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An Experimental Comparison of a Co-Design Visualizing Personal Drug Information and Patient Information Leaflets: Usability Aspects

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Abstract

Providing patients with specific information about their own drugs can reduce unintentional misuse and improve compliance. Searching for information is time-consuming when information is not personalized and is written using medical vocabulary that is difficult for patients to understand. In this study we explored patient information needs regarding visualizing of drug information and interrelationships by conducting a total of four co-design workshops with patients, other users and pharmacists. We developed a prototype and drug ontology to support reasoning about drug interactions. We evaluated individual performance in finding information, understanding the drug interactions, and learning from the provided information in the prototype compared to using patient information leaflets (PILs). We concluded that interactive visualization of drug information helps individuals find information about drugs, their side effects and interactions more quickly and correctly compared to using PILs. Our study is limited to co-morbid patients with transient ischaemic attack with several chronic diseases.

Keywords:

Drug Interactions; Patient Medication Knowledge; Computer Graphics

Introduction

Patients' misunderstanding about their prescribed medicines and their interaction can cause unintentional misuse, poor adherence and less effective treatment [1]. According to the pharmacists' association in Norway, over 1,000 patients die each year as a result of side effects and inappropriate use of drugs. Adverse consequences of the use of drugs are in addition to death or injury. Errors can occur because the patient is using medicines incorrectly due to insufficient information and miscommunication, and patients who are not in charge of their own medication are especially vulnerable to failure [2; 3]. Studies show that patients with limited literacy were more likely to misinterpret instructions, and precise wording on drug label instructions can improve patient comprehension [1]. On the other hand, according to the pharmacists' association in Norway, patients' poor compliance caused one out of three patients in Norway to not take their medicines due to fear of side effects. The number of patients with several chronic diseases is increasing and this has caused a decrease in the likelihood of good compliance due to the difficulty of keeping track of the reasons for taking drugs and how or when to take the medicine, especially by elderly patients [4; 5]. Studies show that better and more accessible information on drugs can help increase patient compliance [6].

There are many drug information sources available in Norway, including patient information leaflets (PILs) and websites for patients. Sources such as PILs, helsenorge.no, Legemiddel-håndboka.no and interaksjoner.no are available for drugs prescribed and marketed in Norway, however the available information is not individualized for each patient and often uses many medical words and phrases that might be difficult for individuals without knowledge in medicine to understand.

Although presenting and visualizing drug information to the healthcare professionals about adverse drug reaction, drug overdoses and drug combinations for multi-drug users has been a subject of interest for many years, enabling patients to easily access their drug information and be informed about adverse reactions has largely been neglected. Therefore, in this study we explored the individual's information needs regarding their medication, and how to visualize drug information (including drug interactions) in a way that is understandable for individuals without a medical background. Based on the collected data and involving patients and pharmacists, we developed a prototype that visualizes personal drug information. We evaluated individuals' performance in finding information, understanding the drug interactions and learning from the provided information in a prototype, compared to using PILs. To limit the scope, we focused on patients with transient ischaemic attack (TIA).

Material and Methods

In order to envisage concrete application examples,we developed personae and user stories in collaboration with a senior pharmacist to describe the target audience of the prototype. Use of personae in an interview with patients and users is a useful approach in order to avoid asking personal questions related to the interviewee's health condition and medication. The experiment was conducted in two parts.The goal of the first experiment was to identify requirements via co-design workshops in order to develop the prototype. The second experiment was performed to compare the visualization of drug information in the developed prototype to the PILs. In each of the experiments we applied different methods that are explained in this section.

Personae

In order to cover the largest possible number of common patient traits, a total of five personae were developed illustrating different types of patients. Three of the personae experienced transient ischemic attacks while suffering from other chronic diseases with the age range of 27- 87 years old. The other two personae were: one female persona with epilepsy was planning to become pregnant, the other persona

had multiple diseases (high cholesterol, diabetes, urinary tract infections) and therefore used number of other drugs with different symptoms such as headaches and depression.

