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Creating Individualized Education Material for Diabetes Patients Using the eDiabetes Platform

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Abstract. Diabetes mellitus (DM) is a chronic disease that affects many people in Switzerland and around the world. Once diagnosed, a patient has to continuously monitor blood glucose, manage medications or inject insulin. Technical skills and competencies as well as knowledge on disease management have to be acquired right after being diagnosed. Diabetes consultants support patients in this process and provide educational material. While the process of generating patient-tailored material is currently complex and time consuming, in future, the eDiabetes platform can help. The platform developed in cooperation with the consulting section of the Swiss Diabetes Society offers the opportunity to create individual patient information and instructions to teach technical skills and knowledge on diabetes. Further, an integrated forum allows exchanging information and discussing issues regarding diabetes counselling on a secure platform. Usability tests showed that eDiabetes is easy to use and provides benefits for diabetes consultants and patients.

Keywords. diabetes mellitus, patient education, information system, information provision

1. Introduction

Diabetes mellitus (DM) is a chronic disease that affects many people in Switzerland and around the world. DM causes blood glucose levels to increase (hyperglycemia). A recent forecast of the International Diabetes Federation predicts that in 2045 more than 625 Million people worldwide will suffer from diabetes [1]. There is even an increasing prevalence of type 2 DM in children and adolescents around the world [2]. Reasons for the overall increase are an ageing society, obesity and lack of physical activity in people [2]. As in other diseases, education plays a key role in the treatment of DM and in the management of the condition by the patients themselves. The treatment success relies heavily on patient accountability and awareness over the restrictions imposed by the condition, in addition to the need for patients to manage their glucose levels. To avoid complications and comorbidities, it is crucial that the newly diagnosed patient learns about the disease, about the events that can occur and the therapeutic management of the disease. There are mobile applications available such as “mysugr” that aim at supporting the individual disease management, but support for diabetes consultants in creating individualized education material is still missing. Patient education for diabetes aims at

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equipping a patient with necessary information to support self-management and avoid complications. Right after being diagnosed with diabetes, patients have to adapt their lifestyle and change habits. They have to absorb a lot of information in a short period of time. In this situation, they are supported by specialists, referred to as diabetes consultants. A diabetes consultant provides information on devices such as blood glucose monitors, insulin pens and lancing devices, on the disease and complications. The amount of information is often overwhelming for patients and the information is not always presented in an adequate form regarding language and comprehensibility. To support this process and to ensure that the patient is remembering all the information, the diabetes consultant provides general leaflets to the patient. Different health literacies and background knowledge, cultural contexts and languages complicate the information provision: Often, explanations are necessary since standard material is too complex or not written in the patient's language, making it difficult for patients to follow the instructions on the leaflets and instructions. On the other hand, the provision and compilation of individualized information materials is time-consuming and cumbersome for the consultants. Studies found out that inadequate health literacy might contribute to the disproportionate burden of diabetes-related problems among disadvantaged populations [3]. Additional interventions are required to improve diabetes outcomes among patients with inadequate health literacy.

To address this challenge, we developed in cooperation with the consulting section of the Swiss Diabetes Society the platform eDiabetes to support diabetes consultants in generating individualized information for diabetic patients to be used in everyday diabetes counselling. Using this platform, patient-related supplements, fact sheets and instructions can be enriched with explanations in the patient's wordings. Studies showed that active involvement of patients into the treatment strongly impacts their behavior and the course of disease. For example, Rachmani et al. found out in a clinical study that "well-informed and motivated patients are more insistent to reach and maintain target values of the main risk factors of diabetic complications" [4]. With the help of eDiabetes, diabetes consultants can quickly compile individualized information materials for a patient. This allows professionals to consider prior knowledge or living conditions of the patient. In the following, we are summarizing the related work, and describing our process of requirement collection. Then, we introduce eDiabetes, a web-based platform for individualizing education material and present usability test results.

