

Understanding the Conflicting Demands of Family Caregivers Caring for Depressed Family Members

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ABSTRACT

Depression is one of the most common disabilities in developed countries. Despite its often devastating impact on families, scant research has focused on how to facilitate the well-being of family caregivers. The aim of this paper is to uncover the challenges faced by family caregivers and support their well-being with the use of technologies. To understand the emotional and social burden of caregivers and how they handle their stress, we conducted in-depth interviews with 15 individuals who have cared for a depressed family member. Our findings reveal the multifaceted dilemma of caring for a depressed family member as well as the various strategies engaged in by caregivers to improve their own situations. Based on our findings, we suggest design implications for healthcare technologies to improve the wellness of caregivers who are looking after depressed family members.

Author Keywords

Depression; family caregivers; stress; healthcare technology.

ACM Classification Keywords

J.3. Life and Medical Sciences, Health, Medical Information Systems; H.5.m. Information interfaces and presentation (e.g., HCI); Miscellaneous.

INTRODUCTION

Major depression is a mental disorder that is “characterized by a combination of symptoms that interfere with a person’s ability to work, sleep, study, eat, and enjoy once-pleasurable activities” [32]. Even though most people experience *the blues*, those diagnosed with major depression experience a far more profound sense of dread and despair. The numbers of such depressed individuals continues to grow, and depression has now become one of the most common disabilities in developed countries [40].

Even though new technologies are being developed to support many other illnesses [6, 18], little HCI research has addressed the needs of depression; this domain remains

largely unexplored. The primary reason for this is found in the difficulties faced by non-mental health professionals to access the field. Due to high sensitivity and the disease’s stigma, high ethical requirements and constraints limit the access of HCI researchers to potential clients [9].

While limited, previous HCI research has explored ways to increase access and engage existing patient care/services [10, 14, 15]. Researchers have also designed technologies to support caregivers so that they can provide more effective and efficient care for patients [13, 16, 29]. Despite the significant influence of major depression on a family [2, 26], little research has focused on supporting the lives or well-being of family caregivers.

By shifting our attention to the lives of family caregivers, typically the spouse, we soon realize that depression drastically changes their lives. For instance, family caregivers are the most likely to be exposed to the agitated or lethargic behavior of the sufferers of depression, since they typically withdraw from social activities and seclude themselves at home [2, 23]. Even when caregivers experience outrageous sufferer attitudes or behaviors, they may repress their reactions to avoid exacerbating the depressive symptoms. Indeed, many guidelines for families with a depressed member suggest not blaming or even encouraging the sufferer [32]. What complicates matters for family caregivers is that they themselves experience a significant reduction in their social activities [2, 26]. They can easily miss the friendships and companionships that the family shared before the depression [22] - they may hesitate to consult with their close friends because they worry about the negative effects on the sufferer or/and on their friendships. Such difficulties and feelings of loss can lead family caregivers to feel sadness and even depression [2].

Understanding the burden on family caregivers and facilitating their well-being are crucial. Family caregivers under extreme stress may not only become depressed themselves but may also negatively impact their sufferers [21]. Support for family caregivers might prevent both the family and the sufferer from tumbling into a vicious cycle that amplifies the stress between the two parties.

In this paper, we focus on the lives of caregivers. Unlike other patient-centric research that aims to assist the care of

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patients, we uncover the challenges faced by family caregivers and support their well-being with the use of technology. More specifically, this work is driven by three research questions: (1) What are the key challenges of caring for a depressed sufferer as a family caregiver? What constitutes their stress and how do they deal with it?; (2) how do various technologies function in family caregiver lives particularly in mitigating the problems faced by caregivers? (3) Finally, what design opportunities exist for technologies that might improve the well-being of family caregivers?

To investigate these questions, we conducted in-depth interviews with 15 individuals who have (or had) taken care of a depressed family member. Through the interviews, we describe the multifaceted dilemma they faced. We believe this work serves as a foundation for designing systems that support the well-being of individuals who are caring for depressed family members.

In the rest of this paper, we first describe the key symptoms of major depression and highlight some healthcare technologies that may alleviate the problems in this domain. We then present our study and the findings from interviews with caregivers of depressed family members and discuss the implications of technology that can address their needs.

BACKGROUND

Major Depression and Social Withdrawal

According to DSM-IV-TR [1], which is a common manual to diagnose mental health conditions, major depression is marked by sad moods and a loss of interest in most activities lasting for more than two weeks. After strokes, for example, sufferers typically withdraw from social activities and avoid social situations for an average of five months [19]. During major depressive episodes, sufferers view social activities negatively and expect that negative outcomes will occur [19, 23]. Such pessimistic attitudes of sufferers negatively affect others, which in turn elicits rejection and a loss of social relationships [24].

