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Supporting Reflection on Medication Adherence: Eliminating a Blind Spot in our Rearview Mirror

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Abstract—Prescription medications are a vital form of medical intervention. About two thirds of adults in Canada and the U.S. have prescribed medications and statistics in comparable countries are similar. It is common for older adults or those with chronic conditions to take multiple different medications. The safety and effectiveness of medication-based therapies requires that patients adhere to their prescriptions. Improving adherence has been identified as a challenge (and opportunity) to increase health and wellbeing. Among the many factors that may impact adherence (including socio-economic status) are forgetfulness, unwanted side-effects, perceived lack of benefit, lifestyle conflicts, etc. Reflecting on past behaviours can help patients (and their care providers) to optimize adherence. Unfortunately, reflection is not well supported by current tools and technologies and relies on patient recollection and crude methods like pill counting. The CHAOS (Collaborative Health Adherence Optimization System) project seeks to address this “blind spot.” This paper reports on the requirements for reflection views elicited in the CHAOS project and a prototype design of a reflection tool.

Keywords—medication adherence, reflective practice, requirements

I. INTRODUCTION

Medication drugs play a key role in managing health processes for a large part of our population. About two thirds of adults in Canada and the U.S. have medication prescriptions and older adults often are on multiple prescriptions [1]. The safety and effectiveness of drug-based interventions requires that the patients *adhere* to their prescriptions. Medication adherence has been defined as the degree to which a patient’s medication behaviours are congruent with the recommendations and instructions of their healthcare provider regarding timing, dose, and frequency [2]. The World Health Organization (WHO) has identified medication adherence as “a worldwide problem of striking magnitude” and an opportunity to increase health and wellbeing [2].

There are many causes for non-adherence, including socio-economic factors, forgetfulness, misinterpretation of instructions, unwanted side-effects, competing lifestyle choices, etc. [3]

While there is no generally accepted metric for adherence, there is consensus that considering adherence is important to

ensure an effective treatment process. As expressed by former U.S. Surgeon General Dr. Koop, “Drugs don’t work in patients who don’t take them” [2].

Adherence may be measured *directly*, i.e., by observing patients while taking their medications, or *indirectly*, e.g., based on patient self-reports, pill counts, pharmacy records on refill rates and intervals, etc. [2] The adherence behaviour of community-dwelling outpatients is rarely measured directly due to the cost and invasiveness of such measures. Unfortunately, indirect measures are currently either crude or unreliable (or both) [2]. Pharmacy records (where available) just show that a prescription has been filled. They provide no information whether it has been taken correctly or at all. Assessments based on the patient’s ability to recall their behaviour or not well supported, inaccurate and prone to bias [2].

A prerequisite for optimizing adherence is to thoughtfully consider the factors that have contributed to (non-)adherence. The term *reflection* is suitable to describe this process, given its meaning as giving “serious thought or consideration” (Oxford Dictionary). *Self-reflection* may enable patients to better understand their subconscious beliefs, experiences, choices, and perceived conflicts. *Collaborative reflection* between the patient and their care provider may be helpful for negotiating an altered prescription that better suits the unique needs of the patient [4].

The CHAOS (*Collaborative Health Adherence Optimization System*) project has the objective to develop tools to support medication adherence. While the scope of the project is wider, this paper focusses on the *reflection* aspect of the CHAOS system, particularly on the requirements for the reflection tools. It presents a preliminary requirements model and a prototype that were informed by a literature review, a preliminary user study, and consultation sessions with domain experts in human-computer interaction and medicine.

The rest of this paper is structured as follows. The next section provides an overview on the work related to this research project. We discuss the requirements elicitation and design process in Section III. Section IV presents the high-fidelity prototype designed in our project and Section V discusses preliminary insights gained while planning a second user study for evaluating the usability of that prototype. Finally, we draw

conclusions and highlight opportunities for future work in Section VI.