Identifying Requirements through Co-Design Workshops

To identify requirements and explore how to visualize drug information, we applied co-design principles [7]. Hence, we conducted a total of four co-design workshops. Two of the co-design workshops were conducted together with pharmacists, and in the other two workshops we recruited participants (patients and volunteer participants) in order to include their perspectives on the design and visualizing of drug information. Results of the co-design workshops have been used to design and develop the digital prototype and competency questions [8] in order to design the drug ontology for the prototype. Details about the designated ontology based on the competency questions are provided in the "Design of the Ontology" section.

Co-Design Workshops with Pharmacists

A total of two pharmacists (one pharmacistwho works at the counter at the hospital pharmacy and one clinical pharmacist) participated in our workshops. They were selected based on the purposive sampling method [9]. The goals of the workshops with the pharmacists were to understand patients' information needs about medicines, explore alternatives on presenting drug information to patients, identify functional requirements that the prototype needs to support, identify the competency questions that the ontology needs to answer, and create the conceptual design [10] of the prototype.

The first workshop consisted of five steps: 1) semi-structured interview on how pharmacists interact with patients; 2) semi-structured interview about what the pharmacists expected the patients' information needs to be; 3) pharmacists were asked to make a sketch of a system that would introduce personal drug information to a patient while thinking aloud; 4) discussion about the designed sketch from part 3; and 5) ranking the identified requirements based on their importance to be considered in the design of the prototype. To ensure the results were not affected by the order of the performed tasks, we reordered steps 2 and 3 for each pharmacist. The goal of the second workshop was to test the designed paper mock-up [10] and receive the pharmacists' feedback on the presentation and user interface.

Co-Design Workshops with Users

Since our project focused on patients with TIA, we contacted St Olav Hospital in Trondheim to recruit patients for our co-design workshops. A total of two patients diagnosed with TIA voluntarily participated in our case study. In addition, we recruited a total of ten students, employees and their families from the Norwegian University of Science and Technology (NTNU). Participation in our case study was voluntary, as we sent emails to student and employee mailing lists and requested volunteer participation. The goal of the workshops with patients and other volunteer participants was to identify drug information needs, elicit requirements for a user-centred design by involving users in the design of the prototype and to test the paper prototype. Furthermore, we also focused on identifying the competency questions that the ontology needed to answer in the workshops.

In the first user-workshop, the personae and user stories were given to the participants and we conducted a semi-structured interview in order to identify requirements with regard to the participants' information needs. In the second workshop, the designed paper mock-up was presented to the participants, and in the semi-structured interview they could give feedback on the presentation, including the detail of the presented information, user interface and navigation, all based on the defined task set to evaluate whether all the tasks could be enacted. Results of the workshops contributed to the conceptual design of the prototype.

Design of the Ontology

To implement the prototype, we built a knowledge model of drug information in the form of an ontology. Competency questions define ontology requirements by indicating which questions the ontology should be able to answer with high-level coverage [8; 11; 12]. The competency questions are the questions that end-users would ask given the ontology about the drugs; hence in the four mentioned workshops we identified a set of competency questions.

We conducted a literature search to investigate the potential available ontologies. We identified Drug Ontology (DrOn) [13; 14], Drug-drug Interaction and Drug–Drug Interaction Evidence Ontology (DIDEO) [15], Drug Interaction Ontology (DIO) [16], Drug–Drug Interactions Ontology (DINTO) [17], and one comprehensive collection of marketed drugs in Japan, the USA and Europe (KEGG DRUG database) [18]. The ontology for our prototype was required to support reasoning and answer all the competency questions, and support Norwegian clinical terminologies (ordnett.no, ICD-10, MeSH terms, finnkode.no and Norsk Legemiddelhåndbok (the *Norwegian Drug Handbook*)). Since we could not address our requirements based on the identified ontologies and database, we designed our own ontology based on the personae, the competency questions and the *Norwegian Drug Handbook*. We note that since the project scope is limited, our ontology is only able to support medical terms and reasoning for the personae we developed for this project. Therefore, information about symptoms treated by a selected list of drugs related to personae (patients with TIA and multiple chronic diseases taking several drugs), active ingredients, adverse effects and dosage, are included in the ontology.