Family relationships are no exception. Family caregivers typically experience extreme stress, which is caused by sufferer's verbal abuse and behavior characterized by apathy, irritability, and self-centeredness [2, 26]. Such stress exposes family relationships to a high risk of dysfunction. Approximately 50% of the caregivers of depressed family members perceived their own family as unhealthy; clinicians rated 70% of families with depressed family members as unhealthy [26].

The symptoms not only penetrate the family caregiver relationships with their sufferers but also their social relationships with others. Although medical literature shows that effective treatments for depression are available [28], and society has begun to openly discuss it, a strong social stigma remains attached to the disease.

In recent years, the Japanese government and the pharmaceutical industry have waged a campaign to reduce social stigma towards depression – “Depression is like a cold in your mind. It is treatable with drugs.” Nevertheless, stigma still exists in the Japanese society. Only about 20% of sufferers seek for treatment; the caregivers also tend not to contact mental clinics or receive training from them. Research reports that this is partly due to the Japanese cultural values that praise the wisdom of “grin and bear it.” “Suffer in silence” is the rule most people continue to play by. Consequently, not only the sufferers but also family caregivers are reluctant to tell others about the disease, which often increases social isolation [2].

Burden of Caregiving

The social isolation of family caregivers undermines their own senses of well-being. As pointed out in previous literature [36, 37], caregivers need to express their frustrations so that they can temporarily escape the stress that accompanies caregiving. The loss of social connections drags them into extremely stressful situations where they need to handle everything by themselves, including the burden and the stress linked to caregiving and maintaining their own lives [4, 30].

Another notable characteristic of major depression, which may impose a burden on caregivers, are sufferer mood cycles or swings, which they typically experience during their recovery process [32]. A basic mood cycle is known as morning depression, where sufferers experience a low mood in the morning that improves by the evening [28]. Besides such mood swings, major depression is a disease liable to recurrence - major depressive episodes commonly occur several times in a lifetime. Furthermore, the risk of future recurrences dramatically increases once a sufferer experiences one recurrence [27]. Another recurrence happens 70% of the time, and a second happens 90% [27]. Such mood swings and the recurrent nature of the disease would trigger confusion and amplify anxiety for family caregivers.

As discussed above, the burden of caregiving for a depressed family member definitely causes extreme stress to the family caregivers. Evidence has shown that caregiving with excessive emotional burden reduces the lifespans of family caregivers [37]. Thus, the burden on family caregivers must be reduced [20].

Healthcare Technologies

Despite the need to reduce the burden on and stress of family caregivers, little HCI research has addressed their needs. Even though healthcare is one of the most common HCI research topics, most studies have focused on designing technologies for better patient care. More specifically, HCI researchers studying depression (or mental healthcare) have focused on designing technologies to improve access and engagement with traditional treatments/services [3, 6, 10, 11, 15]. For instance, electronic contact and online self-help manuals are natural

extensions of face-to-face therapies. Besides, Doherty et al. explored ways to reduce attrition in the online interventions of Cognitive Behavioral Therapy (CBT) for depression [14]. Brosnan et al. reported an animated story building system aimed at depressed teenagers to positively engage in a CBT program [5].

Technologies are not only designed for patient use. Taking a broader look at other healthcare technologies, we can also find examples designed for caregivers. For example, systems and devices are being developed to enable caregivers to monitor patient activities from distant locations [16, 35] and to have better coordination with other caregivers [8, 39]. However, these technologies are not designed to improve the well-being of caregivers but to advance patient care. Even though these technologies may help caregivers efficiently carry out caregiving for their patients, we must keep in mind that they also risk placing extra demands on them [39].

Only a few studies have addressed decreasing the burden of caregivers [13, 29]. While these studies deal with different types of diseases such as dementia and infants at high-risk, they coincide with the need for social/emotional support from the existing social networks of caregivers. Consequently, they usually introduce some sort of telecommunication tool to caregivers that closely resembles the social networking services targeted for patients with chronic illnesses. Examples include such services as PatientLikeMe, Lotsa Helping Hands, and online patient communicates based on Facebook Connect platform [38].

While the above studies demonstrate that those systems successfully provided social support to caregivers, the situation could be less straightforward with the family caregivers of depressed sufferers. As we describe in our study, many family caregivers of depressed individuals were reluctant to consult with close friends and family (parents), avoiding to talk about the disease even when they were provided a chance to talk face-to-face or on the phone. Rather, they elected to talk about their feelings to old friends or to people who they hardly knew.