2. Related Work

Several educational interventions have been tested in patients with DM. Nevertheless, a universally effective model for patients is still unavailable [5]. Health education is recognized as an effective self-management capacity building tool, in which patients are empowered to play an active role in the management of their conditions. The main four pillars for health education are: 1) empowering individuals, 2) leadership, 3) motivation and 4) education and information [6]. All type 1 and 20-30% type 2 diabetic patients require insulin via daily subcutaneous injections. The technique is not complex, but many patients tend to forget and inject insulin incorrectly [7]. Education demands a lot from health care providers and includes specific training, teaching skills and motivation of patients [7]. Initiate education for patients newly diagnosed with diabetes and providing information on self-management skills to help ensure safe post-discharge care are some of the suggested strategies for DM patient education [8].

To support health professionals, national diabetes associations like the consulting section of the Swiss Diabetes Society provide education material. User manuals for glucose meters and insulin pens are offered by the manufacturer. Such general information material often does not address the individual competencies of patients. Studies showed that web-based care management improved glucose control in patients with poorly controlled diabetes [9]. A study showed that both, counseling and web-based diabetic patients' education improve patient outcome, however, counseling was more effective than a web-based education strategy [10].

Several mobile applications for diabetes self-management are available on the market specifically designed for patients. They support documentation of blood glucose values, of meals and weights or they support calculation of carbohydrates [11]. A review by Chomutare et al. confirmed that personalized education is an underrepresented feature in diabetes mobile applications [11]. They found out that the four most prevalent features of the applications available on the online market are 1) insulin and medication recording, 2) data export and communication, 3) diet recording, 4) weight management. Recent work confirms that mobile apps for diabetes management focus on reporting and setting reminders, rather than providing personalized education or therapeutic support [12]. This indicates that there is still potential in offering solutions for patient-tailored education in diabetes counselling. In this paper, we present our concept and the web-based platform eDiabetes to support diabetes consultants.

3. Material and Methods

In order to analyze the situation in diabetes counselling, we made interviews with diabetes consultants and representatives of the Swiss Diabetes Society. Through a literature and web search, we identified limitations of existing tools and approaches and derived a concept for the eDiabetes platform. The system was developed in an iterative process: Feedback on the prototype was continuously collected from experts. Our platform aims at supporting the diabetes consultants. However, it is relevant to know which information needs patients have to be able to develop a system supporting the diabetes consultants. For this reason, a survey with diabetes patients was conducted to analyze the experiences of patients with user manuals of the various devices they have to handle, such as blood glucose monitors, lancing devices and insulin pens. The results and feedback of the patients were considered in the implementation of the tool. 18 questions were prepared for the patient survey. The open and closed questions targeted at assessing the usefulness and comprehensibility of user manuals, difficulties with domain specific terms and challenges in understanding user manuals. In order to reach a large audience, the Swiss Diabetes Society published the survey on their homepage. Furthermore, the participants were confronted with leaflets generated using the eDiabetes platform and feedback was collected.

In addition, a usability study was performed with diabetes consultants to study the user-friendliness of our eDiabetes platform and to identify problems. The results from this survey were prioritized and used for adapting the implementation. The usability questionnaire was developed based on ISO 9241/10 [13]. The 27 questions concerned comprehensibility of the pages and the navigation within the platform. In addition, the participants were asked for their personal opinion on the platform and for suggestions for improvement. The five test persons of the usability study are members of the management board of the consulting section of the Swiss Diabetes Society or diabetes

consultants from a local hospital. Given the restricted time for the project (February 2018 to June 2018), only a test with a limited number of participants could be realized.

The eDiabetes platform integrates a community platform. To select an appropriate platform, we performed a value benefit analysis for integrating a blog, a wiki or a forum. We formulated 10 criteria for required functionalities as collected in the requirement analysis. They include functionalities such as exchanging images and information, searching for postings, create postings, exchange private messages with colleagues.

