

# Changing Moods: How Manual Tracking by Family Caregivers Improves Caring and Family Communication

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## ABSTRACT

Previous research on healthcare technologies has shown how health tracking promotes desired behavior changes and effective health management. However, little is known about how the family caregivers' use of tracking technologies impacts the patient-caregiver relationship in the home. In this paper, we explore how health-tracking technologies could be designed to support family caregivers cope better with a depressed family member. Based on an interview study, we designed a simple tracking tool called Family Mood and Care Tracker (FMCT) and deployed it for six weeks in the homes of 14 family caregivers who were caring for a depressed family member. FMCT is a tracking tool designed specifically for family caregivers to record their caregiving activities and patient's conditions. Our findings demonstrate how caregivers used it to better understand the illness and cope with depressed family members. We also show how our tool improves family communication, despite the initial concerns about patient-caregiver conflicts.

## 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

The onset of mental illness in a family causes a significant burden and stress on its members [3,6,29]. In most cases, mental illness—and its medication—causes unexpected behaviors in sufferers. For example, they might become demanding and disruptive or express extremely negative attitudes or rage [18,24,42]. When family caregivers face such circumstances, they often become puzzled and do not

know how to react. In addition to the difficulty of coping with such unexpected behaviors, social stigma is often attached to such illnesses, making it difficult for family caregivers to consult with others [10]. Under such circumstances, most family caregivers prefer to gather information about the illness themselves [29]. However, finding useful information is also complicated due to the huge individual differences among symptoms. Consequently, family caregivers generally have little choice but to rely on discoveries based on their own experiences [29].

Despite the significant impact of mental illness on families, much HCI/CSCW work on mental illness has focused on either the patient or clinician, aiming for better patient care. Little research has focused on supporting family caregivers.

Our goal is to design a tool that helps family caregivers develop strategies to improve their interaction with care recipients. In this paper, we focus on tracking technology and explore its potential to aid family caregivers. For example, by tracking the care recipient's moods and caregiving activities, family caregivers may be able to experiment new coping strategies and reflect on them by analyzing how their behavior affected the care recipient's moods/symptoms [34]. Such experimentation and optimization of coping strategies might lead to better caregiver-care recipient relationships. Family caregivers' private use of tracking technology also aligns with caregivers' current practices where they opt to develop coping strategies on their own [29].

However, previous research also warns that family caregivers' use of tracking technologies to monitor care recipients' health may create caregiver-care recipient conflicts caused by the care recipients' perception of being under surveillance [20,41]. Since individuals suffering from mental illness tend to have a high awareness of surveillance [28], we need to be cognizant of its risks and pay extra attention to how tracking technologies affect domestic relationships.

In this paper, which is an initial attempt to reach our goal, we explore the following research issues: (1) how a tracking technology might assist family caregivers' development of coping strategies, and (2) how it affects the relationships between family caregivers and care recipients. We investigate these research issues by focusing on caregivers who look after homebound depressed family members.

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To answer these research questions, we first conducted a preliminary interview study to determine the tracking items family caregivers wish to follow and the family caregivers' concerns about using tracking technologies at home. Based on this interview study, we developed a technology probe [22], which is a web-based tracking tool, and deployed it with 14 family caregivers of depressed family members. During the deployment study, the family caregivers recorded their caregiving activities and their care recipient's behaviors/moods for six weeks. The deployment study focused on investigating the impact of tracking technology on the family caregivers' development of coping strategies and the relationships between family caregivers and care recipients.

In the rest of our paper, we first frame this work by introducing previous works. We then present the findings of our preliminary interview study, which revealed the design requirements of our tracking tool. Next, we present our tracking tool and report its deployment study. Finally, we discuss design implications and future directions.

## **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 [18,28,42]. Such attitudes of sufferers often negatively affect others. Family caregivers are no exception. Family caregivers who are living with depression sufferers are generally exposed to these behaviors, since sufferers typically withdraw from social activities and seclude themselves at home during depressive episodes [3,24,42].

Such behavioral changes caused by depression tend to deviate from the sufferer's original personality [24,42]. In such cases, those behaviors seem to create a gap between the caregiver's expectations and the sufferer's actual behaviors [43]. The family caregivers have difficulty understanding such behaviors, especially whether they arose from the depressive symptoms, and do not know how to deal with them. For instance, when caregivers experience extreme sufferer attitudes or behaviors, many seem to get confused whether they should criticize the sufferer or suppress their reactions to avoid exacerbating the depressive symptoms.

Another notable characteristic of depression is its high recurrence rate [26,42]. The risk of future recurrences dramatically increases once a sufferer experiences one recurrence; another recurrence happens 70% of the time, and a second happens 90%. Such recurrent nature of depression may create anxiety in family caregivers who are concerned with triggering a recurrence by their own words/behaviors [23,31].

What also complicates family caregivers is the social stigma surrounding depression [3]. Many family caregivers miss their own companionships from before the depression [3,25] and also tend to avoid mental health clinics [23,43]. While

many family caregivers seek useful information from the web to learn how to interact with depression sufferers, such attempts are often unsuccessful due to the large variance in symptoms and family situations [43]. Consequently, most family caregivers struggle to develop coping strategies by themselves.

### **Technological Support for Mental Healthcare**

If technology could help family caregivers develop strategies for coping with care recipients, it might ameliorate the interaction between family caregivers and care recipients.