To design a system that alleviates the social/emotional stress of the family caregivers of a depressed individual, we need to understand the intrinsic nature of their stress, their needs, and their preferences in managing their social relationships with others. This study contributes to this domain by revealing these issues and identifying how technology could be used to improve their quality of life.

METHOD

Participants

Fifteen adults (11 females and four males whose mean age was 41.9) who were currently caregivers or had experienced caregiving for a depressed family member within the last two years participated in our study. All the caregivers held primary responsibility for looking after a family member diagnosed with major depression. 11

caregivers were the spouse of the sufferer, two were siblings (a brother and a sister) and the remaining two were father and daughter of the sufferers. All but one caregiver lived with the sufferer.

Ten interviews were held in Osaka and five in Tokyo, Japan. Since the caregivers were all Japanese, the interviews were conducted in Japanese.

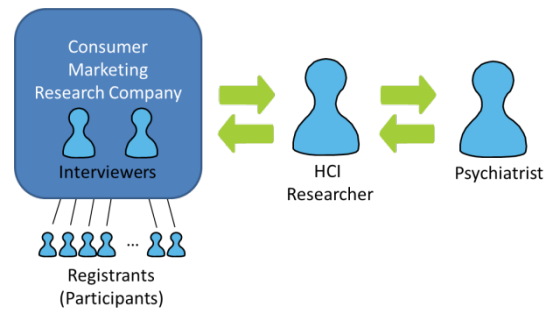


Figure 1. Research framework

Data Collection

Caregivers were recruited through an external consumer marketing research company with approximately 2.2 million registrants who are willing to respond to requests/surveys from companies developing new products and services (Figure 1). We made this decision because we were concerned of caregivers hiding their feelings by apprehending its influence on the sufferers when recruited through a psychiatrist; permission from sufferers was a prerequisite if we recruited them through a psychiatrist. Recruited through a marketing company, it was left to the caregivers whether or not to tell the sufferer about the interview. This way, we expected the caregivers to get more open in talking about their daily lives.

From the same company, two interviewers were also recruited who enlisted the caregivers and conducted the interviews. Although the interviewers were not trained for this particular study, they were professional interviewers involved in many other projects. Direct contact with the caregivers was only made by the interviewers; personal information identifiable of an individual was kept inside the company and not handed to the researchers. This prevented us from having to deal with personal information, which always required extra effort.

Since communication between the researchers and the interviewers became inevitable, several meetings were held to share our project's goal. Recruit conditions, interview protocols and materials were also discussed.

In recruiting the caregivers, the interviewers narrowed down the candidates from the registrant pool by a web survey and phone calls. The web survey included questions about themselves (i.e., family caregivers) and their family members (i.e., sufferers). Registrants who were themselves diagnosed with major depression were excluded. Registrants with a sufferer working for a

telecommunications company were also excluded to preclude any privacy concerns about possible confidential disclosure during the interviews - since the information of primary researcher working for a telecommunications company was not communicated to the caregivers, we wanted to eliminate information that suggested a conflict of interest.

For the interview manuscript, the researchers initially drafted semi-structured interviews in consultation with a psychiatrist. The draft was then reorganized by the interviewers to make it easier to extract a narrative from the caregivers. The interviews explored the caregiver's caregiving experience and how they managed their own lives by focusing on the following central themes: feeling stress and dealing with it during caregiving; whether technologies played a role in alleviating their stress; whether the interaction (style) changed between the caregiver and the sufferer; whether their use of media changed accordingly; whether and how the caregiver's social networks changed; whom they chose as a confidante and why; what media was used for interaction between caregivers and confidantes.

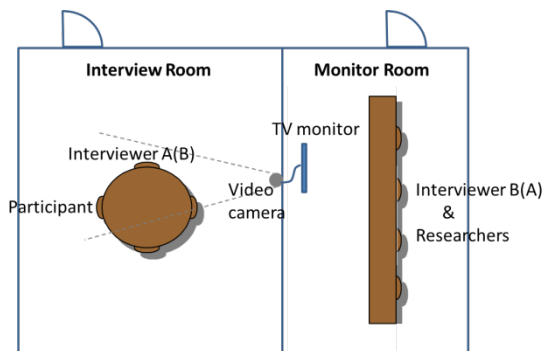


Figure 2. Interview room

The interviews took place at a rental studio designed for interviews because the caregivers preferred participating outside their homes. Before the interviews, some expressed a reluctance to participate at home because they were mindful of their sufferers and wanted to avoid affecting them.

