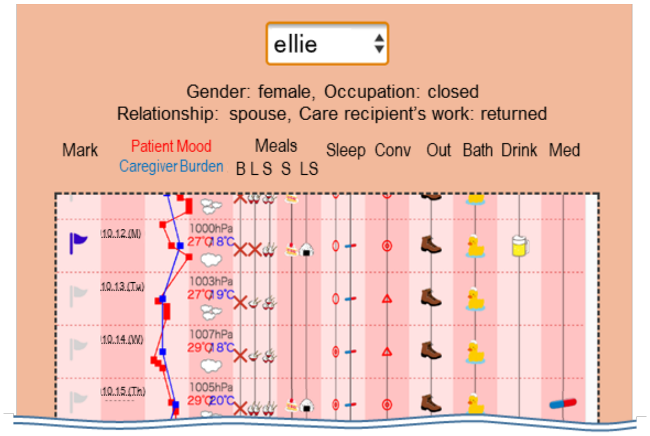
Our study expands Consolvo et al.'s work [7] by examining the impact of sharing information among *family caregivers*. Our study differs from Consolvo's study in several ways. First, the participants in our study (i.e., family caregivers) shared the information of care recipients with other participants. Note that the participants in our study were not allowed to exchange messages among themselves (see "Design" for details). Finally, our work focused on the impact of a sharing feature on caregiver-care recipient relationships.

TRACKING TOOL: FMCT-S

In the current study, we developed FMCT-S (Family Mood and Care Tracker – with Sharing), which is a shared version of FMCT, that allows family caregivers to not only track patient condition and caregiving data but share them with other family caregivers.

Design

FMCT-S consists of four sections: a user profile section, recording, reviewing, and timeline sections. The recording section allows the family caregivers to record data. The



Gender: female, Occupation: closed
Relationship: spouse, Care recipient's work: returned

Figure 1. Reviewing section of FMCT-S (translated into English)

reviewing section facilitates reflective analysis of the data by visualizing them in a single chart. The timeline section chronologically displays the caregiving journals of all the family caregivers.

FMCT-S extends FMCT in a few ways. First, it allows the family caregivers to see the data recorded by other caregivers. Family caregivers can view the reviewing charts of other family caregivers (Figure 1) or read the caregiving journals of others in a timeline (Figure 2). We also added user profiles so that family caregivers can better understand the data of other caregivers.

User Profile (Newly Added for FMCT-S)

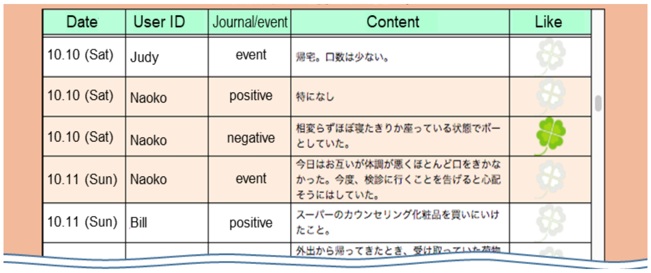
A user's profile consists of his/her user name and some optional information: gender, relationship with patient, and social role of self and patient. Family caregivers can decide whether to share this information with others.

Recording Section (Extended from FMCT)

The recording section allowed the family caregivers to record the patient's moods (on a scale of 1-10), medications, amount of sleep, amount of communication, outdoor activities, bathing/grooming, meals, snacks, alcohol consumption, their subjective burden of caregiving (on a scale of 1-10), creating their own caregiving activities (caregiving journals), and any other unexpected events.

To minimize the input burden, most recording items consisted of multiple-choice questions. For medication, the caregivers registered their care recipient's prescribed medicines and doses and made alterations if there was a change in the daily intake. The weather information (atmospheric pressure, high/low temperatures, and actual weather conditions) was automatically retrieved from the internet.

Note that the family caregivers rated the care recipients' mood based on their observations. Even though the ratings of the family caregivers might be different from the actual moods of the care recipients, a previous study with FMCT indicated that such subjective values remain useful for developing coping strategies [51]. The behaviors of care recipients were also recorded based on their observations. Family caregivers in [51] asked the care recipients about their day (e.g., whether they had lunch or went out for a walk) when observation was not possible, which seemed to please the care recipients.



Date	User ID	Journal/event	Content	Like
10.10 (Sat)	Judy	event	帰宅。口数は少ない。	☘
10.10 (Sat)	Naoko	positive	特になし	☘
10.10 (Sat)	Naoko	negative	相変らずほぼ寝たきりか座っている状態でボーとしていた。	🍀
10.11 (Sun)	Naoko	event	今日はお互いが体調が悪くほとんど口をきかなかった。今度、検診に行くことを告げると心配そうにはしていた。	☘
10.11 (Sun)	Bill	positive	スーパーのカウンセリング化粧品を買いにいけたこと。	☘
			外出から帰ってきたとき、受け取っていた荷物	

Figure 2. Timeline section of FMCT-S (translated into English)

Free-form text boxes were provided for recording their caregiving activities (caregiving journals) and entering details about patient's outdoor activities and unexpected events. For their own caregiving activities, three text boxes are provided to prompt input for positive and negative outcomes of their caregiving activities as well as what was learned.

Extension from FMCT: To promote the development of coping strategies, FMCT-S by default allowed the caregivers to access all the recorded data of other caregivers. However, since sharing personal information can also raise privacy issues [39], FMCT-S allowed the family caregivers to control which information to conceal by pressing the "private" button when they wanted to keep information private.

Reviewing Section (Extended from FMCT)

The reviewing section displayed a chart of the family caregiver's recorded data to facilitate reflection on his/her own caregiving activities. All the data recorded by the caregiver were displayed in a single chart so that he/she could explore it in a holistic manner (Figure 1) [30]. In the chart, patient mood (red line) and caregiver burden (blue line) were shown as graphs, and other patient data were shown as icons. Caregiving activities and unexpected events were shown as pop-ups by clicking on a date.

Extension from FMCT: In FMCT-S, a pulldown menu of other caregivers' nickname was added so that caregivers can see any other caregiver's chart (Figure 1).