Yet few technologies have been designed to support family caregivers or to improve the relationships between family caregivers and care recipients. HCI research on healthcare has focused almost exclusively on designing technologies for better patient care [14,16]. For example, researchers studying depression (or mental healthcare) have focused on designing technologies that improve access and engagement with traditional treatments/services, such as electronic contact, online self-help manuals, and online interventions [4,5,10,11,15,36]. Even though some technologies are designed for caregiver use, their primary focus is on facilitating effective treatment of patients. For example, systems are being developed to enable caregivers to monitor patient activities from distant locations [17,39] and improve coordination with other caregivers for better patient care [8,40].

Less research has addressed the needs of caregivers or focused on improving the relationship between caregivers and care recipients [6,12,32]. Yamashita et al. studied the burden on family caregivers of depressed individuals and suggested building social/emotional support networks that exclude those who have close connections with the care recipient so that caregivers can share their feelings without worrying about the potential impact on care recipients [43]. While previous studies focused on providing emotional support to family caregivers, they did not support building better relationships with care recipients.

### **Health tracking Technologies**

Health tracking technologies are a growing trend in e-health studies [27,33,34]. As represented in the Quantified Self movement, advancements in web technologies, mobile technologies, and smart home technologies are encouraging researchers to develop a wide range of applications, including tools for managing chronic conditions or achieving better health [27,38].

These tools have mainly been developed for individuals to better understand their own illness and promote desired behavioral changes. Few examined the family caregivers' use of health tracking tools or focused on its impact on family communication [19,21,38,41]. Furthermore, the studies that focus on family communication report somewhat contradicting results: while some studies show that automatically detecting care recipients' health information and sharing it with family members create caregiver-care

recipient conflicts [20], others suggest that a properly designed tracking technology can keep family relationship healthy or even improve family communication [21,41]. For example, Toscos et al.'s work on children with type I diabetes argued how a poorly designed tracking technology could exacerbate parent-child conflict [41]. Huber et al. studied the impact of in-home monitoring technologies on family relationships, and showed that the technology enhanced communication between independently-living older adults and their informal caregivers [21]. Grimes et al. studied how tracking technologies can facilitate family health discussions [19]. Overall, these studies argue the importance of understanding the potential impact of health tracking technologies on family dynamics.

Our idea of exploiting caregiver tracking to improve family communication was hinted from these previous works. However, it has not been studied in the domain of mental healthcare. In our case, we must keep in mind that family caregivers who are looking after a depressed family member are having trouble communicating with their care recipients. Thus, careful design considerations must address how to include the care recipients in the system. Introducing a poorly designed tool into homes might severely damage family relationships.

#### **PRELIMINARY INTERVIEW STUDY**

To identify the ways in which tracking technologies could be designed to support family caregivers cope with care recipients who are experiencing depression, we interviewed 14 family caregivers looking after a depressed family member. From interviews, we identified the basic design requirements of our tracking tool.

#### **Data Collection**

We recruited through a consumer marketing company 14 family caregivers (12 females and 2 males, age: min = 24, max = 48, mean = 41.8) who had been caregiving for a depressed family member within the last two years. The care recipients had their initial onset about six years earlier (min=1 year, max=16 years). At the point of recruitment, four had experienced relapses, but all started working/going to school again within the last two years. Ten still regularly saw a doctor and took antidepressant pills daily. All of the caregivers were the spouses of the care recipients and held primary responsibility for looking after them. Four were full-time homemakers, four worked part time, five had full-time jobs outside the home, and one worked at home. The interviews with the family caregivers lasted approximately 1 to 1.5 hours each. For the interview manuscript, we drafted semi-structured interviews in collaboration with the psychiatrist on our research team. The interviews focused on the following themes:

- The current practices adopted for tracking records and their effects on family caregivers: e.g., if care recipients tracked their own health conditions, to what extent did the family caregivers find the records useful? Did family caregivers ever take notes about their care

recipients' health conditions or their caregiving activities?

- The items considered by family caregivers important or relevant to understand the illness and to help them develop strategies for better interaction with the care recipients.
- Finally, family caregivers' concerns about using tracking technologies at home.

All of the data were audio-recorded and transcribed for analysis. The transcripts were analyzed using an iterative approach. Participant comments were extracted from each interview and grouped into categories, which were discussed, reorganized, and integrated by the researchers until they reached agreement.

#### **Summary of Interview Findings**

*Current Practices.* Some family caregivers seemed to keep a caregiving journal, although none wrote in it on a regular basis. In their journal, they only wrote about calamitous events, such as big fights with the care recipient, and described their own feelings about those events to let off steam. Although they sometimes reviewed their journals, they felt that the practice was discouraging and futile because it was filled with negative and emotional descriptions.

According to the family caregivers, some care recipients also kept a diary about their health conditions as part of therapy or treatment suggested by their doctors. However, many family caregivers seemed to perceive such self-reports as unreliable because patients become forgetful during depressive episodes [13].

*Items to Record.* When family caregivers were asked what items they wanted to track, they listed a range of things that could be consequential to care recipient moods: weather, medication, amount of sleep, outdoor activities, meals, drinking, their own caregiving activities, and unexpected events such as phone calls from a friend or fighting. In fact, most of these items are asked when diagnosing depression using Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) [1]. The articulation of "unexpected events" is expected to increase their understanding of the illness [35].