The studio consisted of interview and monitor rooms that were located next to each other (Figure 2). The video camera that captured the interviewers and the caregivers was hidden to avoid disturbing the interviews. To avoid unnecessary pressure by having multiple interviewers, only one interviewer conducted the actual interview. The other worked as a back-up, monitoring the interviews, and checked the interview manuscript if there were any omissions. The researchers also monitored the interviews and wrote additional follow-up in response to specific answers. After the interviews were finished, such questions were handed to the interviewer when she came to the monitor room.

Caregiver Perceptions of Sufferer Condition

Prior to the interviews, caregivers filled out surveys about their sufferer's socio-demographic data and mental condition. To predict the severity of the sufferer's symptoms during major depressive episodes, caregivers also checked the DSM-IV-TR and Quick Inventory of Depressive Symptomatology (QIDS-J¹) items.

Table 1. Caregiver perceptions of sufferer condition

Major depressive episodes	Min	Max	Median
DSM-IV-TR [min: 0, max: 9]	5	9	7
QIDS-J [min: 0, max: 27]	11	27	19

As shown in Table 1, all sufferers had a DSM-IV-TR score exceeding the general accepted cutoff (at least five items) for clinically significant symptoms of experiencing major depressive episodes. Severity of the depression was measured using QUIDS-J. The median of the QUIDS-J scores noted by the family caregivers was 19, indicating "serious (>15)" symptoms during their episodes. All the sufferers had to take time off from work during their episodes. Note that all but one sufferer was capable of organizing his/her social life before getting depressed.

Sufferer ages ranged from 30 to 47 years (Mean= 40.7, SD=5.6). Most of the sufferers were Male (N=11, 73%) and married (N=13, 87%). All the sufferers held jobs before getting depressed; twelve were the primary breadwinners of their families. Fourteen had returned to work: five to their original workplaces and nine had either been transferred or completely changed jobs. At the time of the interviews, five had experienced a relapse accompanied by a leave of absence. All but one regularly saw a doctor and took antidepressant pills every day.

Data Analysis

The interviews with the family caregivers lasted approximately 2-2.5 hours and were audio-recorded and transcribed for analysis.

For data analysis, we used a grounded theory approach [17, 12] as a guide to identify recurring themes from the multiple iterations of our analysis. In terms of the analysis process, we first randomly selected five interviews and extracted concrete descriptions/narratives from the transcripts. Two researchers individually analyzed the descriptions using an open coding method and sorted them into meaningful categories while looking for salient themes/concepts closely tied to major depression. After the researchers discussed and agreed on the salient themes, the primary researcher coded the remaining transcripts to see if those themes were reliable: applicable to other transcripts. Consequently, three important themes were identified, which are presented in the following section.

1. ¹ <http://counsellingresource.com/lib/quizzes/depression-testing/qids-depression/>

FINDINGS

Three central themes emerged from the interview transcripts that shape the emotional/social stress of family caregivers (Figure 3): gaps between caregiver expectations and reality; a conflicting desire to tell others about the disease while wanting to hide it; and a conflicting desire to learn more about the sufferer (including the disease) while wanting to disregard/forget about it. The first theme constitutes the core stress in caregiving for a depressed family member, and the latter two explain the factors that impede family caregivers from alleviating stress.

Note that the quotes presented below are translations of the original Japanese quotes.

Gaps between Expectations and Reality

In the interviews, all the caregivers expressed frustration about failing to meet their own expectations about caring for their sufferers. In what follows, we elaborate on the three aspects about which the caregivers felt stress about looking after their depressed family members. We also highlight some uses of technology that helped reduce the problems.

Influence from Depressed Family Members

Due to their disease, many sufferers experience mood swings, occasionally become forgetful, react negatively to everything, and get offensive. These symptoms are often different from the sufferers' original personality and thus constituted a gap between caregiver expectations and the reality of the sufferers' actual behavior. Such violations of caregiver expectations often became a source of contention.

Mood Swings and Recurrences

Mood swings and recurrences were clearly a source of confusion that created both expectations and disappointments to the family caregivers. As briefly mentioned in the background section, depressed individuals typically experience mood cycles and recurrences that family caregivers are easily swayed by. When their sufferers' symptoms improved, family caregivers placed great expectations on complete recovery, although such expectations were often dashed. In below, each quote is headed by a caregiver number and the relationships between the caregiver and the sufferer.

[Osaka 2, sibling] You can easily get affected by the mood swings. I was so happy when my brother finally returned to work, but then the symptoms recurred. I was so shocked and disappointed as I pictured myself going through the same process once again.

[Osaka 5, spouse] My husband had big up-and-down swings. Sometimes he was all gloomy and sometimes he was grumpy and offensive. I just didn't know how to deal with it.