II. RELATED WORK

A range of technology-based interventions have been proposed for increasing medication adherence [5]. They range from simple reminder systems utilizing general-purpose devices (e.g., phones) to dedicated devices like smart pill bottles [6]. One problem that is common to many current technologies is the lack of scheduling flexibility, i.e., medication schedules are mostly static and always occur at the same times. This fails to accommodate patients with active lifestyles and frequently changing daily schedules, and those patients who need to re-adhere after missing doses. In such cases, patients may want to reschedule medication administration to fit their changing commitments. The main challenge with allowing schedule changes is to ensure that these changes remain adherent to the providers' prescriptions and avoid unsafe situations like, for example, drug interactions due to multiple medications taken too close together. In previous work, we developed a prototype integration of a medication scheduling tool with a general-purpose calendar, which performs automatic safety checks [7]. One of the outcomes of a user study on this prototype was a goal to support *reflection* on past adherence. The current paper focusses on elaborating this user goal with an analysis of the requirements on reflection support.

Reflection has long been an accepted best practice in healthcare from the perspective of a care provider [8]. Unfortunately, current clinical information systems do not provide much support for reflective practice [9]. Janssen et al. refer to this missed opportunity as a *blind spot* that has been overlooked so far [9]. From a perspective of patient self-management, technology-supported tools for self-reflection exist and show promise in promoting healthy behaviour [10][11]. Salib et al. present a prototype study on the role of reflection on adherence to HIV medications [12]. Their results indicated strong patient support for the usefulness of such a tool (80% of participants would use such a tool). Two qualitative findings were highlighted as a result of their study: (1) the need to provide *contextual information* surrounding the medication routine and (2) the need to easily evaluate the data collected [12]. One of the reasons why technologies for managing adherence in patients with HIV has been of particular interest is the cost of the pharmaceuticals involved in these treatments. A related aspect, that has been highlighted in this context is the requirement for *privacy* and the need to consider undesired side-effects of technologies that may lead to stigmatization and depression [13]. These requirements have also been indicated in our earlier user study on a prototype integrating medication schedules with a general calendar [7].

Choe et al. report on a study of the data presentations by members of the quantified-self movement (Q-Selfers) and categorized recurring types of visualization insights presented [14]. Asiniero et al. present Activity River, a tool for visualizing planned and logged personal activities for reflection [15].

Our work was informed by several theoretical frameworks and guidelines for designing and evaluating tools that support reflection. Below we discuss the three works in this area that have been most influential in our analysis and design:

Fleck and Fitzpatrick identify three aspects of reflection: (1) the purpose of reflection, (2) the conditions of reflection (i.e., creating the 'right' environment), and (3) the levels of reflection [16]. For the last aspect, they define five levels: *R0-Description* (simple revisiting of events), *R1-Reflective Description* (revisiting with explanation), *R2-Dialogic Reflection* (exploring relationships), *R3-Transformative Reflection* (fundamental change), and *R4-Critical Reflection* (wider implications) and summarize techniques supporting each level.

Bentvelzen et al. introduce a scale for evaluating personal reflection technologies, based on three dimensions: *insight* (knowledge gained), *exploration* (ease of use/enjoyment) and *comparison* (within social group) [17].

Cuttone et al. introduce four design heuristics for creating and evaluating reflection tools on self-tracking data [18]: (1) make data interpretable as a glance, (2) enable exploration of patterns in time series data, (3) enable discovery of trends, and (4) turnkey metrics into affordances for action.

III. REQUIREMENTS ELICITATION AND ANALYSIS PROCESS

This section provides an overview of the process applied for eliciting and analyzing the requirements for the reflection tool support in CHAOS. The method combines literature research, agile requirements engineering with prototyping, user studies, ideation sessions, and expert reviews. Fig. 1 provides an overview.