Comparison of Patient Information Leaflet and Prototype

We recruited a total of 13 participants by contacting St Olav Hospital and students at the NTNU. In order to reduce the risk of learnability of the scenario subjects, we divided the participants into two groups: one group (seven participants) only used the PILs while the other group (six participants) only had access to the developed prototype. We applied different methods to analyze and compare the PILs and the prototype that visualized the information about the drugs. The applied methods were: 1) pre-test questionnaire (questions about participants' age, their competence using a computer, and previous knowledge about the drugs we were questioning about in the case study to control for previous experience and its effect on the results); 2) scenarios and tasks (persona was given to participants followed by a total of seven tasks); 3) usability questionnaire (System Usability Scale (SUS) forms [19]); 4) semi-structured interview; 5) learning outcome questionnaire (to examine the extent to which the participant learned something from the given tasks without access to the prototype or PILs). In the last step (measuring learning outcome), we considered both 'learning by remembering information', which is linked to the given statements, and 'learning that goes beyond the statements'. This was performed to investigate whether users acquire more knowledge using the prototype with intuitive visualization than with the PILs.

Data Analysis Methods and Metrics

For analyzing the collected data from semi-structured interviews and workshops, we applied the open coding method [20] in order to identify a list of concepts, group them based

on their similarities or related phenomena, explore the relationships between them and generate categories of concepts. We evaluated participants' task success rate by reviewing their written responses to the given questions in the scenario. We also measured the task completion time for each participant and calculated a geometric mean to present overall performance of the participants in task completion time, as the geometric mean is a better estimate for small samples (n <25) [21].

Results

Information Needs

The interview with the pharmacists showed that they believed that all drug information was available on the Internet, but that some of the information was difficult to understand without the professional background of a pharmacist. The language, in which the information is to be presented, should be informal and easy to understand by the patient. As an example, none of the participants in the co-design workshops understood the term 'drug interaction'.

We identified a total of eight themes regarding the information needs: reason for taking a drug, dose and duration of treatment, practical use (when and how the drug should be taken, e.g. without food and with plenty of water), side effects, photos of the drugs, information about generic drugs, combination with vitamins supplements and natural products (herbal medicines), and their interaction. Based on the interview with the pharmacists, we found that information that is given by pharmacists to patients can be misunderstood. For example, one pharmacist told a story about a patient who was given an allergy spray because she was allergic to her cat. Later the same patient returned to the pharmacy because she was dissatisfied with the effect of the allergy spray. The patient explained that she had sprayed the cat every day, but that she was still suffering from allergic reactions. The patient had thus misunderstood and thought that the spray was for the cat and not to be used by her. Therefore, it is necessary to present the method of application or use of medicine and this should include over the counter drugs (OTCs). OTCs could also have side effects, interact with other drugs, including herbal supplements, and can sometimes cause serious health problems, especially in older adults [22; 23].

Visualizing Drug Information and Functionalities in Prototype

In the co-design workshops we explored how to present information about the drugs and visualize their interaction in textual description and graphs. We used the information about drug interaction from the web page at www.interaksjoner.no. However, we presented information using simple language than the web page and did not display any anatomic therapeutic chemical (ATC) codes. We also explored how to add additional features and information to the interaction graph, such as zooming, removable nodes, the ability to highlight specific parts of the graph, adding information about side effects, overlapping effects and interactions. We also explored presenting side effects in a word cloud, tiles inspired by VIE-VISU [24] and how to use the search function to find side effects. In the visualization we also evaluated presenting information to seniors who often have poor eyesight. Figure 1(a) presents our paper mock-up regarding drug interaction and Figure 1(b) presents the screenshot of the prototype.