Forgetfulness

Many of the family caregivers we spoke with reported a significant drop in their sufferers' memories. Since

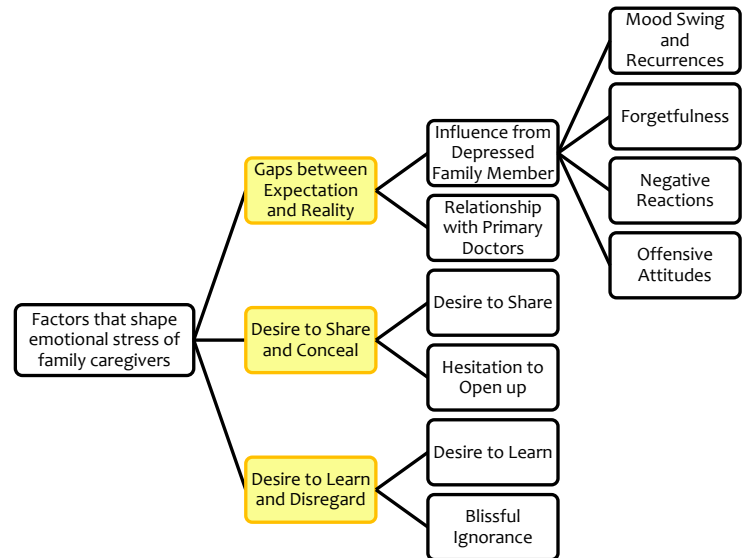


Figure 3. Factors that shape emotional stress of family caregivers

forgetfulness was often not expected by the caregivers, this often became futile “he said/she said” arguments, which frustrated the caregivers. To avoid such arguments and to compensate for the sufferers' short memory, many caregivers started to record what they discussed with sufferers. Some wrote down their schedules/important matters on a shared calendar or a board, and others exploited technologies:

[Tokyo 5, spouse] Oh, we fought a lot about what was said, who said it, and when. He had a lot shorter memory than he used to have. (...) One day, my husband started to write things down on his smartphone calendar so that he wouldn't forget what we discussed.

[Tokyo 4, spouse] When I asked him for a favor, he would always forget and claim that I hadn't told him about it. So, I decided to send him a text message right after I told him. (...) Also, it sometimes seemed difficult for him to concentrate on one thing, like reading my message from the top to the bottom. When I asked him three things, he would just read the one on the top and leave the other two. So I decided to send messages in fragments, one item in one email, so that he can at least remember the number of things I asked him.

Some caregivers established a rule with sufferers to clarify whether their text messages were actually read or forgotten by the sufferers:

[Osaka 5, spouse] We set a rule that my husband would send me a response right after he reads the message, even it's just “ok”.

Negative Reactions

Another big change noticed by family caregivers about their sufferer behaviors was their negative attitudes. Even though negative reaction is one of the notable symptoms of depression, the caregivers sometimes seemed confused by

receiving an unexpectedly negative reaction from the sufferers:

[Osaka 4, spouse] I was stumped when casual words or even sympathetic words like "Take it easy" were taken negatively. She furiously responded, "You don't give a damn about me."

The caregivers noted that such unexpected negative reactions occurred more frequently when they were not with the sufferers. This was attributed to the difficulties of reading their sufferer moods from a distance.

Offensive Attitudes

In addition, some family caregivers (particularly those caring for sufferers with gentle character) seemed to get confused by the offensive attitudes of their sufferers during depression:

[Tokyo 5, spouse] Before his depression, my husband used to play games with the kids and lose on purpose. But when he became depressed, he became a sore loser. (...) He even yelled at them for being noisy when they were just walking. My husband never used to be like that.

[Osaka 6, spouse] My husband used to be a calm person. But when his symptoms worsened, he got angry very easily. Even with tiny things, he would get so upset. (...) In such cases, I just didn't know how to deal with it - whether I should talk back to him or just ignore it. (...) I didn't want to aggravate him, so I learned to cower and put up with it.

The family caregivers expressed frustration about their inability to understand such behavior, especially whether it arose from the disease, and not knowing how to deal with it:

[Tokyo 1, spouse] I sometimes wonder if it's part of the depressive symptoms or just indulgence. (...) I even feel that he is sometimes pretending a little to act depressed. I'm not sure if I should be tolerant or get angry.

Relationship with Primary Doctors

The family caregivers not only expressed frustration about their sufferers' unexpected behaviors that were caused by the disease but also surprisingly, often disappointment with the primary doctors who were expected to cure the disease:

[Osaka 1, parent] I once accompanied my mom when she visited her doctor, who looked nice. But considering our long waiting time, the consultation time was too short, as if we just came to refill a prescription. (...) I asked the doctor how long it would take her to recover, but he didn't know. I was somewhat disappointed and felt distant from the doctor.