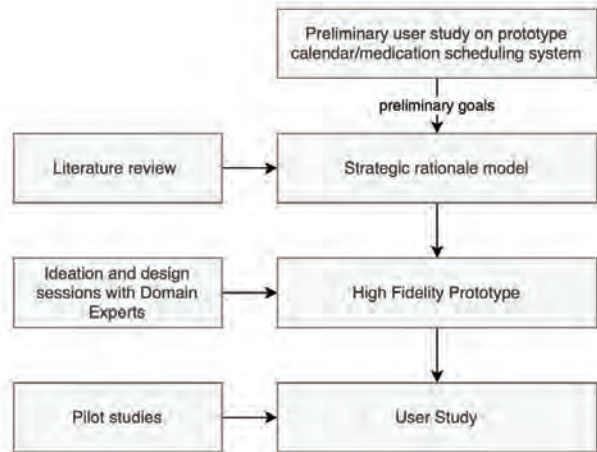


Fig. 1. Research method - overview

A. Preliminary user study

The requirement to support reflection and considerations related to such a feature resulted from a preliminary user study with an early prototype of the CHAOS system, which did not support reflection. It focussed on the integration of medication scheduling functionality with the functionality of a general-purpose calendar app. The preliminary user study involved 12 participants between 35 and 65 years old, who were either taking prescription medications or helping a family member or friend with their prescription medications. The results have been detailed in [7]. We use the following quote from a study participant to provide context for the first goal *G1 - Self-*

reflection: “Medication entries should have separate designs for entries that are future and those that are past. Past entries should allow for reflection of past medication-taking behavior by confirming whether the user took the medication or not.”

Several quality goals have been identified because of the preliminary user study; Some of them are generic to “good” design, such as the goal to avoid clutter and the goal to leverage design elements that are familiar to the user. These goals have been considered in our work, but we do not discuss them here due to their generic nature. Still, two quality goals are worth highlighting since they are of relevance to our application focus on medication adherence.

Quality Goal QG1-Privacy Study participants raised the need for *privacy* related to their medication information. Calendars are frequently used tools and people in the proximity (e.g., colleagues and family) may catch a glimpse of sensitive health information. Moreover, calendars are collaboration tools. Information in calendars is sometimes shared with peers (e.g., collaborators, family, friends, etc..) to facilitate joint events. Some peers may have permission to allocate events or “move things around.” The risk of privacy violations needs to be recognized not only during regular calendar use but also during reflective use.

Quality Goal QG2 – Unobtrusiveness Participants mentioned the desire for *unobtrusiveness* with respect to the medication information. They did not want to be constantly reminded of their health condition whenever they look at their calendar. A quote from a participant provides context on this goal: “Well, I don’t like again, but there’s so much emphasis on the medication, it’s almost like the medication takes precedence. And everything else that you’ve got going on your life is almost insignificant.” [7] Again, this goal is relevant beyond event management and extends to reflection tools.

B. Strategic Rationale

As the second step in our process, we set out to analyze the strategic rationale and dependencies of the actors involved in medication management, adherence, and reflection. This process was informed by the literature (medicine and HCI) and the domain expertise provided our interdisciplinary research team members, which includes a health care practitioner, an information visualization expert, and a software engineer.

We chose the iStar method (version 2.0) for modelling and analysis [19]. An iStar strategic rational (SR) model consists of agents (roles), their goals (functional as well as quality goals), and the dependencies of agents on other agents to reach their goals. The iStar notation represents actors (roles) as circles, goals as ovals, quality goals as clouds, tasks as diamonds, resources as rectangles, and dependencies as relationships linking a depender role via a dependum (goal, resource, or task) to a depedee role, see Fig. 2.

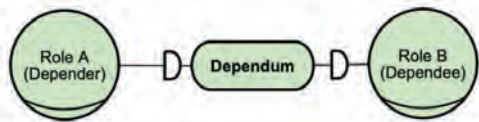


Fig. 2. General form of an iStar dependency

1) Roles

Since our system integrates regular calendar functionality with medication management and given the quality requirements for privacy and unobtrusiveness when using the app, we decided to separate two separate roles for the user, the general *Calendar User*, and the *Patient*. Analogously, the application (app) appears in to separate roles, the general *Calendar App* and the health-focused *Calendar and Medication App*. We also modelled the *Healthcare provider* and the *Social peer* (e.g., colleague, family member, friend interacting with the user’s calendar) as separate roles, given their importance.

Fig. 3 depicts the identified roles and their strategic rationale in iStar notation. The diagram highlights the three previously identified goals (G1, QG1, and QG2) in yellow. Resources that specifically focus on self-reflection are highlighted in blue. The following subsections describes the rationale and dependencies for each role in more detail.

