

Investigating unintentional medication non-adherence to inform technology design

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Abstract

Medication non-adherence is a common phenomenon that can undermine the effectiveness of medical treatments. In the last few years, modern technology has been leveraged as a tool to reduce unintentional non-adherence to medications, including strategies such as reminders and medication tracking. This paper presents the preliminary results of a study investigating patients' perspectives on unintentional non-adherence, with the goal of informing technology design. Our findings indicate that there is an opportunity to target forgetfulness caused by a disruption in the user's routine through context aware systems.

Introduction

Many patients fail to take prescribed medications consistently. Non-adherence can be intentional (when patients purposefully do not take a medication, or take a different dose than what is prescribed), or unintentional (when patients want or intend to take the medication, but fail to take it consistently).¹ While there is no standard for classifying adherence, a common threshold for adequate adherence is taking medicine at least 80% of the time.² Past studies have shown that only 50-60% of medications are taken as prescribed.³ In the U.S., poor medication adherence is estimated to lead to 125,000 deaths every year,⁴ and direct and indirect costs of non-adherence are estimated to be between \$100-300 billion per year.³ Forgetfulness is among the leading causes for unintentional non-adherence.⁵

Recently, patient centered interventions in the form of reminders and medication tracking have been proposed as potential solutions for unintentional non-adherence. Mobile applications, SMS reminders, as well as smart pill bottles and smart pillboxes have been studied,⁶⁻⁸ and many mobile applications are available for Android and iOS systems.⁶ Reminders have been shown to significantly improve medication adherence, but effect sizes are limited.⁹ The interventions that result in the most substantial improvements include complex combinations of different strategies, but these programs are costly and difficult to implement in large scale.^{10,11} It is possible that there are external factors that influence the effectiveness of low cost strategies such as reminders, but they are not well understood. A more in depth understanding of barriers to adherence interventions could reveal opportunities for technology design to improve the effectiveness of current tools.

To gain an in depth perspective on barriers to medication adherence strategies, we are in the process of conducting an interview study with people who take prescription medications for hypertension at least once a day, and forget to take their pills at least once a week. We chose this population because hypertension affects one third of U.S. adults,¹² it is controlled with medication, and medication non-compliance rates are high for this population.¹³ We have conducted 22 interviews and are currently in the process of analyzing the data. In this paper, we report the preliminary findings based on the analysis of seven interviews.

Methods

We are conducting an interview study aimed at better understanding what barriers to medication adherence strategies patients face. Participants were recruited online, through forums such as Reddit and Craigslist. These platforms allowed us to reach a diverse population, residing in different areas of the United States. Recruitment posts were carefully written to conform with both platforms' rules and guidelines, and followed individual community rules when applicable. Each potential participant filled out a questionnaire to ensure that they met the study's criteria. Participants are required to be 18 or older, live in the U.S., take prescription medications for high blood pressure at least once a day, and forget to take their medications at least once a week. Selected participants were contacted by email to schedule the interview.

Among the seven participants, 2 were female and 5 were male. Their ages ranged from 39 to 74 (median = 50). They lived in three different states in the U.S., and each took between 2 and 20 prescription medications (median = 6). Other than hypertension, they also had other chronic illnesses such as mental illness, chronic pain, diabetes, arthritis, and hormonal disorder.

Interviews took place online, and lasted 45 minutes on average. During the interviews, we asked participants about their health history, their prescription medications and supplements, their medication routine, their medication management strategies, and how they experienced unintentional non-adherence. Each interview was audio recorded.

To analyze the data, we transcribed the audio of each interview. We read the transcripts and used an open coding technique¹⁴ to extract preliminary themes from seven interviews. After themes were extracted, we read each transcript to check for inconsistencies. The findings that emerged from this preliminary analysis are described in the next section.

Findings

We found barriers for each of the strategies our participants used, and we present them in this section.

Having a routine helps participants to remember their medications, as the task of taking pills becomes part of the routine. For P2, who has type 1 diabetes, checking his glucose and taking insulin is a part of his daily routine, and taking medications has been incorporated into it.

"[It's] a matter of routine and keeping a schedule. Which is of the utmost importance as far as my diabetes. Once I have a routine and I stick to it, things are the same and even every time. That's the easiest for me. [...] I take my basal insulin in the morning. So while I'm doing that, it's medicine time. I take the pills. It's just so simple, it's just part of the routine at this point." (P2).

Similarly, P6 explained that taking medications with breakfast facilitates remembering.

"I try to take my medications first thing in the morning. right before or right after I eat. [...] [It's] part of my routine. so I try to make sure that it get's done that way. It helps me not to forget" (P6).

Several participants reported that they often forgot their medicine due to being distracted by a change in their usual schedule, or by being in a hurry. For instance, P6 talked about how receiving unexpected calls in the morning, before he has taken his pills, often causes him to forget to take them.

"If someone calls me in the morning and it messes up my routine, or something happens that I have to leave the house suddenly in the morning, I get distracted. I'm doing something else, and then I'll forget. [...] There were three or four days where I forgot everyday, just because I was talking with my kids a lot. [...] And I receive a lot of phone calls from clients. Those are the things that I get on a continual basis, that will always throw my schedule off. And it happens five times out of a seven day week." (P6).

Participants also sometimes decided to take their pills later on purpose due to conflicts between side effects and their personal or professional lives. As an example, P3 avoids taking water pills before she needs to leave the house during the day. When going out is part of her schedule, she often decides to take them later in the day. But, because this decision affects her usual schedule, it can lead to forgetting to take the medicine that day.