Timeline Section (Newly Added for FMCT-S)

The timeline section displayed all the family caregivers' journals (i.e., positive, negative, and lessons learned) and unexpected events in a chronological order (Figure 2). This section was automatically shown to the caregivers when they logged into the system. When a caregiver likes or empathizes with someone else's post, he/she can check the post by clicking the empathy button. Note that the empathy button is not designed to provide feedback to the author; it helps the caregiver quickly identify the posts he/she liked

ID	Sex	Age	Relative	# chars Min-Max (avg.)	#acs _pat	#acs _jnl	Intv.	Work	T1	T2	T3	T4	T5	T6
1	F	20's	daughter	101-523 (265)	20	148	x	FT-out	9	4	5	0	0	0
2	F	40's	wife	54-293 (124)	43	107		FT-hm	--	--	--	--	--	--
3	F	30's	daughter	138-1193 (412)	2	129	x	FT-out	8	1	4	2	3	1
4	F	30's	sister	0-248 (90)	0	44	x	PT	1	7	2	0	1	0
5	F	30's	wife	9-192 (58)	0	53		FT-out	--	--	--	--	--	--
6	F	40's	wife	146-1298 (399)	20	383	x	FT-hm	3	3	0	1	0	2
7	F	30's	wife	305-1986 (817)	19	216	x	FT-out	6	9	8	4	6	6
8	F	40's	wife	0-210 (55)	18	85		FT-out	--	--	--	--	--	--
9	M	50's	husband	224-1183 (445)	75	245	x	FT-out	2	0	3	3	4	3
10	F	40's	wife	0-200 (89)	19	45	x	FT-hm	5	0	3	4	1	1
11	F	40's	wife	10-301 (142)	35	150	x	HM	2	2	2	1	2	3
12	F	20's	sister	0-60 (8)	7	31		HM	--	--	--	--	--	--
13	M	50's	father	15-64 (33)	7	47	x	FT-hm	4	0	2	2	0	0
14	F	40's	wife	17-161 (67)	6	71		FT-hm	--	--	--	--	--	--
15	F	50's	mother	19-239 (96)	4	66	x	FT-hm	1	3	1	2	1	1

Table 1 Participant demographics and prevalence of each theme (# chars: average number of characters entered, # acs pat: number of accesses to other participant's health records, # acs jnl: number of accesses to other patients' caregiving journal, Intv: Interviewed, FT-hm: full-time homemaker, FT-out: full-time jobs outside the home, PT: work part time, HM: work at home. T1-T6 indicates the themes emerged from the interview coding.

from a pile of them. In other words, caregivers can see their own checks, but they cannot see other caregiver's checks or those they have received. As the number of check for a particular caregiver increase, all the inputs from that caregiver are highlighted (i.e., background color of his/her input gets darker) on the reader's screen.

Note that FMCT-S did not allow the family caregivers to exchange messages with each other like many other social networking sites. This decision was made based on the feedback from family caregivers of the FMCT study [51]: When asked about exchanging messages with other family caregivers, many raised the concern about the potential burden for answering to other caregivers' comments. Some were also concerned about other caregivers giving advice to them without fully understanding their family situation. We were also concerned that stronger bonding among family caregivers may result in increased complaints about the care recipients which may deteriorate the caregiver-recipient relationships.

In sum, FMCT-S provides family caregivers the chance to learn from others by only seeing the information of other caregivers.

DEPLOYMENT STUDY

Fifteen family caregivers (12 females and 3 males, mean age = 43.0) who identified themselves as primary caregivers of a depressed family member were recruited through a consumer marketing company. Upon recruitment, we excluded family caregivers who were themselves diagnosed with a major depression. The participants were informed at their recruitment that this is a two-phase deployment study of a tracking tool and that their posts in the first phase (i.e. FMCT study) would be shared in the second phase (i.e. FMCT-S study). All of the family caregivers agreed to participate in both studies from the beginning of recruitment. The family caregivers filled out surveys about their socio-demographic data and the mental conditions of their care recipients and gave informed consent before the FMCT study began. We also required consent from care recipients for participation. Both studies were reviewed and approved by the ethical committee of the first author's organization (ethics review ID: H27-011).

Participants: Family Caregivers

Two months following the FMCT study [51], the family caregivers participated in a six-week follow-up study using FMCT-S. One family caregiver who dropped out from the initial study with FMCT returned and participated for the current study. The following are the relationships of the 15 caregivers, nine spouses, two parents, two daughters, and two siblings (Table 1). All of the caregivers lived with their care recipient and held primary responsibility for looking after them. Six caregivers provided one-to-one care and nine provided care with other family members living together. Seven caregivers were full-time homemakers (FT-hm), six had full-time jobs outside the home (FT-out), one worked part-time (PT), and one worked at home (HM).

Conditions of Care Recipients

The ages of the care recipients ranged from 24 to 59 (mean=43.1). Eight were male, and seven were female. On average, the care recipients had their initial onset of depression about eight years earlier (min.=1 year, max.=19 years). Nine had experienced relapses. All of the care recipients held jobs or went to college before getting depressed. They were all homebound when they were recruited for the FMCT study, but two (*IDs 10* and *13*) returned to work during the FMCT deployment study. All regularly saw a doctor and took antidepressants daily.

Procedure
During the two-month interval between the FMCT and FMCT-S deployment studies, we added the sharing feature to the tracking tool. Before the FMCT-S deployment, we mailed the details of the sharing feature to the participants' homes and we also notified them by telephone. We asked the participants to do the following three actions: (1) enter their profile before the FMCT-S deployment study, (2) remove or privatize their previous posts from the first phase (by pressing the "private" button) if any, and (3) reconfirm with their care recipients about sharing information with others and obtain consent from them again.

Once the study started, the family caregivers used FMCT-S for six weeks in their homes. The family caregivers were again asked to use it every single day, if possible. After six weeks of deployment, we randomly selected ten family caregivers (indicated by "x" in the "Intv." column of Table 1) and individually interviewed them each for 1-1.5 hrs.