4. Results

4.1. Requirements

4.1.1. Requirements of diabetes consultants

The consulting section of the Swiss Diabetes Society currently offers a multilingual leaflet folder with educational material online. The members have the possibility to print the leaflets or to use them as a reference book. This material should be made available on the platform and adding individual comments should be enabled. More specifically, a web-based platform is desired to support healthcare professionals during a consultation with a patient allowing them to generate individualized patient education material. Further, the system should provide an exchange opportunity in the form of a community platform to enable diabetes consultants to exchange materials or latest information on diabetes counselling. The requirements analysis revealed that the diabetes professionals are experiencing difficulties to teach foreign-language patients about diabetes. The existing leaflets are more text-based than image-based which are hard to understand for patients with another mother tongue. Accordingly, a system is required that explains relevant information and processes using images. A system should support in generating annotations of the images according to the patient needs.

4.1.2. Information needs of patients

Six out of ten participants answered all questions and were included in the results. The participants fall into the following age ranges: age of 30-39 (2 persons), 40-49 (1 person), 50-59 (2 persons), older than 60 (1 person). They originated from Turkey, Sri Lanka, Germany and Switzerland. Five persons were diagnosed with type 2 Diabetes and 1 person with type 1 diabetes. All six persons were diagnosed with diabetes 3 years ago or more.

For most of the participants, the user manuals of the blood glucose meters, lancing devices and insulin pens are self-explanatory. The biggest difficulties with the instructions for use arise in understanding the texts and learning the processes. Some participants have problems because the texts are not written in their mother tongue, which confirms the perception of the diabetes consultants (see section 4.1.1). In addition, the pictures in the user manuals are not meaningful and it is difficult to understand the process of operation only by reading texts. A major challenge in dealing with the disease is the change of eating habits and the general adaptation of everyday life to the requirements of the disease.

In order to get a better overview on the process of dealing with the different medical devices needed for diabetes management, it would be helpful for the patients if the individual steps would be numbered. This would help them to have an accurate,

understandable manual when using blood glucose meters, insulin pens, and lancing devices. It would also be helpful if the leaflets or instructions for use are more visual and contain less text.

4.2. eDiabetes platform

To address the requirements of the diabetes consultants, we developed the eDiabetes platform. It is expected to be used by diabetes consultant while counselling a particular patient. The platform provides two main functionalities: creating individual education material and share it with a patient, and exchanging information with other diabetes consultants through a forum (see Figure 1 and 2). These functionalities and their realization within the platform are described in the following.

In collaboration with the patient, the education material is created dynamically using eDiabetes. The platform enables a diabetes consultant to tailor leaflets and instructions individually to a patient and his or her competencies, language and background. Consultants add comments and explanations directly in the platform. This is realized by text fields. In order to create explanations for the use of devices (glucose meter, etc.), images that visualize the single steps can be arranged and text can be added (Fig. 3). As a result, individualized leaflets or instructions that are better understandable for a patient can be forwarded to the patient as PDF or printed. In case a patient is unsure about a particular steps in the instructions for a device in its daily practice, he or she can always refer to these sheets and follow the indicated steps. Content-wise the platform allows creating individual explanations for symptoms of hypoglycemia, as well as describing the steps how to react in case of a hypoglycemia and instructions on how to use the devices.