*Concerns about Possible Conflicts.* Although many participants showed interest in developing strategies to cope better with their care recipients, they also expressed concerns about using tracking technologies at home. Consistent with previous literature [19,20,41], many worried that care recipients might feel paranoid that they were under surveillance if they were recorded. However, when asked whether they would use the system without the consent of their care recipients, most disagreed, expressing a desire to get permission for recording their data. On the other hand, when asked about the possibility of tracking and reflecting with their care recipients, all preferred *not* to do so for fear of fights/conflicts. For example, they worried about offending the care recipients or that the care recipients'

frequent negative reactions might inhibit them from generating constructive/positive reflection. Indeed, most of the family caregivers mentioned that they actually avoided discussing the illness at home. Note that the psychiatrist in our team also recommended not forcing the care recipients to reflect with a non-professional (i.e., family caregiver) because it could lead to fatal consequences.

*Technology Requirements.* The preliminary interview suggest that our system should:

- promote unbiased recording (i.e., not just bad events) to support positive self-reflection by the family caregivers.
- let family caregivers record and reflect on the logged data (including care recipients' health information) on their own after getting permission from the care recipients.
- include the following recording items: weather, medication, amount of sleep, outdoor activities, meals, drinking, their own caregiving activities, and unexpected events.

### TRACKING TOOL

Based on our interviews and suggestions from the psychiatrist on our research team, we developed a web-based tracking tool called the Family Mood and Care Tracker: FMCT.

#### Design

The design of our tracking tool was speculative. We designed our tool as a technology probe [22] and kept its design as simple as possible because we wanted to explore the family caregivers' attitudes toward the technology in a real-world setting before further complicating the system.

FMCT consists of two sections: recording and reviewing. The recording section allows the family caregivers to record data, and the reviewing section facilitates reflective analysis by family caregivers by visualizing the recorded data in a chart.

#### Recording Section

The recording section allows the family caregivers to record all of the items identified above in the preliminary interview study: patient mood, medication, amount of sleep, outdoor activities, meals, drinking, their own caregiving activities, and unexpected events.

Figure 1 shows a page of the recording section. To minimize the family caregivers' input burden, most recording items consist of multiple-choice questions. For example, for patient sleep, the caregivers select the amount from four choices: long, normal, short, and unknown. The weather information (atmospheric pressure, highest/lowest temperatures, and actual weather conditions) is automatically retrieved from a weather information site. For medication, the caregivers first register their care recipient's prescribed medicines and usual doses from a menu. After

**Figure. 1** User interface of recording section (translated into English)

that, they enter the data (i.e., adding or deleting medicines) only when there is a change in the daily medicine intake.

Based on previous research, the patient mood was recorded on a scale of 1–10 [2,14,16,37]. Note that the family caregivers rated the care recipients' moods based on their appearances. Even though the family caregivers' ratings might be different from the care recipients' actual mood, we assume that this subjective value remains useful for developing coping skills.

Free-form text boxes were provided for three items: outdoor activities, own caregiving activities, and unexpected events. For outdoor activities, the caregiver enters the details of where the care recipient went and for how long. For own caregiving activities, three free-form text boxes were prepared as prompt input for the positive and negative outcomes of their caregiving activities as well as lessons learned. We expected these three items to facilitate caregivers' unbiased reflections on their own daily caregiving activities and help them develop future coping strategies. Finally, a free-form text box was provided to facilitate reflection about unexpected events. Since such events happen sporadically, the data input for this field was optional.

#### Reviewing Section

The reviewing section displays a chart that facilitates caregiver reflections on caregiving activities and care recipient conditions (Figure 2). All data were displayed in a single chart so that caregivers can holistically explore them [30]. The chart shows the patient mood (red line) and the caregiver burden (blue line) as graphs, weather information, and other data as icons. Family caregivers can also see the unexpected events and the caregiving activities recorded on a particular day by clicking on a date, which makes a textbox pop up and show the record. Another textbox for the details of outdoor activities also pops up by clicking on the shoe icon. We expect such a chart to help family caregivers identify

health condition patterns and develop coping strategies. From Figure 2, for example, we see that the care recipient tends to stay indoors or skip breakfast/lunch when he is in a bad mood (as highlighted by green rectangles).

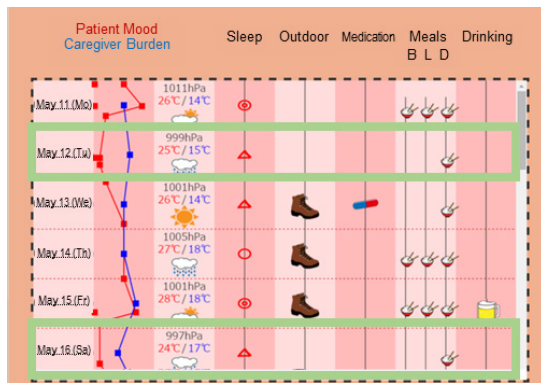


Figure 2. User interface of reviewing section (translated into English)

## DEPLOYMENT STUDY

We ran a six-week deployment study with FMCT to investigate how family caregivers' tracking behaviors impacted their caregiving activities and interaction with their care recipients. The study was reviewed and approved by the ethical committee of the first author's organization (ethics review ID: H27-011).