Some caregivers also expressed frustration with primary doctors who focused almost exclusively on the sufferers:

[Tokyo 4, spouse] I wish I could ask the primary doctor - how far have we come, has my husband recovered yet, how long will he be on medication, and how should I deal with it. But it's not easy, you know. First of all, I'm not sure if I can make an appointment without my husband. If my husband is there, I doubt that I can get a frank opinion from the doctor. I don't think doctors want to discourage their patients.

Some even questioned doctor diagnosis/judgments that were based on information provided by the patients:

[Tokyo 1, spouse] I once visited my husband's primary doctor without telling him and learned that my husband had provided information to the doctor that put him in a much better light. He didn't mention his drinking. (...) Unfortunately, my impression is that the doctor is basically controlled by my husband. When my husband says he's not ready to get back to work, the doctor agrees. When my husband says he's ready, then he's ready. (...) After the visit, doubts welled up within me, wondering if we are on the right path. Is my husband going to get better?

Desire to Share and Conceal

As described above, the family caregivers were all confused and stressed by the changes caused by depression. All the caregivers expressed a strong desire to share with others and vent their stress. However, despite such needs, they also expressed a conflicting desire to hide it from others. As a result, most caregivers with whom we spoke had little luck finding someone to share with.

Hesitation to Open up

In the interviews, caregivers gave several reasons why they did not want to tell others about their sufferer's disease. First, they considered their sufferers and did not want to hurt them by telling others. Consequently, they showed particular reluctance to share with their common friends:

[Osaka 5, spouse] I had difficulty telling our neighbors and family friends. If I talk too much, I was worried about hurting my husband. I was also afraid of people talking about us.

When the caregivers had a chance to talk about their sufferers, they took great care in what they said:

[Osaka 1, parent] I want my friends and families to know that we're having a difficult time. But I don't want them to know the details, like my mom is crying every day.

[Tokyo 1, parent] When my husband felt better, he went to a sports gym and even traveled during his medical leave. It was very frustrating, but I couldn't tell our friends. If his colleagues were to hear about it, how would they feel?

Another concern that discouraged the caregivers from talking to others was a fear of being looked down upon. Due to such social stigma, caregivers were reluctant to discuss their sufferers with those who had little understanding of the disease. They were sensitive about whether the person was receptive; when the caregivers were unsure, they preferred not to talk about it. The following examples show how caregivers tended to make negative assumptions about the attitudes of others toward the disease:

[Tokyo 5, spouse] I was totally obsessed about my husband's depression and didn't feel like going out for lunch with friends. There is no point talking to people who don't have a good understanding about the disease.

[Tokyo 2, spouse] I wanted to keep it a secret. (...) I once got annoyed by someone who got extremely aggressive due to the same disease. Because of this bad impression, I worried that others would look at us in the same way.

Not only did the caregivers show reluctance to talk to others about the disease but they even expressed hesitation to talk about it with relatives, even their parents. Only two talked

to their parents about the subject in depth. Besides a hesitation to worry their parents, the caregivers provided similar reasons for their unwillingness to talk to their parents: anxiety about affecting their sufferers and being judged:

[Osaka 4, spouse] I cancelled our annual New Year's visit to my parents, telling them that my wife had a cold. My wife didn't want me to tell them about her disease. Well, we can visit them after my wife recovers. We don't always have to tell them the truth, you know.

[Tokyo 5, spouse] I told my parents that my husband was missing work because of sleep deprivation. I thought they should know something about it because I might have to ask them for help. But I couldn't tell them that my husband was depressed. My parent's generation tends to think that depression is a sign of weakness. My parents also think that such a personality is inherited.

Overall, even though the caregivers had desire to vent/share their problems about depression with others, and they did have such opportunities, their pride as well as their concerns about affecting their sufferers worked as a brake. Because of these conflicting demands, caregivers were unlikely to talk about the subject – they concealed their situations from others.

Actual Sharing

Since caregivers had difficulty sharing with close friends and parents, they needed to locate other outlets to help themselves. Our interviews revealed that the majority of caregivers chose old friends and those in similar situations:

[Osaka 5, spouse] I used to send text messages full of complaint every day to an old friend who didn't know my husband.

[Tokyo 3, spouse] I often complained to a friend whose husband was also depressed. She doesn't live nearby, so we used to exchange text messages and sometimes talked on the phone when our husbands weren't at home. All we did was moan and let off steam to each other. But having someone to share with was very important. I felt a great sense of solidarity.