Data Collection
We wanted to analyze the family caregiver reactions to the sharing feature as well as whether they changed how they recorded the information and whether sharing practice impacted their relationship with the care recipients.

Log Data: We gathered the data entries to FMCT-S during the six-week study to see if there were any changes in the participants' tracking activity. Each entry was stored with a user ID and a timestamp.

Semi-structured Interviews: Similar to a previous work [51] (i.e., the first phase), we drafted semi-structured interviews through collaboration with our research team's psychiatrist. The interviews explored the family caregiver's experiences with FMCT-S by focusing on the sharing feature's impact. The family caregivers were asked detailed questions about the impact of sharing their own data and seeing others' data on their daily lives: their feelings, caregiving activities, and communication with their care recipients.

The interview data were all audio-recorded, transcribed, and analyzed using inductive qualitative methods [45]. The first author arranged the quotes into an affinity diagram and inductively generated high-level themes in the data. The themes were then discussed to iteratively refine the codes. The findings below emerged from this collaborative analysis.

RESULTS
The sharing feature seemed to affect the caregivers and their communication with their care recipients in multiple ways. In this section, we report the overall effects of the sharing feature by comparing the tool usage patterns between phase 1 (FMCT) and phase 2 (FMCT-S) and present our findings in detail based on semi-structured interviews.

General Usage Patterns
Family caregivers continued using the same device as in the first phase to record their data: seven caregivers used smartphones, four used personal computers, six used a family-shared computer, and one used a family-shared tablet (including multiple uses of devices). The family caregivers who provided care with other family members talked about FMCT-S to them. While some family caregivers seemed to share their findings with other members, few showed the screen or collaboratively recorded the data.

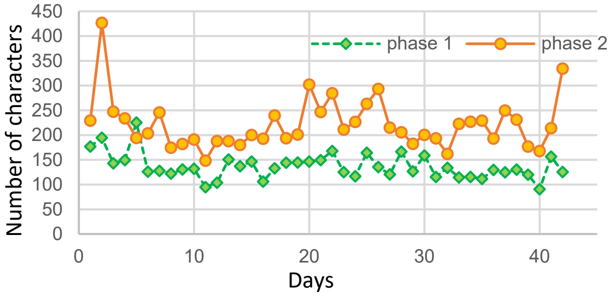


Figure 3. Average number of Japanese characters entered per person.

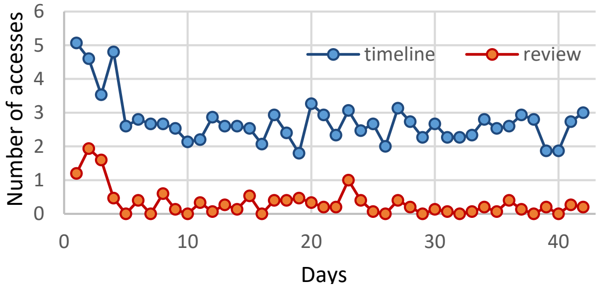


Figure 4. Average number of accesses to other caregivers' records per person.

Amount of Text Input
To measure the caregivers' active engagement with the tool, we counted the number of characters entered in the free-form textboxes. The frequency of access was not used because some caregivers did not log out and it did not reflect their engagement. Figure 3 shows the average number of Japanese characters per person during phase 1 (without the sharing feature) and phase 2 (with it). The min/max and average number of characters entered by each participant during phase 2 is shown in Table 1 (#chars). Overall, the family caregivers tended to enter more data in the second phase than in the first; on average, 221 characters were entered per day per person in the second phase, which exceeds the average of 137 characters in the first phase. A paired t-test indicated that the average amount of caregiver input significantly increased in the second phase (t[41]=-11.74, p<.01). According to the family caregivers they added more contextual information to their descriptions so that others can easily follow the contents.

Frequency of Seeing Others' Records
Figure 4 shows the average number of accesses to other patients' health records ("reviewing section" of other participants) and caregiving journals ("timeline section")

per person over time. The total number of accesses to other care recipients' health records and caregiving journals are provided in Table 1 (#acs_pat, #acs_jnl). Overall, the family caregivers looked at other caregiving journals far more frequently than other patients' health records. The details of how they used the records of others will be provided below in the interview findings.

Interview Findings

Six themes emerged from the interview coding. The prevalence of each theme is reported in Table 1 (columns T1-T6).

T1. Learning from Others

All the participants we interviewed noted that they were inspired by reading the caregiving journals. Although the caregivers presumed that the coping strategies of others may not work for their case, they still found useful tips from the caregiving journals. For example, one participant said:

> *[ID 7, full-time job outside, wife of care recipient]* There are no correct answers to these things. The caregiving tips of other people may not work for my case, but it's important to know how others are dealing with this kind of stuff. I can gain new insights, apply their strategies, and try new things.

Participants not only learned from others' success stories ("positive outcomes" and "lessons learned") but also from their failures ("negative outcomes"). One participant described how she could see things more objectively and be creative in finding ways to resolve others' problems:

> *[ID 1, full-time job outside, daughter of care recipient]* ID3 wrote in her caregiving journal that she had argued with her mother over food. Her mother gave her some food that she liked but she didn't take it. It sounds silly, but I've actually had similar arguments with my mom, too. When I read about their arguments, I thought ID3 should depend on her mother more. At the same time, I realized that I should do the same with my mom.

Even though the family caregivers gained insights by reading other caregiving journals, they seemed to learn little from seeing the conditions of other patients. Many said that the patients' health records (graphs) were too detailed to gain insight or transferrable knowledge. Some also mentioned that they were reluctant to look at other patients' data because they felt it was too personal:

> *[ID 3, full-time job outside, daughter of care recipient]* I somehow felt uncomfortable looking at other patients' health records. I felt like I was stepping into their privacy, like peeking into their homes. I don't think I looked at other health records more than just a few times. (…) It was good to see many different patterns in how depression affects people. But other than that, there wasn't much to learn from other patient graphs.