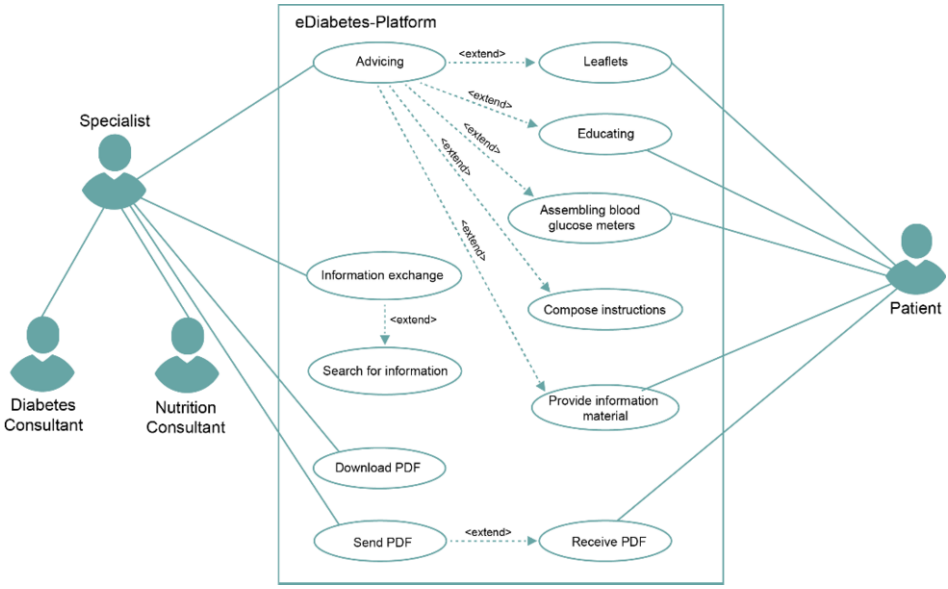

Figure 1. Use case diagram for eDiabetes.

As best suited community tool to be integrated into eDiabetes, a forum was selected based on the results from the value benefit analysis. Thus, as a second functionality of the eDiabetes platform, the open source forum software MyBB (https://mybb.com/) was integrated. The forum allows experts to discuss with each other, exchange information, discuss diabetes issues or ask for a second opinion. The forum is open to all members of the Swiss Diabetes Society.

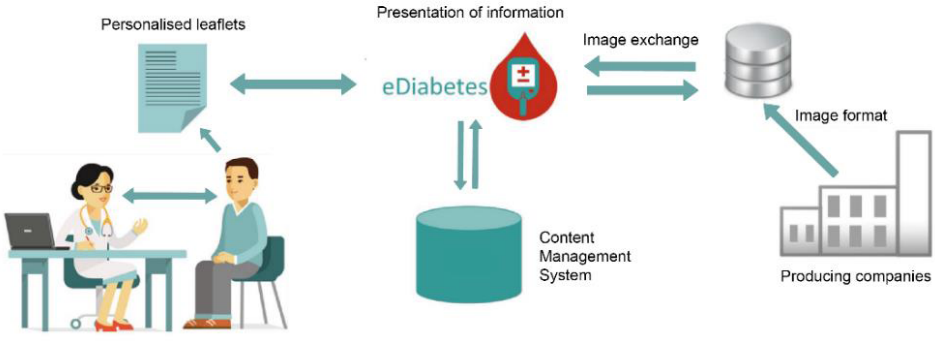

Figure 2. eDiabetes platform: For instructions on devices, original image material from the manufacturer is required. This can be uploaded to a database that can be accessed by the eDiabetes platform.

The platform is running on a web server. This was set up using LAMP Stack, Apache Version 2.4.18, MySQL 5.7.2, PHP 7.0.22 und phpMyAdmin 4.5.4.1. For developing the views of eDiabetes, Java script, CSS and PHP were used.

The underlying information material on devices originates from the manufacturers of glucose meter and insulin pens. In the course of the project, 11 manufacturers were contacted to get approval of using the original images in our prototype. An update of the material is required when new devices are put on market or modifications on existing devices are made. To realize this, our concept foresees that the manufacturer can upload the image to a database from which the eDiabetes platform collects the image files (Fig. 2).