"Hydrochlorothiazide is a water pill. If I have no appointments or I'm not scheduled to work that day, I take it in the morning. But if I'm out during the day I don't take it until later, until I'm back home. Because it's a water pill, so obviously I need access to a restroom. And I don't like using public restrooms. [...] If I'm on a regular routine that day, then my pill taking will be regular. But if I venture out from the norm, then my routine is going to be disrupted." (P3).

For other participants, it was challenging to establish a routine for taking medications, because their schedule not regular enough. P5 explained how he did not have a routine for taking medications, because his overall daily routine was very irregular, and that made it difficult for him to remember.

"I try to take it when I remember. Which is at some point during the day. Unfortunately I don't have a consistent time that I take them, so I end up end up forgetting a lot. That's the problem. [...] My days are so haphazard as far as you know, I have meetings and calls and appointments. so even if I get a reminder and I'm in the middle of a call or a meeting, I'm not very good about remembering that later on. " (P5).

Reminders to take medications in the form of alarms were used by multiple participants, most often on their phone or other personal device. For example, P7 uses an alarm on this smartwatch as a medication reminder.

“I have an Apple watch and I have that remind me.” (P7).

Reminders can become unnecessary for patients who have an established routine, but they can be useful when the medication schedule changes, particularly when those changes are temporary. For example, P2 explained that he used alarms in the past, when he had a complicated temporary medication regimen after having heart surgery.

“After the surgery, well I was taking medications every four hours. It helped to have the reminders to do that every so often, but like I said, because my schedule has been simplified now I’m actually just doing it twice a day, it’s not a problem.” (P2).

Participants also shared that they often dismiss their reminders, or do not take the medication as soon as the reminder rings. That is the case of P7, who says that a more persistent reminder could be more effective for him.

“I use the Apple watch, and I have an app on my iPhone that is connected to my Apple watch, which reminds me to take my meds. Believe it or not I still forget. It’s on my wrist, it’ll buzz me three times. See, that’s the problem, it buzzes me three times. I look at it and say, okay I’ve got to get up and take my meds. And then, five minutes later it’ll buzz me again. And for whatever reason, either I don’t feel like it or I’ll look at it and go, ‘okay I’m gonna get up right now.’ Next thing you know, I forgot about it, and it only buzzed me three times. If it kept going I’d be like alright, I’d get up and do it. But it doesn’t give the option to do that” (P7).

Further, all of the issues that affect the routine strategy also affect reminders, since they are set to a specific time. When participants’ schedules change, the reminder alerts them at the wrong time, and it is ineffective.

Increasing the visibility of the medications was a common strategy used by our participants to improve their adherence. This strategy consisted of placing their pill bottles on a visible place, where they are likely to see them, as P5 and P6 reported doing.

“The reason I put them in my bag is because I found that [I’m] a little more consistent if it’s in my backpack, because I have to open it when I get to work and I see it. And I will remember to take it. But if I leave it at home I just forget, so busy. I end up just overlooking it.” (P5).

“I’m trying to keep it up in front of me, so when I get up first thing in the morning, I see it by my TV now. That’s the way I remember, it is right on the TV. I can’t miss it.” (P6).

The participants said that this strategy increased their adherence, but we observed that it was not enough to ensure consistency. Participants who used this strategy still were very affected by barriers such as disruptions in their routine.

Just forgetting, despite having strategies for medication adherence. Multiple participants expressed that they might still forget to take their medications, even when they have an established routine, and there is nothing out of the ordinary that they can identify as causing them to forget. P4 described one of those instances, which had happened recently:

“I just forgot to take it. And [the medications] are there, staring me in the face in the cabinet right above me. I just didn’t take it.” (P4).

In summary, our participants used different strategies to improve their medication adherence. The most common and impactful barrier we observed was disruptions in the participant’s routine. Dismissing reminders before taking the medication also seems to make this strategy less effective. And there are still instances of forgetting for which the participants were not able to identify a particular cause.

Discussion

Our findings suggest that there are many different reasons that lead to unintentional non-adherence, and it is likely that a single solution could not address all of the possible circumstances. People’s needs change dynamically, and they might need different strategies depending on how well they are able to remember their medications, and also depending on changes in their daily lives. Stawarz et al.¹⁵ argued that medication reminding systems should attempt to help users to remember on their own, by associating the medications with a particular task that they already do daily. This approach can assist users to have a routine that can help them to remember. For users who are able to remember

on their own most of the time, reminders may become unnecessary often, and easy to ignore. Reminders might be more effective when they are only active when the user has not taken the medication. Further, they might also become more effective if they respond to disruptions in users' routines by changing the time of the reminder to alert users at a convenient time.

A context aware reminder that detects when the user has not taken their medicine at the usual time, and determines the best time for a notification, could better address this problem. For example, a system that can detect whether users have taken their medications could interrupt the reminder when it is not needed, and continue to alert the user until the medication is taken. To respond to the user's routine, it could utilize information from a calendar and other systems including phone call applications, and activity trackers. It could also remind users when they are engaged in activities that can be interrupted by a reminder, such as reading the news or accessing social media on a personal device.

Conclusion

In this paper we present the preliminary results of an interview study investigating unintentional non-adherence to medications. Our findings indicate that experiencing disruptions in a regular routine, or having a schedule that changes often can cause forgetfulness. Context aware systems are likely to be better suited for addressing these situations in comparison with strategies such as timed reminders.

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