The caregivers felt more comfortable talking about the disease/sufferer to people who didn't know their sufferers. Some could not find anyone to open up to in their social networks. For those caregivers, reading the blogs of people in similar situations provided emotional support:

[Osaka 5, spouse] I often read the blogs of depressed people and their family members. Their raw emotions are described, and I feel empathy toward them. (...) So I also decided to write my own blog, describing the disease, our family, and my own feelings. Of course, I haven't told anyone.

Some shared their feelings with people they did not know:

[Tokyo 1, spouse] Having someone to vent was very important to me. But the thing is, you can't share with people in close relations. (...) So I talked about my feelings to an insurance salesman who periodically visited my home. I felt safe talking to him because we had nothing in common. Even if he knows stuff about my family, it wouldn't affect anything.

Desire to Learn and Disregard

Desire to Learn

In addition to searching for a place to share feelings, family caregivers strove to learn about their sufferer's diseases. Not only were they eager to learn about the symptoms and medications for depression but they were also keen about how to deal with it and how to reduce their own stress about the future:

[Osaka 6, spouse] I used to search on the Internet all day looking for a person like me: married, no children, low income, and a depressed husband with similar symptoms. I had no luck, but what I really wanted was to know how others coped with the disease.

[Tokyo 4, Spouse] For search keywords, I usually used "depression, poverty, suicidal, and two children." I wanted to learn from the experiences of others and get a picture of what might happen next. You can't get such information from books.

Even though many caregivers used the Internet for acquiring a variety of information related to depression, some questioned its reliability, pointing to the inconsistency among information from different sites:

[Tokyo 4, spouse] I don't know what to believe. So many web sites claim totally different things.

For caregivers with sufferers who had returned to work, since their concerns emphasized possible future recurrences, some expressed a desire to keep tabs on the sufferer's mental condition when they were away:

[Tokyo 5, spouse] I felt more anxious about my husband when he returned to work. I was so worried that I sent him more than 10 text messages a day – asking if he got on the train ok, if he arrived at his office, if he had lunch, etc. My husband got mad and called me a stalker, but I couldn't help it.

[Tokyo 4, spouse] Even now, [three months after the sufferer returned to work], I want to monitor my husband's mental condition while he's at work. I don't want it to happen again. The whole family, the children are at stake. I want to do my best to eliminate the possibility of a recurrence.

Blissful Ignorance

Despite being anxious about the future and wanting to know more about improving their current situation, some caregivers also expressed a desire for free time apart from their sufferers:

[Tokyo 4, spouse] My husband had strong suicidal wishes. Although I worried that he might hurt himself, it was so frustrating to see him doing nothing but playing games all day. (...) I told him to spend a week at his parent's house. I needed to get away from all of the stress.

[Osaka 5, spouse] It was so stressful when my husband was home all day. No one could visit our house. Now that he has gone back to work, I feel free.

[Osaka 6, spouse] I didn't feel good hearing him complaining about work. (...) If I knew too much about his office matters, I might get worried. I prefer the bliss of ignorance.

The interviews suggest that the caregivers wanted information that might be beneficial, including information

about suicide prevention, information that might reduce their anxiety about the future, and information that might help them improve their current situations. Meanwhile, they wanted to escape from information that would only increase their stress or anxiety about the future.

DISCUSSION

Summary of the Findings

Our study reveals a multitude of emotional and social challenges faced by caregivers who are looking after depressed family members. Figure 3 summarizes the findings. From the interviews, we found out that caregivers were stressed because they felt their expectations based on their lives before depression were betrayed. Such changes included sufferer tendencies to become forgetful, aggressive, and have mood cycles. The caregivers were also depressed because they couldn't satisfactorily communicate with and receive advice from doctors.

Under such highly stressful conditions, the family caregivers were desperately grasping for ways to improve their current situations. Many sought useful information and looked for blogs that addressed similar situations, although they weren't always successful. The Internet contains much contradictory information, which complicates decision-making. Looking for similar people with specific family situations was also difficult.

The caregivers definitely needed a place to share their feelings. Interestingly, however, they did not choose their closest friends or parents. Instead, they chose old friends, friends who also had a depressed family member, and people whom they had never even met. It was not that they lacked opportunities to meet their closest friends. Indeed, they conveyed minimum information of their sufferers even when they talked with their closest friends. The fact was that the caregivers were concerned about their sufferers. They feared negatively affecting their sufferers. They were also afraid of getting hurt by negative responses after sharing. Rather than sowing worry, they chose to bottle their stress inside themselves, hoping that the situation would improve in the near future.