### Participants: Family Caregivers

We recruited 15 family caregivers (12 females and 3 males, mean age = 43.0) for the deployment study from the same consumer marketing company in our preliminary interview study. Upon recruitment, we excluded family caregivers who were themselves diagnosed with a major depression and recruited 15 family caregivers who were currently looking after a family member who was experiencing depression. Nine caregivers were spouses of care recipients, three were parents, two were daughters, and one was a sibling. All of the caregivers lived with the care recipient and held primary responsibility for looking after them. Six caregivers were full-time homemakers, six had full-time jobs outside the home, and two worked at home.

### Procedure

Before the study, we explained it to the family caregivers by telephone. The family caregivers filled out surveys and gave informed consent before the study began. The surveys included questions about the care recipient's socio-demographic data and mental conditions. Agreement from care recipients was also required for participation.

Once the study started, the family caregivers used FMCT for six weeks in their homes. The family caregivers were asked to use it every single day, if possible. One dropped out because another family member was hospitalized during the study. After six weeks of deployment, we individually interviewed the family caregivers in 1-hour sessions.

## Conditions of Care Recipients

The ages of the care recipients ranged from 24 to 59 (mean=43.1). Eight were male, and six were female. On average, the care recipients had their initial onset about eight years earlier (min.=1 year, max.=19 years). At the point of recruitment, nine had experienced relapses. All of the care recipients held jobs or went to college before getting depressed, but none had returned to society at the point of recruitment – they were all homebound. Two returned to work during the deployment study. All regularly saw a doctor and took antidepressant pills daily.

## Data Collection

*Log Data:* All data entry to FMCT was made by the family caregivers. We gathered all of the data entries during the six-week study. Each entry was stored with a user ID and a timestamp.

*Post-study Surveys:* In post-study surveys, the family caregivers rated whether they perceived themselves becoming more attentive to their care recipients' moods/behaviors or more careful with their own attitudes/behaviors toward their care recipients. They also rated the workload caused by FMCT and evaluated the usefulness of each recording item.

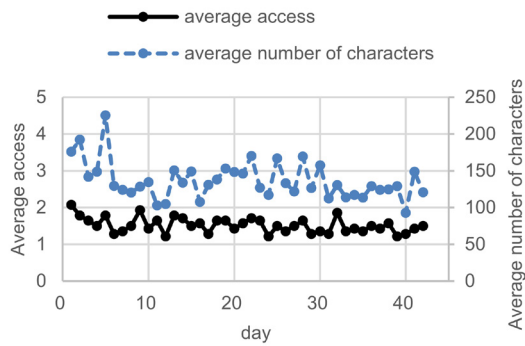
*Semi-structured Interviews:* Similar to the preliminary interview study, we drafted semi-structured interviews through collaboration with our research team's psychiatrist. The interviews explored the family caregiver's experiences with FMCT by focusing on the following central themes and questions: How did they incorporate FMCT as part of their daily routine? Did they find self-reflection useful in terms of developing their own coping strategies? If so, how? Did they notice anything different or new about their care recipient or their caregiving activities from using FMCT? Did using it change their own caregiving activities? If so, how? Did the relationships between the family caregiver and care recipient change after using FMCT? If so, how?

The interview data were all audio-recorded, transcribed, and analyzed using inductive qualitative methods [9]. The first author arranged the quotes into an affinity diagram and inductively generated high-level themes in the data. The themes were then discussed by the researchers to iteratively refine the codes. The findings below emerged from this collaborative analysis.

## RESULTS

Although the design of our tool was speculative, our tracking tool received a surprisingly high evaluation from the family caregivers. Indeed, most participants (twelve) noted in interviews that they became more actively engaged in the care, gained better control over the moods of their care recipients, and increased/improved communication with them. Below, we analyze how such changes were made through the data obtained by FMCT.

The results are presented in three parts. We start by reporting the family caregivers' general usage patterns of FMCT,



**Figure 3. Average number of accesses and Japanese characters entered per person**

followed by its usability issues; we then present the findings from our semi-structured interviews, which explored whether providing family caregivers with a simple tracking tool assisted the development of coping strategies with care recipients and how it impacted the relationships between family caregivers and care recipients.

### General Usage Patterns

During the deployment study, seven participants used smart phones, four used personal computers, six used a family-shared computer, and one used a tablet (including multiple use devices).

Figure 3 shows the average number of accesses and Japanese characters entered in the free-form textboxes per person over time. The system was stably accessed by the participants throughout the deployment period. They accessed FMCT an average of 1.52 times per day per person, ranging from 0 to 6 times per day. Overall, the system received stable input throughout the deployment period. Participants entered an average of 137 characters per day per person, ranging from 0 to 940 characters.