T2: Gaining Emotional Support

Emotional support was another benefit gained by the family caregivers from using the shared feature. In line with previous works, for most of our family caregivers, seeing other caregivers experiencing a similar situation everyday served as a type of emotional support [7,46]. One participant explained how sharing a caregiving journal with others was different from other forms of sporadic support:

> *[ID 6, work at home, wife of care recipient]* I know people who are caring for a depressed family member. I can share my feelings with them, but we don't talk every day, just when there is big news. But with FMCT-S, I felt like we are living through the same time. (…) Just knowing that there are people going through the same difficulties made me feel better.

Another caregiver echoed that sentiment:

> *[ID 4, work part time, sister of care recipient]* I learned that others are also distressed. They are all worried and anxious about the people they are caring for. I didn't feel alone. We are sharing similar problems.

As with *IDs 6* and *4*, although FMCT-S's sharing feature did not allow the family caregivers to exchange messages, they still seemed to gain emotional support by reading other caregiving journals.

T3: Being Considerate of Others when Writing

Gradually, the family caregivers started to see others as peer learners who are facing similar challenges. Such sense of belonging changed their writing styles. For example, many caregivers said that they added more contextual information to their journals, which increased the number of characters in them (Figure 3):

> *[ID 7, full-time job outside, wife of care recipient]* I noticed that it's easier to follow others' posts when there was contextual information. To learn from others' posts, we need to know why and how something happened. (…) I decided to add contextual information to my posts too, so that others can follow them more easily.

In addition, the caregivers became more cautious about what they write in their caregiving journals. One participant, whose husband returned to work during the first phase, explained how she refrained from writing about joyous events in the presence of other caregivers:

> *[ID 10, work at home, wife of care recipient]* My husband got much better, and we finally took a family trip. We had so much fun and I wanted to write about it in my journal, but I chose not to. Many are still groping around in the dark, some can't even leave their houses. If they read my good news in my journal, they may feel offended or discouraged. They might retaliate against their own sick person. I didn't want them to feel that way.

Family caregivers not only avoided writing about extremely good events but they also refrained from expressing negative feelings about caregiving. According to the participants, they were reluctant to express their criticism about their caring situations for two reasons. First, the family caregivers did not want to lower the moods of others by expressing negative feelings. One participant said:

> *[ID 3, full-time job outside, daughter of care recipient]* We all want to learn from others' posts. (…) I tried not to complain in my caregiving journal because I didn't want to read the complaints of others. Complaints just make me feel bad, and they don't solve anything.

Second, the caregivers were concerned that the care recipients might read their posts and feel crushed or cause an argument. Since the caregivers sometimes used a shared device (with a shared login password) to access FMCT-S, the care recipients could access it even without the caregivers. One participant who sometimes showed others' records to her husband said:

> *[ID 11, work at home, wife of care recipient]* Although I normally enter the data when my husband is not around, I don't write complaints. (…) My husband might accidentally see them. I don't want to argue about them.

Overall, the sharing feature of FMCT-S appeared to make family caregivers accountable for their own writings, making their posts more considerate and thoughtful.

T4: Using Others' Data to Discuss Sensitive Matters with Care Recipients

While family caregivers normally read others' records by themselves, they sometimes shared others' information with the care recipients. However, when they did, they were careful about what information to share and how they shared with the recipients. According to the caregivers, most of them started by talking about others having similar problems. For example, one participant described how she used others' data to encourage her daughter when she was impacted by low atmospheric pressure:

> *[ID 15, work at home, mother of care recipient]* I told her that she isn't the only one affected by low atmospheric pressure. She didn't really look at the data that closely, but she did seem encouraged by knowing that she wasn't alone.

The caregivers chose whether to discuss further by observing the recipient's reaction. They showed others' data and discussed further only when the recipients showed interest. Some caregivers were successful in using others' data to discuss sensitive family issues with their care recipients. One participant described how others' data helped him discuss a problem with his wife:

> *[ID 9, full-time job outside, husband of care recipient]* I found a post describing how things could be messed up and go wrong once an argument gets out of hand. We have exactly the same problem, so we looked at it together and discussed how to solve it.

Another family caregiver used others' records to explain his coping strategy to his daughter:

> *[ID 13, full-time homemaker, father of care recipient]* I showed the records of others to my daughter and explained how the patients and caregivers can easily fall into a negative loop. I explained why I distanced myself from her during her bad periods–it's not that I'm abandoning her, I just need some space to avoid that negative loop.

As with *IDs 9* and *13*, many family caregivers who shared others' data with care recipients seemed to find others' information useful for initiating conversations when they wanted to talk about their own issues.

T5: Increased Involvement With Care Recipients

For the care recipients, seeing other caregivers' records seemed to affect them in multiple ways. According to the caregivers, some care recipients showed interest in how other caregivers cared for their depressed family members, and they tried to learn from them. For example, *ID 9* who had constant arguments with his wife said:

> *[ID 9, full-time job outside, husband of care recipient]* Previously, she always claimed that I should be more considerate of her feelings. But that's so difficult. I've always told her that I can't read her thoughts unless she expresses them. (…) After seeing that other caregivers are also struggling with similar problems, I think she came to understand that I'm not the only one who cannot assess the feelings of their care recipients. (…) She started to express her feelings more.

In addition, some care recipients seemed to feel accountable for their own behavior by realizing that their data are being shared with others [11]. For example, one participant whose husband returned to work during the first phase said:

> *[ID 10, work at home, wife of care recipient]* My husband once asked me what I was going to write about that day. I asked him what he wanted me to write. He suggested that I write about him going to the library. He explained how difficult it is for a depressed person to go out and read. (…) He seemed to want to encourage other caregivers by showing his own recovery.

Such feeling of accountability sometimes led the care recipients to make more effort to engage in positive behaviors than they might otherwise have made. For instance, another participant who was caring for her husband explained:

> *[ID 7, full-time job outside, wife of care recipient]* In the second phase, he did more work around the house. (…) He started to say things like "I'm going to hang up the laundry." I think he was pleased and felt encouraged by reading about other caregivers who were working hard for their care recipients. I think he wanted me to write about his activities and show others that he too was making a big effort.