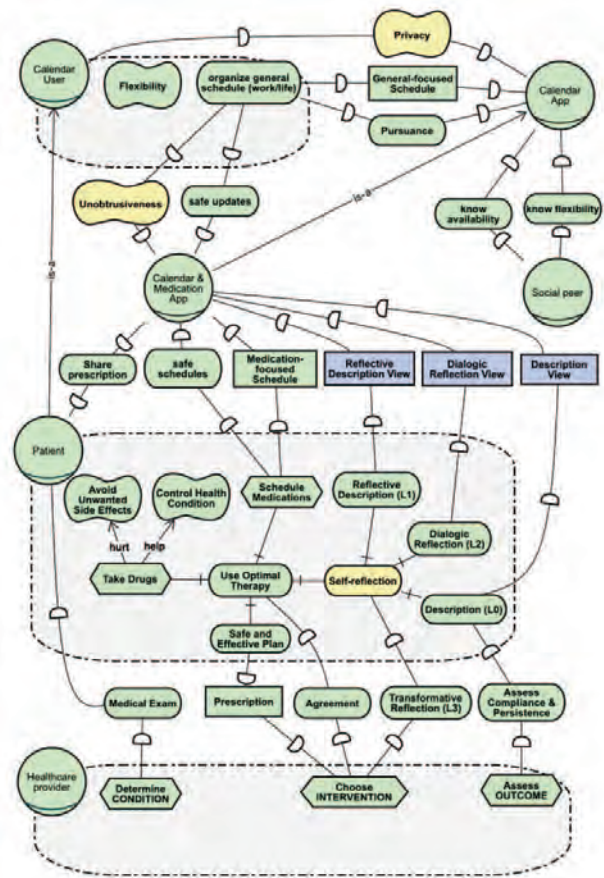


Fig. 3. Strategic Rational Model for the CHAOS Reflection Tool

2) Patient Rationale and Dependencies

The patient’s primary quality goals are to control their health condition and avoid unwanted side effects associated with the treatment. The drugs patients take to help control their health condition may hurt their goal to avoid side-effects. Patients have the goal to find the optimal therapy for them, which means it must be safe and effective (as assured by the healthcare

provider's prescription) and it must work for them upon reflection and considering alternatives. Patients need to schedule their medications using the Calendar and Medication App (CMA), such that the resulting schedules are safe, i.e., they agree with the prescription. They depend on the CMA to check safety.

The patient's goal for self-reflection has been broken down into three sub-goals, following literature guidance on the various levels of self-reflection [16]. The reason to separate these levels is to allow quick and efficient interaction with the application [18]. As Fleck and Fitzpatrick point out, reflection takes time and happens at distinct levels of engagement [16]. At the lowest level (Description – L0), patients merely describe which (medication) actions were taken. The information at this level is sufficient to judge the degree to which the medication plan was followed. At the second level of reflection (Reflective Description – L1), patients include justifications or reasons for action (or inaction) in a reportive manner. The third level of reflection (Dialogic Reflection – L2) explores relationship between pieces of knowledge, e.g., patterns of actions related to unwanted side effects, observed health outcomes, or aspects of work-life scheduling concerns. These reflection goals are supported by appropriate views provided by the CMA.

3) Provider Rationale and Dependencies

When it comes to drug-based therapies, healthcare processes can be characterized as iterative loops where the healthcare giver determines the condition of their patient (for example by using lab tests or other forms of examination), choosing an intervention (for example, writing a prescription), and assessing the outcome of the intervention (considering the changes to the patient's condition as well as whether the patient adhered to the recommended therapy).

Decisions on interventions have shifted from healthcare providers as the main (or sole) decision-makers to a shared decision model, empowering patients as essential partners in the process [20]. Effective medical decisions require agreement between caregivers and patients. Most current definitions of the term *adherence* (in the medical context) presuppose patient/provider agreement. For example, the WHO defines adherence as “*the extent to which a person's behaviour ... corresponds with agreed upon recommendations from a health care provider*” [21]. Of course, it is possible to follow the recommendations of a provider without (fully) agreeing to them. It is also possible to agree with a recommendation without following it. The medical literature uses the term *compliance* rather than adherence to describe this property [22]. While the term adherence is favoured in modern healthcare due to its emphasis on shared decision-making, it is useful for reflection to separate the objective concern about what happened (actions or non-actions) from the concern about the alignment of opinions about the treatment plan. A third concept used in the context of medication adherence is that of *persistence*, which has been defined as “*the length of time between initiation and the last dose, which immediately precedes discontinuation.*” [22].