The implemented functionalities, based on the co-design workshops and feedback received from pharmacists, patients and users, are: login with high level of security (level 4) in Norway, which requires a national identity number, security token from a bank and a personal password [25]; add and remove drugs (including non-prescribed drugs) in the personal drug list; present possible side effects and indicate how common and how serious they are; present possible drug interactions and indicate how common and how serious they are; present what disease the drugs are intended to treat; present multiple drugs with the same active substances; display warnings for food and beverages that should not be combined with the drug(s); display warnings if the drug affects the ability to operate heavy machinery; present long-term effects of taking drugs; a warning to seek medical advice when necessary; include a photo of the drug; support to report experienced adverse reactions for each user; and display the expiry date of the drugs, customize how much information should be visible to them, and customize the display of information to specific populations (e.g. for elderly patients with poor eyesight). The prototype supports a search function, so it is also possible to search the drug symptoms either by entering the search keyword or by clicking on the body part of a human figure designated in the interface. The drug interactions and symptom interactions are presented in the graph in different colored clickable nodes with details presented in a pop-up window. The prototype supports the automatic updating of the interaction graph and the search results if a new drug is added to or removed from the drug list.

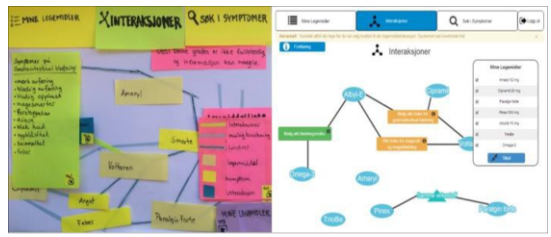

Figure 1– (a) Paper mock-up, (b) Prototype- in Norwegian

Comparison between Drug Information Leaflet and Prototype

People aged 23 to 70 participated in our experiment; the average age in group 1 (PILs) was 37.8 and in group 2 (prototype) 34.5 years old. Based on the pre-test questionnaire, all participants had good computer skills, their educational level was generally high, but was on average slightly higher in group 2. The term 'drug interaction' was unclear to the participants. Figure 2(a) presents a comparison of the geometric mean of task completion time between the two groups. Figure 2(b) presents the average SUS score between the two groups. Figure 3 presents the percentage of the task completion rate between the two groups.

We considered two different forms of learning in the evaluation (learning by remembering information linked to the statements and learning that goes beyond the statements). Figure 4 presents the percentage of learning outcome for group 1 and group 2. The learning outcomes were low for both groups, but we could see that users acquired some knowledge about their medicines, both through the PILs and the prototype; however, participants using the prototype seemed to learn more (learning by remembering information) about the drugs compared to the other group. Based on the presented comparison between the two groups, we could see that 'learning beyond the statements' was very low in both trials, but it was higher when using the PILs.

Based on the semi-structured interviews, participants stated that the PILs language was difficult to understand, lacked proper structure and contained too much information; it took quite a long time to read through the whole leaflet. They had to skim through the content rather than reading everything in detail. In addition, although some of the participants using the PILs could identify the drug interaction, they did not consider the statements to be correct as they did not understand the presented information. The prototype was described as intuitive, time-saving, easy and effective to use in finding information, logically structured and easy to understand. Several participants emphasized that the interaction graph made it easy to find information about drug interactions and how all the drugs worked together.