The positive behaviors of care recipients were generally embraced by caregivers. However, it is important to note that they were sometimes perceived as slightly competitive by the care recipients. For example, *ID 9* who often read the records of others with his wife said:

> *[ID 9, full-time job outside, husband of care recipient]* One day we found a post from a caregiver who went to a Louvre exhibition with her family. My wife suggested that I should write about us going to a Magritte exhibition.

T6: Changes in Family Communication

As the involvement of care recipients increased, some care recipients seemed to access the app even without the caregivers. Indeed, some participants noticed that their care recipients read their caregiving journals while they were out of the house. Interestingly, such "spying" by the care recipients was perceived positively by the caregivers. For example, *ID 11* who never showed her own caregiving journal to her husband said:

[ID 11, work at home, wife of care recipient] I started to notice that he was actually reading the journal. (…) One day, I wrote that it was tough to listen to his complaints. The next day, he explained why he made them. Even though I didn't directly confront him, it was obvious that he had read my journal. (…) I can directly express my thoughts, but depression makes things complicated. For certain things, I'm not sure how I should express them to my husband. I don't want to cause a fight, so I suppress myself, which is probably not good for either of us. (…) It was very nice to have a way to indirectly express my feelings without causing trouble. I think it's also important for the care recipients to know what the caregivers are thinking.

As with *ID 11*, the sharing feature sometimes served as a new communication channel through which family caregivers could reveal their feelings to their care recipients. According to the caregivers, *indirectly* expressing their feelings in the presence of other caregivers helped them reveal their feelings without getting too emotional:

[ID 7, full-time job outside, wife of care recipient] When I revealed my thoughts in the caregiving journal, I often imagined my husband as my reader. (…) I explained my thoughts in detail and carefully chose my words so that everyone, including my husband, could understand them without getting hurt. (…) FMCT-S helped me convey feelings to my husband that I couldn't express directly. After a while, my husband also started to convey his true feelings to me. This definitely helped reduce family troubles.

The caregivers noted that *indirectly* conveying thoughts to the care recipients deepened family communication without causing problems in the family. Even though such use of FMCT-S was not very common among the participants (three out of ten), many caregivers still mentioned that communication with their care recipients improved:

[ID 6, work at home, wife of care recipient] Family trouble has decreased. Before, he seemed to think that he was the only one who was suffering. But after seeing other caregivers' records, I think he learned that it's not just him who was suffering. The caregivers are also struggling to support their care recipients. He seemed pleased and became more considerate to me.

According to the caregivers, the care recipients were pleased to read other caregivers' journals and appreciated the efforts of the caregivers, creating a positive communication cycle.

DISCUSSION

In summary, most participants in our interviews reported that the sharing feature was beneficial for improving their home care and family communication. In line with previous works, the caregivers learned from the caregiving experiences of others and gained emotional support by reading their caregiving journals. Unexpectedly, the sharing feature also seemed to positively affect the care recipients who gained emotional support by reading other caregivers' records and sometimes were even motivated to engage in positive behaviors. In addition, the sharing feature sometimes played the role of enhancing family communication or/and mediating communication within the family. For instance, some care recipients seemed to actively mention their conditions/behaviors to their caregivers so that their information could be shared with others. Some caregivers initiated conversation about sensitive family issues to the care recipients by alluding to the records of other caregivers. Finally, some caregivers indirectly revealed their thoughts and feelings to their care recipients by writing them down in their journals.

Positive Reactions from Care Recipients

Despite our initial concerns that the care recipients may negatively react to caregivers who shared their information with other participants, none of our participants reported getting such negative reactions. Record anonymity is of course a contributing factor. Another possible reason why FMCT-S's sharing feature might have worked so well is that the caregivers chose their words very carefully, especially when they wrote in their journals (*ID3, 11*). Similar to the findings in previous works [40,48], our study's participants did not want to read the complaints of other caregivers, and this concern compelled them to refrain from writing complaints themselves (*ID 3*). In addition, the caregivers were concerned about the potential impact of complaints on the care recipients when they accidently read them (*ID 11*). Such concerns made their caregiving journals more considerate and thoughtful. Consequently, such thoughtful posts turned out to be encouraging for the care recipients, who seemed pleased to realize that the caregivers are working hard for their depressed family members and hence showed more appreciation to them (*ID 6*). We suspect that the emotional support gained by the care recipients from the tool outweighed the negative feelings of surveillance.

However, such positive effects on the care recipients rely on the good intentions of family caregivers. If someone wrote a thoughtless journal entry or complained about a depressed family member, the care recipients who read that post would probably be affected. We infer that the caregivers were strongly self-controlled to avoid writing complaints or rude posts because their care recipients were aware of their tracking activities: the care recipients had already given their consent to participate in this study.

Involvement of Care Recipients

Our findings show how the sharing feature gradually increased the care recipients' involvement with the tool (*ID 9, 10, 7*). Since increased involvement of the care recipients improved the family support and communication, one might suggest designing a tracking tool that facilitates the participation of care recipients.

A straightforward way to increase care recipients' participation is to divide the role of recording (i.e., care recipients recording their conditions themselves) with the caregivers. Such an approach has been suggested and studied elsewhere [20]. Although previous works show promising results for this approach, we argue that it is less applicable for our case. First, the family caregivers in our study are trying to optimize their *own* coping strategies. Dividing the role of recording with the care recipients may spark conflicts. Indeed, many caregivers seem skeptical about the self-reports of the depressed family members because they become forgetful during depressive episodes [39,51]. Thus, we believe that it is best for the family caregivers to assume full responsibility for the recordings. In addition, note that many of the positive effects found in our study were actually caused by excluding the care recipients from the system. If the care recipients could directly record their conditions into the system, they may no longer actively tell their condition to the caregivers (*ID 10, 7*). The indirect communication channel through which family caregivers reveal their feelings to the care recipients would also disappear (*ID 11, 7*).