Design Implications

As indicated in the study, family caregivers sought ways to improve the care of their sufferers as well as maintaining their own well-being. To lighten the stress of caregiving, they engaged in various strategies by exploiting technologies. Based on our study findings including such strategies, we next suggest specific designs for healthcare technologies to improve the well-being of caregivers who are tending to depressed family members.

Support for Adaptation to Changes

Sufferers often become forgetful due to the decline in their cognitive abilities caused by depression [32]. Even a dedicated person who would never forget the items on his schedule might forget what he was told by his caregiver. This often caused quarrels between sufferers and caregivers.

To avoid such trouble, the caregivers used text messages and electronic diaries. Sharing the important messages with sufferers and caregivers might also be effective. Furthermore, sending automatic reminders to sufferers might prevent them from forgetting and compensate for their short-term memories.

Places to Share

As our study shows, the family caregivers endured much stress due to the large changes caused by the depression suffered by their sufferers. As previous studies suggest, the importance of social connections has increased for such stressed caregivers. However, regardless of the need to vent their stresses, the caregivers rarely sought help from their closest friends or parents. Most tightened their social networks and became isolated.

Many techniques have been designed to improve the social connections of physically or emotionally isolated people. For instance, "digital family portraits" is designed to improve social connections between distant family members [31]. For the emotional support of caregivers, Czaja proposed a system that facilitates communication among family caregivers and remote family members [13]. Liu proposed a system that indicates the stress levels of caregivers and shares them with support groups [29].

However, our findings suggest that the caregivers of depressed family members are often *unwilling* to share their feelings to their closest connections because they fear the impact on their sufferers. Even when they have opportunities to share, they prefer not to do so. Thus, simply providing them with a telecommunication tool might not work. Also, they might not want to reveal their own stress levels to their close friends and parents because they do not want to reveal the causes of their stress. Since many caregivers chose weaker connections (i.e., people unacquainted with the sufferer) and people in similar situations to share with, a technique might work that encourages caregivers to talk with people in similar situations who are unacquainted with the sufferers.

One way to realize this idea is to combine anonymous blogs with social networking services. First, anonymous blogs might be a place for caregivers to express their feelings. As shown in our findings, one caregiver released her stress on a blog. Even though she did not notify anyone about the blog, the writing process itself had a therapeutic effect and improved her health [25]. A social networking service (SNS) may be useful in sharing such blogs with people in similar situations [33]. However, as our findings suggest, extra care that ensure anonymity may be helpful. Even if a blog does not show any personal information of the user, his/her description of everyday matter could be enough in identifying the person particularly for those in close relationships. To ensure anonymity and exclude a group of people in close relationship with the user (or/and the sufferer), social graph (friends network detected from SNSs) may be used - the invert of social graphs could be

used to detect who is *not* in the focal user's social network (or the sufferer's social network). In this way, caregivers have a place to share their feelings and empathize with others in similar situations, while feeling safe about impacting their sufferers.

Place to Learn

As depicted in the "Desire to Learn" section (Osaka 6 and Tokyo 4), many caregivers searched for blogs of people in similar situations. Note that they were not only looking for people with depressed family members but also with similar family structure, incomes, and symptoms. Connecting with people in similar/specific situations would not only improve their emotional states but also provide a place to learn from others. To enhance such learning, a function that prioritizes or makes recommendations of others' blogs with similar situations might be useful. A "helpful" button may also be useful for voting up and sharing useful strategies among people in similar situations. Furthermore, a know-how database that allows caregivers to easily search for particular symptoms or incidents along with its countermeasures might help. Sorting articles of similar family situations on a timeline may also be beneficial to caregivers with corresponding family situations in anticipating possible future symptoms; people feel less frustrated if events unfold along predictable lines [34].

While caregivers searched for information and blogs on the web, some worried about the reliability of the information. A web repository that collects limited links that are certified by doctors might increase the information's reliability. Doctors could also comment on the above know-how database to improve its reliability.

CONCLUSIONS

The paper is significant in two ways. First, our study uncovered the factors that shape the emotional stress of family caregivers caring for depressed family members, revealed their needs, and their preference in managing their social relationships with others. We shed light on their frustrations due to multifaceted dilemmas which are quite unique to the caregiving of depressed family members. Furthermore, learning various strategies the caregivers had engaged in order to improve their stressful situations gave us precious information for deliberating how technologies might improve the situations of the caregivers. Second, based on our analysis, we proposed various design implications for network services that reckoned with complicated preferences and needs of caregivers looking after depressed family members. Although further study is required to see if the same is equally true of other cultural regions, we believe this study provide insight into how family caregivers handle their stress and how technologies might be used to improve their quality of life.

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