Figure 2– (a) Geometric mean of task completion time, (b) Right: average SUS score

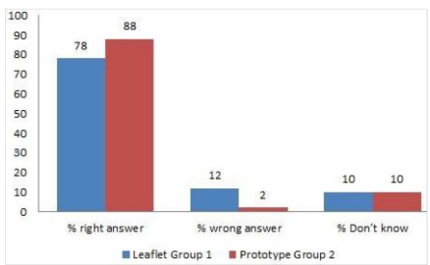

Figure 3– Comparison of task completion between two groups

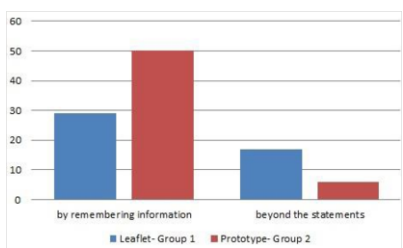

Figure 4– Comparison of learning outcome (in percentage)

Discussion

Based on the results in Figure 2, participants could finish the tasks faster when using the prototype than the PILs. We are aware that faster task completion may have led to more errors and affect the task success rate. Therefore, we compared the task completion time versus task success rate in order to analyze the time spent in relation to the number of correct answers. Figure 5 presents the average time spent for each correct answer for the two groups. As is presented in Figure 5, the time spent (in seconds) was lower per correct answer using the prototype. Taking the participants' age and education into account and their effect on task completion time, we could not see any correlation between them.

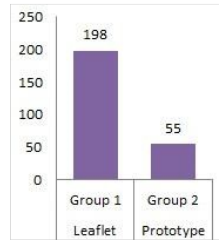

Figure 5– The average time spent (s) for each correct answer

We added adjectives to the SUS scores, as suggested by Bangor et al. [26], to better understand the SUS scores. The results of our SUS scores and their mapping to an adjective ranking scale are presented in Figure 6. We could see that the prototype is in the 'acceptable–excellent', while the PILs are in the 'marginal–low' range. This supports our findings from interviews and the results that are presented in Figure 2 and Figure 3, i.e. that the prototype is more usable than the PILs.

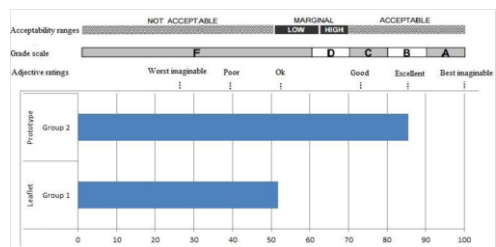

Figure 6– Adjective rating scale [26] *added to SUS scores*

One limitation of this study is that the sample is biased towards 13 participants, who could only access either the PILs or the prototype. Another limitation is that our prototype only supports certain personae and was limited to a certain number of drugs based on the developed personae. We did not evaluate the system in a clinical setting, and patients could have access to the system at home. This will be considered in future work. Conducting a case study in the future on both sources of information for all participants with a different set of tasks is another consideration. A new experiment may be carried out to explore how visualization could be adapted to different patient groups. For example, there is an opportunity to examine whether cancer patients have different needs to stroke patients, or whether women and men prefer different ways to view personal drug information.

Considering the results from the learning outcome, specifically 'learning that goes beyond the statements', a detailed study is required to investigate why users learned more from the PILs than the prototype, or to evaluate whether the results from our case study are generalizable or can be different with another set of participants.

Conclusion

In this paper we present the process of co-design to identify requirements for developing a prototype system for interactive and visualizing personal drug information. In addition, a case study was conducted to compare the developed prototype to PILs and evaluate users' task completion success rate, task completion time, learnability and usability. The analysis led to the assertion that using the prototype to find information is faster than using the PILs and the prototype is more usable than the PILs. Participants who used the prototype made fewer

mistakes. Understanding the drug interactions based on the PILs was cumbersome for the users. The results showed that presenting a lot of information in the PILs and using high-level language with no degree of personalization affected the task success rate and the time spent in finding answers. The experiment showed that, using the prototype users were more successful in recalling information related to the assessment of the statements. We conclude that the visual representation makes drug information more accessible and understandable to patients than PILs. The prototype is useful as it provides patients with the ability to assess their own drug use and to answer their concerns.

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