Facilitating Social Support in the Family

Our findings suggest that the sharing feature improved/enhanced the social support from family caregivers. While previous works on health-tracking technologies have also tried to facilitate support for care recipients from family (and friends) [14,35,37,49], studies show that the attempts have generally failed. In those studies, care recipients are typically cast as the primary users of the tracking technologies. To facilitate support from family and friends, the care recipients are provided a feature that can invite a support person from their personal social networks to their interventions. Unfortunately, findings have shown that care recipients are generally reluctant to choose a support person [35,37]. They seemed to perceive it as problematic or at least unhelpful to share their health issues with a person who is not pursuing the same health goal, even if he/she is a close friend or a family member [14].

In contrast to previous works, family caregivers are the primary users of tracking technologies in our study. While care recipients in previous works did not feel the need to share their problems with family [14], the family caregivers in our study seemed to perceive it as beneficial to share their problems with the care recipients. This makes sense because family caregivers are struggling with issues associated with care recipients (while care recipients are normally struggling with their own health issues). Thus, caregivers were more likely to take the opportunity to discuss their problems with care recipients. We suspect that such discussion made the care recipients realize that they were sharing similar values with the caregivers [2], which eventually increased the active involvement of care recipients. Such involvement of care recipients led them to healthier family communication and enhanced the social support from family caregivers. Note that our tool does not offer caregivers a direct link to communicate with care recipients as in previous works. Since family caregivers were initially hesitant to discuss family issues with the care recipients due to the fear of starting conflict, we doubt that the family caregivers would have used it, even had we provided it. We argue that other caregivers' records served as *indirect ways* to facilitate family communication and solicit social support from family caregivers.

Negative Effects of Sharing

Although the family caregivers in our study generally reported that FMCT-S positively affected homecare and their relationships with the care recipients, the sharing feature did seem to import new concerns that would not have emerged otherwise. As reported in previous studies, the sharing feature introduced competition among the care recipients (*ID 9*) [7,28]. The caregivers also refrained themselves from writing joyous events because they feared offending other caregivers and causing envy (*ID 10*). However, some caregivers who did not know the situation complained that those people were not committed enough in their caregiving role and not paying much attention to the care recipients. Another issue we found was that one of the caregivers who had experienced depression himself described that it was sometimes difficult to read others' journals because it reminded him of his hard time in the past. Future work should address these concerns.

LIMITATIONS

One limitation of our study is that most of the family caregivers were women. Since men and women experience different types of caregiver burden [43], the generalizability of our findings may be limited. Family caregivers' relationship with the care recipients might also had an impact on family communication. For example, siblings and parents of the care recipients rarely showed the app to the care recipients when talking about others because they did not want to be preachy and annoy the recipients. Future work should investigate the impact of these variables on family communication.

CONCLUSION

This paper showed how information sharing among family caregivers affected homecare and family communication. We developed a tracking tool that allows family caregivers to record their caregiving activities and care recipient's conditions and share them with other family caregivers. A deployment study of our tool revealed that the sharing feature not only helped the caregivers improve their coping strategies but also positively affected the care recipients. Our most significant finding is that the tool provided the caregivers and the care recipients with *indirect ways* to discuss sensitive home issues. Our findings describe how the sharing feature helped them avoid direct communication/conflict while still allowing them to indirectly discuss problems. The sharing feature also provided care recipients indirect ways to learn and gain emotional support from other caregivers, which sometimes motivated them to engage in positive behaviors. We believe these findings will contribute to the field of HCI by suggesting new ways for designing health-tracking technologies and information sharing.

ACKNOWLEDGEMENTS

This work is supported by Grant for Scientific Research (A) 17H00771 from Japan Society for the Promotion of Science (JSPS).

REFERENCES

1. Nili R Benazon and James C Coyne. 2000. Living with a depressed spouse. *Journal of Family Psychology* 14, 1: 71–79.
2. Andrew B. L. Berry, Catherine Lim, Andrea L. Hartzler, Tad Hirsch, Edward H. Wagner, Evette Ludman, and James D. Ralston. 2017. How Values Shape Collaboration Between Patients with Multiple Chronic Conditions and Spousal Caregivers. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '17)*, 5257–5270. https://doi.org/10.1145/3025453.3025923
3. Jed R Brubaker, Caitlin Lustig, and Gillian R Hayes. 2010. PatientsLikeMe: Empowerment and Representation in a Patient-Centered Social Network. In *CSCW '10 Workshop on research in healthcare: past, present, and future*. Retrieved September 19, 2017 from http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.460.6665&rep=rep1&type=pdf
4. Scott E Caplan and Jacob S Turner. 2007. Bringing theory to research on computer-mediated comforting communication. *Computers in Human Behavior* 23, 2: 985–998. https://doi.org/10.1016/j.chb.2005.08.003
5. Yunan Chen, Victor Ngo, and Park Sun Young. 2013. Caring for Caregivers: Designing for Integrality. In *Proceedings of the ACM 2013 Conference on Computer Supported Cooperative Work (CSCW'13)*, 91–102. https://doi.org/10.1145/2441776.2441789
6. 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 SIGCHI Conference on Human Factors in Computing Systems (CHI'14)*, 1143–1152. https://doi.org/10.1145/2556288.2557372
7. Sunny Consolvo, Katherine Everitt, Ian Smith, and James A. Landay. 2006. Design requirements for technologies that encourage physical activity. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '06)*, 457–466. https://doi.org/10.1145/1124772.1124840
8. Sunny Consolvo, Predrag Klasnja, David W. McDonald, Daniel Avrahami, Jon Froehlich, Louis LeGrand, Ryan Libby, Keith Mosher, and James a. Landay. 2008. Flowers or a robot army?: Encouraging awareness & activity with personal, mobile displays. In *Proceedings of the ACM Conference on Ubiquitous Computing (UbiComp'08)*, 54–63. https://doi.org/10.1145/1409635.1409644
9. Neil S. Coulson. 2005. Receiving Social Support Online: An Analysis of a Computer-Mediated Support Group for Individuals Living with Irritable Bowel Syndrome. *CyberPsychology & Behavior* 8, 6: 580–584. https://doi.org/10.1089/cpb.2005.8.580
10. David Coyle and Gavin Doherty. 2009. Clinical Evaluations and Collaborative Design: Developing New Technologies for Mental Healthcare Interventions. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI'09)*, 2051–2060. https://doi.org/10.1145/1518701.1519013
11. Andy Crabtree, Peter Tolmie, and Will Knight. 2017. Repacking "Privacy" for a Networked World. *Computer Supported Cooperative Work: CSCW: An International Journal* 26, 4–6: 453–488. https://doi.org/10.1007/s10606-017-9276-y
12. Karen Donelan, Craig A Hill, Catherine Hoffman, Kimberly Scoles, Penny Hollander Feldman, Carol Levine, and David Gould. 2002. Challenged to care: informal caregivers in a changing health system. *Health aff (Millwood)* 21, 4: 222–31. https://doi.org/10.1377/HLTHAFF.21.4.222
13. Susannah Fox and Joanna Brenner. 2012. Family Caregivers Online. *Pew Research Center Internet & Technology*. Retrieved September 19, 2017 from http://www.pewinternet.org/2012/07/12/family-caregivers-online/
14. Victoria Louise Franklin, Alexandra Greene, Annalu Waller, Stephen Alan Greene, and Claudia Pagliari. 2008. Patients' engagement with "Sweet Talk" - a text messaging support system for young people with diabetes. *Journal of medical Internet research* 10, 2. https://doi.org/10.2196/jmir.962
15. Carolina Fuentes, Valeria Herskovic, Jurgen Heysen, and Monica Tentori. 2013. Towards a technology for caregivers' emotional expression and self-reflection. In *Proceedings of International Conference on Ubiquitous Computing and Ambient Intelligence (UCAmI '13)*, 143–150. https://doi.org/10.1007/978-3-319-03176-7_19
16. D Gammon, E Arsand, O A Walseth, N Andersson, M Jenssen, and T Taylor. 2005. Parent-child interaction using a mobile and wireless system for blood glucose monitoring. *Journal of Medical Internet Research* 7, 5: e57. https://doi.org/10.2196/jmir.7.5.e57
17. Roland Gasser, Dominique Brodbeck, Markus Degen, Jürg Luthiger, Remo Wyss, and Serge Reichlin. 2006. Persuasiveness of a Mobile Lifestyle Coaching Application Using Social Facilitation. In *Proceedings of International Conference on Persuasive Technology*