The ability of healthcare providers to assess the outcome of a therapy depends on their patient's descriptive reflection goal. At a more fundamental level, healthcare providers and patients may engage in a transformative reflection process with the intent

to revise a therapy or contextual factors like lifestyle choices, etc. Such deeper reflection is referred to as Transformative Reflection (Level 3) in Fleck and Fitzpatrick's taxonomy.

4) Calendar User Rationale and Dependencies

The goal of the Calendar User is to organize their general work/life schedule with the help of a Calendar App that provides a general schedule of events and helps with the pursuance of commitments (for example by issuing reminders). The main quality goal considered in our model is flexibility. Calendar users in our target group lead active lives and need to be able to update their schedules frequently. However, these updates should stay safe with respect to their medication therapy. Calendar owners rely on the CMA to check updates for safety. They otherwise want the CMA to be unobtrusive. Calendar users rely on the Calendar App to protect their privacy, with respect to social peers who may interact with the app.

5) Social Peers Rationale and Dependencies

Social peers need to know the availability of the Calendar User to schedule joint meetings (or schedule meetings on behalf of the Calendar User). Social peers may also need to know flexibility constraints, so that they can suggest resolutions to conflicts. Some events may be movable while others may not be. These constraints may be complex when drug therapies are involved.

6) CMA and Calendar App Rationale and Dependencies

The ability of the CMA to check the safety of schedules depends on the Patient sharing their prescription (in computer-interpretable form). The Calendar App does not depend on any role.

IV. HIGH FIDELITY PROTOTYPING

Our requirements engineering method is agile and makes extensive use of prototypes [23]. In our earlier work, we created a set of alternative low-fidelity prototypes in a preliminary user study to elicit requirements and design considerations for integrating medication schedules with regular calendar apps [7]. The requirements to support reflection, privacy and unobtrusiveness were elicited because of this prototyping work. An analysis of the strategic rationale of the involved actors (informed by a literature review) has identified the need to support reflection at distinct levels (*L0-Descriptive*, *L1-Reflective Descriptive*, and *L2-Dialogic*). The corresponding reflection views are indicated with blue colour in the iStar model (Fig. 3). Moreover, a fourth level of reflection (*L3-Transformative*) has been identified as a shared dependency between patient and health provider. The development of tool support for this fourth level is out of the current scope of our project.

Informed by our earlier prototype study and the analysis of strategic rationales, we designed a high-fidelity prototype of an integrated calendar/medication scheduling app. The design of this prototype was iteratively refined through joint ideation sessions with domain experts and several pilot user studies. This section describes the high-fidelity prototype resulting from this process.

Since the goal of the work has been to integrate medication adherence management with the functionality of a normal

calendar system, we decided to develop our prototype based on an existing calendaring tool, rather than to construct it from scratch. We reviewed open-source calendaring applications as potential candidates for our implementation and selected *FullCalendar* (fullcalendar.io) due to its familiar appearance and its extensible architecture. *FullCalendar* is browser-based and its “look and feel” is like that of other commonly used browser-based calendars (e.g., Google Calendar). Its architecture is based on extensible frameworks including React, VUE, and Angular.

In the following subsections, we describe how the three levels of reflection are supported by this high-fidelity prototype. (Given that the specific focus of this paper is on *reflection*, we do not discuss other aspects of the prototype, e.g., entering of prescriptions.)

A. Description – Level 0

Looking forward in time, scheduled medications appear in the calendar as *planned* actions. Looking backwards, however, descriptive reflection is about recording which actions happened, as well as contextual information. (Such functionality is not normally supported by calendar applications.)

1) Medication action status

Medication actions that appear in the past are associated with a *status* attribute, which can take one of four values:

- *pending* (default): waiting for user input (i.e., it is unknown by the system what happened with this planned action),
- *taken*: the medication has been taken,
- *missed*: the medication action has been missed,
- *unsure*: the user is not sure whether this action was taken.