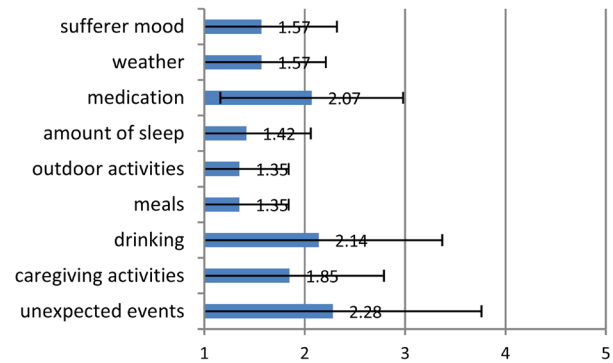
### Usability Issues of FMCT

#### Input Burden

Although we were concerned about the family caregivers' burden of manual tracking [7], their perceived workload was not as high as we expected. In post-study surveys, the participants rated their burden on a 5-point Likert scale: 1=very high, 5=no burden at all. Their scores ranged from 2=moderately high to 5=no burden at all, and their average score was  $M=3.5$  ( $SD=0.94$ ). Some participants who perceived a high workload explained that they felt anxious when they had nothing to write in the free-text forms. Others without a mobile device to access FMCT complained about the inconvenience of sharing a computer, since they sometimes had to wait for access.

#### Evaluation of Recording Items

In the post-study surveys, the participants evaluated the usefulness of each recording item on a 5-point Likert scale: 1=very useful, 5=not useful at all.



**Figure 4. Perceived usefulness of recording items (1=very useful, 5=not useful at all)**

The family caregivers in our study generally found FMCT's recording items useful (Figure. 4). However, some asked for adjustments in the recording items. For example, family caregivers whose care recipients did not drink wanted to omit this item. As for "unexpected events," some family caregivers complained about the inability to record the event's time. Since FMCT did not allow them to specify the time, the family caregivers tried to record them immediately after the event, which they found inconvenient. Finally, some caregivers suggested adding a few more patient behaviors to the recording items: snacks, taking a bath, and amount of communication.

### Interview Findings

Six themes emerged from the interview coding. The prevalence of each theme was: 18 times over 12 participants for "Becoming attentive to care recipient's behaviors", 35 over 12 for "Making better sense of care recipient's behavior", 22 over 12 for "Developing concrete action plans", 19 over 9 for "Changing views on care recipients", 13 over 7 for "Being generous to care recipients", and 34 over 13 for "Better communication with care recipients".

#### Becoming Attentive to Care Recipient's Behaviors

In general, the survey results showed that family caregivers perceived themselves as becoming more attentive to their care recipient's behaviors ( $M=1.93$ ,  $SD=0.65$  on a 5-point Likert scale: 1=became very attentive, 5=did not become attentive at all.) One participant described how using FMCT produced greater attentiveness toward her care recipient's moods and behaviors:

*[ID 7, full-time employee, daughter of care recipient]* Since I'm always busy in the morning, I didn't really care whether she was in a good or bad mood. But after I started to use this [FMCT], I paid more attention to her condition to find something to record. Like her mood while eating breakfast and her tone of voice.

Another participant, whose husband experienced a relapse two years ago, mentioned that she started to pay extra attention to his medication:

*[ID 1, homemaker, wife of care recipient]* I feel more involved with my husband's illness. I started to watch him more carefully, and I realized that he often forgot to take some of his medication.

Although the family caregivers' access to FMCT was limited (1.52 times per day), the family caregivers perceived themselves as getting more attentive to the moods and behaviors of their care recipients. In particular, the recording items seemed to remind them of aspects to which they should pay attention when they were with their care recipients. Such attentiveness often led them to new findings about their care recipient's behaviors.

#### *Making Better Sense of Care Recipient's Behavior*

By becoming more attentive to their patients' moods and behaviors, family caregivers seemed to notice subtle things that they had previously overlooked. These details provided cues for better understanding of mood changes and behavioral patterns. For example, one participant realized that her mother's mood was greatly affected by the weather:

*[ID 2, full-time employee, daughter of care recipient]* I wasn't even aware that the weather affected my mother's moods. During the study, I realized a couple of times, that when she was out of sorts, the weather was also bad.

As with *ID 2*, many family caregivers realized that there are underlying reasons for the mood changes of care recipients. Although our study gathered no concrete evidence that their individual discoveries were true, the family caregivers seemed to feel that they could make better sense of their care recipients' behaviors by recording and reviewing their moods and activities every day.

#### *Developing Concrete Action Plans*

Such discoveries of care recipient moods/behaviors affected the family caregivers in multiple ways. For example, the discoveries helped them develop concrete action plans to effectively support their care recipients. In other words, the family caregivers gained a clearer sense of what they should and should not do/say to them. *ID 1*, whose husband often forgot to take his medicine, described how she came to provide help:

*[ID 1, homemaker, wife of care recipient]* I talked to my husband when I noticed that he hadn't taken all of his medication. I thought he knew, but to my surprise, he didn't. Since he is a well-organized person, I had been assuming that he could manage by himself. But I realized that there were certain things that he couldn't manage. I decided to support him in these areas.

Other family caregivers reviewed the FMCT graph and searched for clues to cope better with their care recipients. For example, one family caregiver described how she successfully handled her mother's unexpected behavior by reviewing the FMCT record:

*[ID 7, full-time employee, daughter of care recipient]* My mother was in a good mood while eating supper, but she suddenly got very quiet and toned down. I wondered why and reviewed the [FMCT] record. While tracking back, I started to wonder what things made her happy. Then I found a case where my mom became happy when I praised her cooking. I instantly thought this might be the case. I realized that I had just eaten silently without praising her cooking. I went to her and said, "Your cooking was so delicious that I completely forgot to thank you." I was relieved to see her returning to normal.