(Persuasive'06), 27–38. https://doi.org/10.1007/11755494_5

18. Rachael Gooberman-Hill and Shah Ebrahim. 2006. Informal care at times of change in health and mobility: A qualitative study. *Age and Ageing* 35, 3: 261–266. https://doi.org/10.1093/ageing/afj065

19. Ian H. Gotlib. Interpersonal and Cognitive Aspects of Depression. *Current Directions in Psychological Science 1*, 149–154. https://doi.org/10.2307/20182162

20. Andrea Grimes, Desney Tan, and Dan Morris. 2009. Toward technologies that support family reflections on health. In *Proceedinfs of the ACM Conference on Supporting Group Work (GROUP'09)*, 311–320. https://doi.org/10.1145/1531674.1531721

21. Gillian R. Hayes and Gregory D. Abowd. 2006. Tensions in designing capture technologies for an evidence-based care community. In *Proceedings of the SIGCHI conference on Human Factors in computing systems (CHI '06)*, 937–946. https://doi.org/10.1145/1124772.1124911

22. Lesa Lorenzen Huber, Kalpana Shankar, Kelly Caine, Kay Connelly, L. Jean Camp, Beth Ann Walker, and Lisa Borrero. 2013. How In-Home Technologies Mediate Caregiving Relationships in Later Life. *International Journal of Human-Computer Interaction* 29, 7: 441–455. https://doi.org/10.1080/10447318.2012.715990

23. Jina Huh and Mark S Ackerman. 2012. Collaborative Help in Chronic Disease Management: Supporting Individualized Problems. In *Proceedings of the ACM Conference on Computer Supported Cooperative Work (CSCW'12)*, 853–862. https://doi.org/10.1145/2145204.2145331

24. M Jacob, E Frank, D J Kupfer, and L L Carpenter. 1987. Recurrent depression: an assessment of family burden and family attitudes. *The Journal of clinical psychiatry* 48, 10: 395–400. Retrieved September 18, 2017 from http://www.ncbi.nlm.nih.gov/pubmed/3667537

25. Thomas Joiner and James C. Coyne. 1999. *The interactional nature of depression: Advances in interpersonal approaches*. American Psychological Association. https://doi.org/10.1037/10311-000

26. Gabor I. Keitner, Chrisine E. Ryan, I. W. Miller, R. Kohn, D. S. Bishop, and N. B. Epstein. 1995. Role of the family in recovery and major depression. *American Journal of Psychiatry* 152, 7: 1002–1008. https://doi.org/https://dx.doi.org/10.1176/ajp.152.7.1002

27. Gabor I Keitner and Ivan W Miller. 1990. Family functioning and major depression: an overview. *American Journal of Psychiatry* 147, 9: 1128–1137. https://doi.org/10.1176/ajp.147.9.1128

28. Predrag Klasnja and Wanda Pratt. 2012. Healthcare in the pocket: Mapping the space of mobile-phone health interventions. *Journal of Biomedical Informatics* 45, 1: 184–198. https://doi.org/10.1016/j.jbi.2011.08.017

29. Juddy Kopp. 1988. Self-monitoring: A literature review of research and practice. *Social Work Research and Abstracts* 24, 4: 8–20. https://doi.org/10.1093/swra/24.4.8

30. Ian Li, Anind Dey, and Jodi Forlizzi. 2011. Understanding My Data, Myself: Supporting Self-Reflection with Ubicomp Technologies. In *Proceedings of the ACM Conference on Ubiquitous Computing (Ubicomp'11)*, 405–414. https://doi.org/10.1145/2030112.2030166