Fig. 4 shows an example of a calendar view looking at medication events “in the past”. Their status is indicated by circular icons, where a green checkmark means “taken,” a red cross means “missed,” a yellow exclamation mark means “pending,” and a blue question mark means “unsure.”

Fig. 5 shows two “dashboard-style” summary views of a patient’s adherence overall. The left-hand side (A1) provides a simple, directly actionable score for adherence, which is simply computed based on the medication events marked as “taken”. The right-hand side (A2) provides a more detailed view, which breaks down the adherence score with respect to missed (but scheduled), missed (unscheduled) and pending events.

The status of a past medication action can be recorded in a pop-up dialogue (see Fig. 6).

2) Contextual information

a) Timing

Timing is perhaps the most important contextual information when describing medication actions for adherence. In a Calendaring system, the simplest way of recording that a past medication action deviated from its planned time is by moving it to a different time slot in the (past) schedule. (Moving a past medication action into a future time slot automatically converts it back to a planned action. Moving a planned medication action

to the past converts it to a past action with a default status set to “taken.”) Time deviations can also be recorded in the descriptive dialogue (Fig. 6).

b) Dosage

Dosage is another important contextual information to be reported. After discussions with domain experts and pilot users, we decided to limit our design to two *dosage states* (“normal” and “modified”) as part of the *structured* information content. Users are free to enter any details (such as the actual dosage amount) in the (unstructured) “Notes” section (cf. Fig. 6). Modified doses are shown as green half circles in the calendar retrospective view (cf. Fig. 5, centre).

c) Gastric status

Many medications interact with food, and some may upset the stomach. Therefore, prescriptions often contain directions like “take with food” or “take on an empty stomach.” Medications that should be taken with food are indicated with a “knife and fork” icon in the calendar (cf. Fig. 5). Medications that should be taken on an empty stomach use a crossed out “knife and fork” symbol (not shown in our example).

Independently of whether the provider recommended a gastric status in a prescription, it may be useful for patient reflection to record whether they had a full or an empty stomach when taking a medication action. For example, a patient may experience a side effect (like nausea) only in certain gastric conditions. Our recording dialog supports this (Fig. 6). If a gastric status was recommended, the dialog defaults to the recommendation. Otherwise, it defaults to a global user setting.

To limit cognitive load, recorded deviations from a provider recommended gastric status does not use a separate symbol in the calendar overview. Rather, it uses the “taken with modifications” symbol (green half circle), cf. Fig. 4.

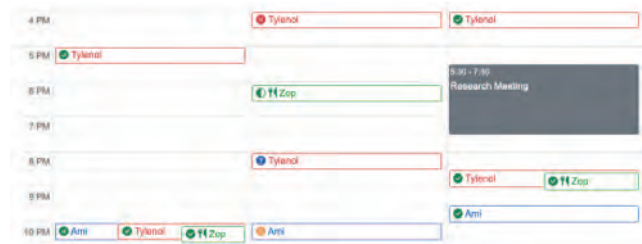


Fig. 4. Representing medication status for descriptive reflection

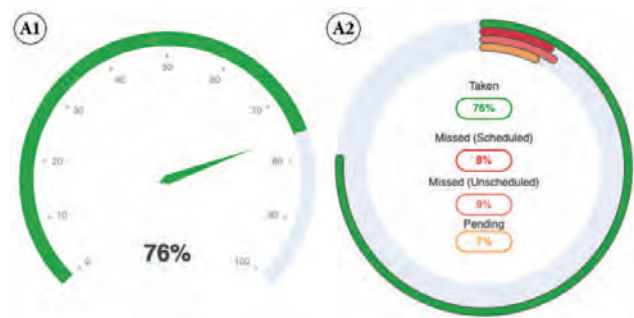


Fig. 5. Summarized Display of Compliance, based on Medication Status

second user study includes an evaluation of the new reflection functionality, it also covers other facets of the application (e.g., entering prescription schedules, comprehending safety warnings, resolving conflicts, etc.).