As with *ID 7*, some caregivers reviewed the FMCT record during bad periods for their care recipients, developed a hypothesis and an action plan to improve the situation, and tested it. Again, we do not claim to know that *ID 7*'s hypothesis was correct; the care recipient may have had different reasons for her tone down. However, the important point is that FMCT appeared to provide family caregivers useful clues for developing new coping strategies. By experimenting those coping strategies, family caregivers started to see some connections between their own behavior and the care recipients' mood/behavior. Some family caregivers even noticed patterns between the two:

*[ID 4, full-time employee, husband of care recipient]* Previously, I couldn't understand why she was so moody. Although I had a feeling that I'd said something wrong, it quickly faded from my memory. By tracking and reviewing every day, I noticed certain patterns. Similar things happened over and over. Somewhere in my mind, I knew that praising her was good, but I came to realize just how important it was to praise her, as a real experience.

Such discoveries seemed to help the family caregivers realize that there are certain things that they as family caregivers can do to improve the current situation. According to the family caregivers, the "lessons learned" section was particularly useful for tracking the trial-and-error results of their hypotheses and finding better coping strategies. The holistic view of the care recipients' mental state and caregiving activities also seemed to help them analyze the connection between the two and to devise new coping strategies. Throughout the process, many family caregivers perceived themselves as more attentive to their own behaviors ( $M=2.28$ ,  $SD=0.78$  on a 5-point Likert scale: 1=became very attentive, 5=did not become attentive at all).

#### *Changing Views on Care Recipients*

The family caregivers' discoveries about care recipient moods/behaviors also seemed to affect their views of the care recipients. Many said that they had been making incorrect assumptions about their care recipients. For example, one family caregiver who had experienced depression himself described how he realized that advising his daughter based on his own experience could be inappropriate:

*[ID 10, working at home, father of care recipient]* I recently realized that my daughter's experience with depression might be different from mine. Hers is seasonal, but not mine. I knew that for a fact, but I didn't actually understand the difference. (...) I tended to give her advice based on my own experience. I guess I was being over-possessive at times. (...) While reviewing the graphs, I noticed a correlation between the weather and her moods, and I started to understand that her depression might be totally different from mine.

Some also mentioned that their views about the care recipients gradually changed as they entered the "positive outcomes" field of their daily caregiving activities:

*[ID 11, full-time employee, wife of care recipient]* I realized that he himself is making an effort. For example, one day when he went to the library, he borrowed a book for me because he thought I might like it. By keeping records, I realized how much he cares about me, the small things that I would normally pay no

attention to. (...) I used to think that it was always me, the caregiver, who provides support, but after using this tool, I felt that we could care for each other.

Overall, the FMCT recording items (particularly filling out the “positive outcomes” field) seemed to facilitate positive self-reflection of the family caregivers’ caregiving activities. It provided them a chance to reconsider their caregiving habits and how they had been communicating with their care recipients. As a result, many family caregivers became aware that their views on care recipients had been one-sided or/and judgmental, which helped them avoid negative assumptions about their care recipients.

#### ***Being Generous to Care Recipients***

According to the family caregivers, such changes in their views also changed their attitudes and made them more generous toward their care recipients:

*[ID 10, working at home, father of care recipient]* I don’t think this [FMCT] tool is really that critical, but it does have its uses. It changed the way I communicate with my daughter. I used to push her away and criticize her opinions. But I started to feel that I should be more generous: to listen to her until she was finished without criticizing her, even when I think she’s wrong.

*[ID 11, full-time employee, wife of care recipient]* I can now see that the disease is the troublemaker, not him. (...) I started to avoid saying negative things to him.

Consequently, FMCT seemed to give family caregivers breathing room to take a step back and communicate with their care recipients in a more relaxed manner.

#### ***Better Communication with Care Recipients***

Finally and most importantly, although we were concerned that the family caregivers’ use of FMCT might create patient-caregiver conflicts, none of the family caregivers reported such an effect. In fact, most reported the opposite:

*[ID 7, full-time employee, daughter of care recipient]* Previously, when my mom was feeling down, I would just avoid talking with her and go back to my room. By tracking her moods, I realized that there are certain reasons which make her feel unhappy. Then I felt perhaps I could help her eliminate those causes. (...) Since I recorded the topics that she liked to talk about, I could start a conversation on those topics and ask things like “What happened after that?” I think asking these questions shows that I remember what she said in the past and I care about her, which is important.

As with ID 7, some family caregivers seemed to find a way to communicate with the care recipients even when they were in bad mental states. Furthermore, some family caregivers mentioned that asking the care recipients about their health improved their communication:

*[ID 2, full-time employee, daughter of care recipient]* The amount of communication with my mom definitely increased. Previously, communication often started with a complaint, like “Why did you do this or that?,” and so our communication tended to be aggressive. (...) During this study, I had to ask her some questions to record her daily activities. After I returned from work, I asked her about her day, whether she had lunch, how she was feeling, etc. There was no reason to become aggressive about

these questions. I could ask them in a normal tone. My mom also looked pleased when I asked them. I think she felt cared for.

Some even reported that the care recipients became more proactive when talking about their health conditions.