31. Deborah Lupton. 2016. *The quantified self : a sociology of self-tracking*. Polity.

32. Clara Mancini, Yvonne Rogers, Keerthi Thomas, Adam N. Joinson, Blaine A. Price, Arosha K. Bandara, Lukasz Jedrzejczyk, and Bashar Nuseibeh. 2011. In the best families: tracking and relationships. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '11)*, 2419–2428. https://doi.org/10.1145/1978942.1979296

33. Mark Matthews and Gavin Doherty. 2011. In the mood: Engaging teenagers in psychotherapy using mobile phones. In *Proceedings of the SIGCHI conference on Human Factors in computing systems (CHI'11)*, 2947–2956. https://doi.org/10.1145/1978942.1979379

34. Jeff Mitchell. 2008. Understanding Depression: A Complete Guide to Its Diagnosis and Treatment, 2nd ed. *Primary Care Companion to The Journal of Clinical Psychiatry* 10, 3: 257. Retrieved September 18, 2017 from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2446480/

35. Jami L Obermayer, William T Riley, Ofer Asif, and Jersino Jean-Mary. 2004. College smoking-cessation using cell phone text messaging. *Journal of American College Health* 53, 2: 71–8. https://doi.org/10.3200/JACH.53.2.71-78

36. Laura R. Pina, Sang-Wha Sien, Teresa Ward, Jason C. Yip, Sean A. Munson, James Fogarty, and Julie A. Kientz. 2017. From Personal Informatics to Family Informatics: Understanding Family Practices around Health Monitoring. In *Proceedings of the ACM Conference on Computer Supported Cooperative Work and Social Computing (CSCW '17)*, 2300–2315. https://doi.org/10.1145/2998181.2998362

37. William Riley, Jami Obermayer, and Jersino Jean-Mary. 2008. Internet and mobile phone text messaging intervention for college smokers. *Journal of American College Health* 57, 2: 245–248. https://doi.org/10.3200/JACH.57.2.245-248

38. John Rooksby, Mattias Rost, Alistair Morrison, Matthew Chalmers Chalmers, John Rooksby, Mattias Rost, Alistair Morrison, and Matthew Chalmers Chalmers. 2014. Personal tracking as lived informatics. In *Proceedings of SIGCHI Conference on Human Factors in Computing Systems (CHI '14)*, 1163–1172. https://doi.org/10.1145/2556288.2557039

39. Marco de Sá, Luís Carriço, and Pedro Antunes. 2007. Defining personalized therapies for handheld devices. In *Proceedings of the ACM Symposium on Applied Computing (SAC '07)*, 163–164. https://doi.org/10.1145/1244002.1244043

40. Deborah A. Salem, G. Anne Bogat, and Christina Reid. 1997. Mutual help goes on-line. *Journal of Community Psychology* 25, 2: 189–207. https://doi.org/10.1002/(SICI)1520-6629(199703)25:2<189::AID-JCOP7>3.0.CO;2-T

41. Marén Schorch, Lin Wan, David William Randall, and Volker Wulf. 2016. Designing for Those who are Overlooked - Insider Perspectives on Care Practices and Cooperative Work of Elderly Informal Caregivers. In *Proceedings of the ACM Conference on Computer-Supported Cooperative Work & Social Computing (CSCW '16)*, 785–797. https://doi.org/10.1145/2818048.2819999

42. Karen A. Schwarz and Cheryl S. Elman. 2003. Identification of factors predictive of hospital readmissions for patients with heart failure. *Heart Lung* 32, 2: 88–99. https://doi.org/10.1067/mhl.2003.15

43. Nidhi Sharma, Subho Chakrabarti, and Sandeep Grover. 2016. Gender differences in caregiving among family - caregivers of people with mental illnesses. *World journal of psychiatry* 6, 1: 7–17. https://doi.org/10.5498/wjp.v6.i1.7

44. Misook Sohn and Jeunwoo Lee. 2007. UP health: Ubiquitously persuasive health promotion with an instant messaging system. In *CHI '07 Extended Abstracts on Human Factors in Computing Systems (CHI EA '07)*, 2663–2668. https://doi.org/10.1145/1240866.1241059

45. Strauss AL and Corbin JM. 1998. *Basics of Qualitative Research : Techniques and Procedures for Developing Grounded Theory*. Sage publications. Retrieved September 18, 2017 from file:///C:/Users/dezel/Downloads/BASIC+OF+QUALITATIVE+RESEARCH-Strauss&Corbin+1998(1).pdf

46. Matthieu Tixier and Myriam Lewkowicz. 2016. "Counting on the Group": Reconciling Online and Offline Social Support among Older Informal Caregivers. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '16)*, 3545–3558. https://doi.org/10.1145/2858036.2858477

47. Tammy Toscos, Kay Connelly, and Yvonne Rogers. 2012. Best Intentions: Health Monitoring Technology and Children. In *Proceedings of the SIGCHI conference on Human Factors in Computing Systems (CHI '12)*, 1431–1440. https://doi.org/10.1145/2207676.2208603

48. Cornelia F. van Uden-Kraan, Constance H. C. Drossaert, Erik Taal, Bret R. Shaw, Erwin R. Seydel, and Mart A. F. J. van de Laar. 2008. Empowering Processes and Outcomes of Participation in Online Support Groups for Patients With Breast Cancer, Arthritis, or Fibromyalgia. *Qualitative Health Research* 18, 3: 405–417. https://doi.org/10.1177/1049732307313429

49. C Y Wang and M M Fenske. 1996. Self-care of adults with non-insulin-dependent diabetes mellitus: influence of family and friends. *Diabetes Educ* 22, 5: 465–70. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/8936125

50. Marsha White and Steve M Dorman. 2001. Receiving social support online: Implications for health education. *Health Education Research: Theory & Practice Pages* 16, 6: 693–707. https://doi.org/10.1093/HER/16.6.693

51. Naomi Yamashita, Hideaki Kuzuoka, Keiji Hirata, Takashi Kudo, Eiji Aramaki, and Kazuki Hattori. 2017. Changing Moods: How Manual Tracking by Family Caregivers Improves Caring and Family Communication. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '17)*, 158–169. https://doi.org/10.1145/3025453.3025843