The design of the second user study is currently pending ethics review and, thus, the results are not yet available at the time of writing this paper. Still, we can share insights gained while designing and piloting the second user study with respect to reflection. Such insights may assist other researchers when preparing a user study for evaluating tool support for reflection.

When planning the part of our user study that focused on reflection, we found it helpful to consider the three dimensions of Bentvelzen et al.'s Technology-Supported Reflection Inventory (TSRI) scale: *Insight*, *Exploration*, and *Comparison* [17]. The TSRI includes nine generic questions that are rated on a 7-point Likert scale. We did not use these questions, because the primary objective of your validation was to assure the usability and acceptability of all aspects of our application (not just reflection). We also found some question of the TSRI not applicable, since they are more suited to a longitudinal field trial of a reflective application with *real* users rather than simulated users who participate in a short-term lab study. Nevertheless, we included specific tasks and questions that cover all three dimensions.

One observation we made when piloting our study design with test participants was that tasks and questions targeting reflection may easily lead to time overruns. Reflection tends to be time-consuming and open ended, particularly at the “high levels.” Piloting user studies is important in any case, but it is particularly crucial when the study evaluates reflective tasks. We piloted three version of our user study before arriving at a study design that was deemed feasible in the allotted time limit (60 minute per user). We found that the tasks and questions that focussed on reflection needed to be revised several times to avoid users running out of time. For obvious reasons, the risk of this problem occurring increases with the level of the reflection (from descriptive to dialogic and beyond).

For example, the question “*Describe what you can learn about the users’ adherence from [view]*” (taken from an early version of our study design) was found to be too open ended, resulting in time overruns. In contrast, targeted questions like “*By looking at [view], which medication is the user most adherent in?*” are less problematic. If open ended questions are desired, they should be moved to the end, indicate an explicit time box, and allow participants to provide an “easy” answer if they are challenged. For example, the question “*Do you want to mention any other things you can learn about the user from [view]?*” allows participant to answer with “no” after spending some time on reflection.

VI. CONCLUSIONS AND FUTURE WORK

The ability to reflect on medication adherence has been recognized as an opportunity to provide a more informed assessment of the outcome of treatment programs and increase their overall efficacy. The work presented in this paper focusses on analyzing requirements for an integrated calendar/medication scheduling tool with a focus on reflection. This work was motivated by results from an earlier user study on evaluating

design alternatives for such a scheduling tool [7]. The requirements discussed in this paper are informed by a literature survey and the consultation of domain experts in HCI and medicine. They have been implemented in a high-fidelity prototype system, which will be subject to a second user study in our agile RE process. The purpose of this second user study is to evaluate usability and acceptability, including but not limited to the reflection functionality of the application. While the results of the second user study are not yet available, we have offered a few preliminary insights gained during the design of this study. Of course, when it comes to evaluating the actual impact of reflective tools on medication adherence, the next step would be to conduct a clinical study with real patients. We plan to carry out such a clinical study utilizing the TSRI scale as an evaluation instrument in the future.

When it comes to the reflective functions currently supported by our prototype, we see opportunities to integrate emerging solutions in the space of smart and wearable health devices. For example, smart medication dispenser may simplify reflection at the descriptive level (Level 0) by automatically recording medication times [6] and wearables may automatically report important contextual information (e.g., heartrate and arrhythmia). Wearables like smartwatches may facilitate Level 1 reflection, for example by presenting specific watch faces or “complications” to indicate the current adherence status. Such watch faces have been used effectively to improve adherence to other health goals like physical activity and workout. For dialogic reflection (Level 2), we see potential opportunities to integrate with conversational artificial intelligence (AI) services like chatbots that have been trained to help patients understand relationships between their behaviour and any recorded contextual information [24].

At this point, the tool support developed in the CHAOS project focuses on patients as users, i.e., it primarily considers patient self-reflection. Still, our agent-based requirements model (SR model) highlights the importance of reflection in shared decision-making between patients and providers. Reflection that results in transformative changes (Level 3 in [16]) will often require collaboration between patients and their providers. While our tool does not directly support collaborative reflection processes at this time, we believe that its capabilities may be used to inform shared decision-making, at the discretion of the patients. Developing tool support with dedicated support for collaborative reflection and shared decision-making on adherence is left to future work.

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