*[ID 3, homemaker, wife of care recipient]* To record his condition, I often asked him some questions, like whether he slept well last night and so on. Gradually, he started to talk about his condition before I even asked him. (...) Previously, it was like, “I’m tired” or “I’m exhausted,” and nothing else. But he started to elaborate on his conditions and show that he is thinking about the future. (...) I felt like he was indirectly participating in the study. It’s good to have a common goal, collaborating to keep the record and fight the disease.

As with IDs 2 and 3, although family caregivers initially asked questions of the care recipients (e.g., whether they had lunch) to maintain the FMCT records, those questions seemed to please the care recipients and introduced thoughtful communication between care recipients and family caregivers. Overall, the recording items sometimes served as tickets to start safe conversations. Together with the family caregivers’ relaxed attitudes, such conversations seemed to lead them to a positive communication cycle.

## **DISCUSSION**

In summary, most participants reported that FMCT positively affected their daily lives, although two participants did not seem to notice any change; one became ill during the study, and another didn’t seem to care whether her husband recovered. All other participants seemed to feel that they became more actively engaged in the care, gained better control over their care recipients’ moods, and increased/improved communication with them.

### **Strategies for Better Coping with Care Recipients**

Our deployment study showed how tracking technologies could help family caregivers develop coping strategies. One possible scenario is that family caregivers first became more attentive to their care recipients’ moods/behaviors by manually filling out the FMCT forms every day [31]. Through observations, they started to catch subtle cues that triggered patient mood changes and behavioral patterns. These discoveries seemed to help the family caregivers make better sense of their care recipients’ illness or/and unexpected behaviors, which also helped them develop strategies for coping with their care recipients.

While this finding coincides with previous research where health-monitoring technologies facilitated user reflections and active engagement in care [32,41], it remains quite surprising if we consider that all the data (including sufferer’s condition) was manually captured by the family caregivers. That is, the care recipient’s actual health condition may be different from the family caregiver’s subjective observations. Consequently, the individual discoveries of the family caregivers based on such logging could be misleading or even incorrect. Despite such shortcomings, the family caregivers did seem to find FMCT helpful for tracking their trial-and-error processes of their



caregiving activities and clarifying a sense of what they should and should not do/say to their care recipients.

What seemed relevant and critical to the family caregivers was the recording activity itself. The family caregivers' direct engagement with data collection facilitated careful observation of the care recipients, which helped them realize aspects and details they would not have noticed otherwise. As suggested by previous works, such an effect would probably have been reduced or non-existent if the data were automatically retrieved by sensors [7,31].

With regards to the risk of family caregivers forming false beliefs about what causes mood changes of the sufferers, the psychiatrist in our team argue that the risk of caregivers' false beliefs to cause fatal consequences should be low because i) the false beliefs of the caregivers are unlikely to affect medical treatment of the care recipients, and ii) the tool directly affects family caregivers who wish to better cope with the care recipients.

In terms of recording the FMCT items, the selected recording items seemed to help the family caregivers efficiently clarify the source of their reflections. For some family caregivers, some of the items introduced new perspectives on what to watch for when observing the care recipients (e.g., *ID2*). In addition, the "positive outcome" field apparently facilitated positive reflections on caregiving. Indeed, all of the participants who took notes about their caregiving activities before joining the study (7 of 14) mentioned that their notes tended to be emotional and negative, whereas FMCT provided an opportunity to take a step back and think of the positive aspects of their caregiving activities. This resembles previous studies that argued for the importance of providing positive feedback to encourage positive behavioral changes [e.g., 19].

Overall, through the process of filling out the daily FMCT entries, many family caregivers seemed to realize that their views about the care recipients had been one-sided, and they became more generous and considerate to them. It also seemed to help them realize that they could devise steps or plans themselves to improve their current situations.

### **Impact on Family Communication**

Many family caregivers in our study also reported that their communication with their care recipients increased and improved. Such an effect was evident for those who often asked the care recipients about their conditions. Even though the family caregivers initially asked questions to maintain the FMCT records, the care recipients seemed pleased to be asked about their health conditions. For the family caregivers, recording mundane events functioned as a ticket to initiate safe or even amiable conversation with their care recipients. For some caregivers, asking care recipients about their health condition for filling out the FMCT forms became a habit (e.g., *ID 3*). According to the caregivers, some care recipients gradually started to actively provide information about their health and activities. For those families, care recipients

became collaborators in fighting depression, rather than a target at which to throw care. This is significant progress, considering that the family caregivers had avoided talking about the illness with their care recipients.

This finding is particularly interesting because previous literature suggested that family caregivers who are monitoring the health of care recipients might create conflicts. Our interviews suggest two factors that might cause this positive effect. First, family caregivers who exhibit concern by asking the care recipients about their conditions seemed to generate a positive cycle between the two parties (e.g., *ID2*, *ID3*). Second, the coping strategies that family caregivers developed during the deployment study seemed to successfully improve communication (e.g., *ID7*).

However, note that the first factor did not emerge in all of the family caregivers, especially siblings of care recipients who seemed reluctant to ask about health conditions because they did not want to annoy their care recipients. Thus, the factors that contribute to better caregiver-care recipient relationships might depend on their own family relationships.

### **Design Considerations and Future Directions**

Based on our findings, next we discuss how health monitoring technologies might be designed to assist family caregivers' development of coping strategies and improve caregiver-care recipient relationships.