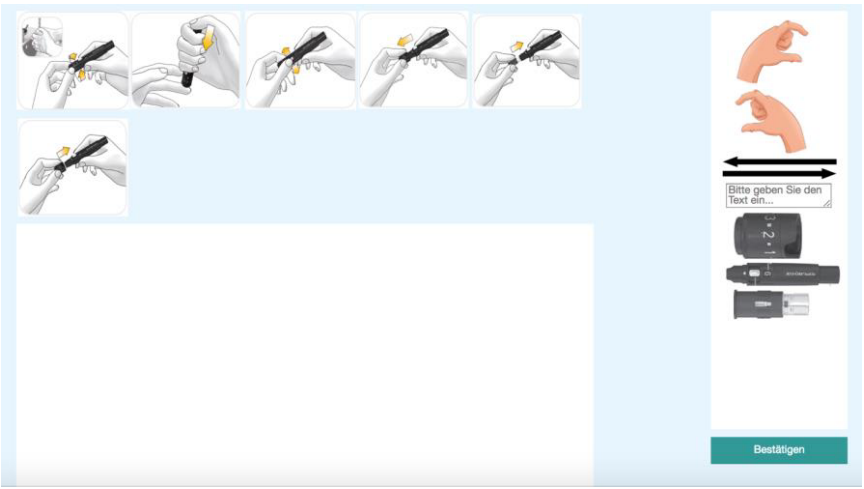

Figure 3. Screenshot of the drag and drop functionality to create a user manual specifically for a patient. The images can be arranged in the order as needed by the patient.

4.3. Usability study

Usability in our context concerned on the one hand the interaction with the eDiabetes platform and on the other hand, the appropriateness of the individualized leaflets that are generated with the platform. The feedback on the eDiabetes platform by the diabetes consultants was very positive; they confirmed that the platform is simple, clear, and easy to use. They felt comfortable in interacting with the platform. However, two test persons had difficulties in interacting with the platform. Further assessments on this issue has shown that these two persons are older than the others and are using the computer less often during their work. Nevertheless, the survey showed that interacting with the eDiabetes platform is easy to learn without external help or a user manual. Test persons claimed that they liked the platform, because it provides many possibilities for extensions. They even asked for more options to add individual descriptions.

Patients on the other side confirmed that all relevant information is available on the leaflets. The personalized leaflets help them, since the image-based process descriptions provide a step-by-step presentation of the instructions which is clear, and all relevant information is summarized briefly and concisely. They stated clearly that personalized leaflets are better than the original instructions for use. In addition, information sheets are more understandable for foreign-language patients than text-based leaflets. However, they are still missing advices on what to pay attention to when using one of the devices.

5. Discussion and Conclusions

In this paper, we introduced a web-based platform for supporting diabetes consultants in creating patient individualized information material. With this platform, we provide a solution for addressing treatment challenges caused by limited health literacy in patients. Studies showed that a low health literacy is associated with lower diabetes outcomes [14]. Patients who cannot understand instructions of glucose meters and insulin pens will have problems in using the tools and thus, will have more variability in their glucose level. Our system supports in these cases and can help in teaching skills and formulating instructions in patient's wordings together with the patient. Martin et al. showed evidence that verbal communication between patients and clinicians results in a better adherence to the given instructions [15]. Therefore, it is the aim of our eDiabetes platform to support the verbal instruction by a diabetes consultant in an efficient and effective manner.

Gillani et al. showed in a randomized controlled trial that provision of structured and individualized information to people with diabetes positively influences the level of patient activation, promotes better engagement and opens the potential to improve other crucial diabetes outcomes [16]. To provide individualized und understandable information at the beginning of the instruction process for a newly diagnosed diabetes is the main focus of our eDiabetes platform. Through our assessments, we achieved first hints that personalized leaflets and instructions can be useful for patients with diabetes. According to patient opinions, material which is adapted to their individual life circumstances will help them in better managing their diabetes. Additional studies are necessary to prove the effectiveness of our approach for the diabetes consultants and the positive effect of the patient’s adherence with the consultant’s instructions. It is also of interest whether patients show a better self-management competence of their diabetes.

Our platform in its current shape provides mainly support for diabetes consultants. When presenting the platform on the national congress of the Swiss Diabetes Association,

the participants suggested adding additional functionalities for nutrition consultants in the context of diabetes. The positive effects of patient education on disease outcomes had been shown already [14].

In future, contracts with manufacturers have to be established to ensure a continuous update of the data material. The creation of individual leaflets and instructions might be of interest as well for other diseases that require use of medical devices or need instructions on how to deal with complications. The overall concept is transferable, however, the content needs to be replaced.

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