#### *Providing Balanced and Non-Sensitive Recording Items*

To facilitate unbiased self-reflection, we suggest providing family caregivers with a balanced set of recording items. Since family caregivers are generally feeling anxious and tend to focus on negative events, a semi-structured format that induces positive reflections on caregiving is important.

Furthermore, to trigger safe and amiable communication between family caregivers and care recipients, we suggest to record mundane events because it seemed to function as a ticket to initiate safe and amiable conversation with their care recipients. We particularly suggest avoiding sensitive items such as the degree of forgetfulness or increased lethargy or listlessness. Although these items are closely related to the symptoms of depression, broaching them can lead to conflict.

#### *Appreciating the Advantages of Manual Input*

Another design recommendation is to allow caregivers to manually input care recipients' conditions. Despite the various challenges of manual input (e.g., high burden for logging data, lack of scientific rigor), our findings showed two clear advantages in the context of family caregiving: (1) it facilitated careful observation of care recipients, which led them to discover effective coping strategies, and (2) it triggered thoughtful communication between family caregivers and care recipients. The first advantage is consistent with previous works, which showed that self-reports (i.e., manual tracking) increase self-awareness and engagement [7,31]. Even though the overall trend of health-tracking technologies is toward passive tracking where the

data of health-related behaviors are automatically collected, our study provides additional evidence to appreciate the advantages of manual tracking.

While manual input afforded the above advantages, it certainly posed the family caregivers burden of capturing data. Previous works noted that people have difficulty maintaining manual tracking [7,27]. However, the family caregivers in our study seemed to maintain engagement with our system. One possible explanation is that family caregivers gradually manifested their care to the care recipients by using the system. Since the care recipients knew that the family caregivers were using the system to improve their support at home, such use reflected that they cared about them. Particularly for those whom it became a habit to ask the care recipients about their health condition (e.g., *ID 3*), entering the FMCT records became important because it was built into their communication.

#### *Considering the Effects of Excluding Care Recipients*

Finally, we suggest the designers of mental healthcare technologies to consider the option of excluding the care recipients from the design space. Existing systems, which allow family caregivers to monitor the care recipients' health conditions, often include care recipients by either automatically detecting the care recipients' physiological/behavioral data or leveraging their self-tracked data [19,20,41]. However, we excluded the care recipients from our system because family caregivers in our preliminary interviews expressed strong resistance to reflect on the data with their care recipients. It is risky to force the care recipients to reflect with the family caregivers particularly in a sensitive home setting where family members avoid talking about the illness. At the same time, consistent with previous work [19], family caregivers in our study expressed resistance to track their health information without the consent of the care recipients. Getting permission by explaining the purpose of the system (i.e. to better support the care recipients) appeared to be a good way to address this tension because family caregivers could record data on the care recipients without feeling that they are holding secrets.

Even with the consent of the care recipients, we were still concerned that the family caregivers' use of the system may create caregiver-care recipient conflicts because individuals experiencing depression tend to have a high awareness of surveillance [28]. Despite our concerns, most of our family caregivers reported that their communication with their care recipients increased and improved. It is important to note that the side effect of excluding care recipients from the system contributed to this result. By not allowing the care recipients to contribute to the data logging, the family caregivers often had to ask the care recipients for their health information, which eventually created a positive communication cycle. Although previous research valued the importance of sharing health information and transparency with family members [19], our study shows a new way of facilitating family communication in a sensitive home setting.

It is also worth noting that the psychiatrist in our team pointed to another possible advantage of caregiver tracking. Despite our concerns that caregiving tracking might deviate from the patient's actual condition, caregiver tracking may provide more objective data than patient self-tracking because patients during depressive episodes tend to be forgetful or have difficulties objectively recording their own conditions [42].

#### *Future Directions*

Our experiences deploying FMCT sparked two promising research areas. First, the family caregivers in our study expressed the desire to share their tracking records with other family caregivers so that they could learn from others. Since such a sharing function and communication between users has also been recommended in previous literature [12,32], we are planning to provide a sharing function in FMCT. Of course, we need to exert extra caution in developing such a function. For example, providing family caregivers a channel to communicate with others might impose an extra burden on them, e.g., by making them feel obligated to respond to others. It also risks shifting the relationships between family caregivers and care recipients into that of "family caregivers vs. care recipients" by allowing family caregivers to bond.

Second, we are interested in investigating the impact of FMCT on the care recipients. While many family caregivers in our study reported that their relationships with their care recipients improved, we are interested in learning whether the care recipients had same impressions.

#### **CONCLUSION**

This paper showed the potential of tracking technologies to support family caregivers for better interaction with a depressed family member. The deployment study of our simple tracking tool revealed that the system effectively supported the caregivers to develop coping strategies. The manual input of care recipient's moods/behaviors by family caregivers promoted higher attentiveness to the care recipients and the selected recording items introduced new perspectives to them. The most significant finding is that the family caregivers' data entry served as a trigger to introduce a conversation with their care recipients. The results from this study identified three design decisions which were crucial for helping family caregivers develop coping strategies and improving communication between family caregivers and care recipients: 1. family caregiver's manual input of care recipient's moods/behaviors and own caregiving activities, 2. barring the care recipients from contributing, 3. balanced and non-sensitive recording items. We believe our study will open up new ways of using tracking technologies in the field of mental healthcare.

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