Balancing Overreliance and Mistrust in Data-Driven Decision Making: A Critical View on the Role of Quantified Self in Diabetes Management

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Abstract

New self-care practices, such as self-management of chronic diseases, have emerged through mobile applications and devices, often designed, developed, and used outside the healthcare context. The development may lead to increased patient empowerment, shared decision-making and better communication, which is expected to benefit the care process. However, there are also potentially harmful effects related to safety, reliability, and security, with a corresponding need for understanding underlying algorithms and biases that may affect users. This calls for socio-technical perspectives, which take into consideration both the technological aspects of developing the app, as well as the social aspects of stakeholder involvement and collaborative design. In this paper, we describe the design and development of a mobile app for food nutrition information as part of diabetes self-management and critically discuss its implications for patients and designers. Our findings show that important learning aspects are connected to self-management, but there are also risks involved if too much or too little reliance is placed on the mobile app in the decision-making process.

Keywords

Healthcare, Decision making, Quantified Self, Self-Management, Mobile application, Critical research, Socio-technical design

1. Introduction

Healthcare globally is facing major challenges. Thanks to medical and technical developments, we are seeing an increasingly aging population, as people are more likely to survive previously fatal diseases, and many patients are living longer with chronic diseases [e.g., 1]. The development has also enabled patients to become more involved in making decisions about their health and treatment. At the same time, there is increasing pressure on how to prioritize and best utilize limited resources to meet the rising costs of healthcare. The use of digital technology, such as self-management through mobile applications and wearables, can achieve sustainable care, reduce costs, and increase medical quality, access, and quality of life [2, 3]. Patients and citizens today use multiple technologies and devices for work, learning, and entertainment, and thus they have higher demands and expectations of healthcare services to provide the same possibilities available in their personal lives [4]. The notion of "flipped healthcare" has been used to illustrate the emerging new role of patients who are more engaged and bring information and data gathered from apps and platforms developed and used outside of the healthcare context into their clinical interactions [5, 6]. In all, this calls for more research to capture the socio-technical aspects of the design and development of digital health technologies, looking beyond traditional standalone systems [4, 7].

The increased use of digital technology by patients has led to significant growth of patient-generated health data as well as of digitally engaged patients who are involved, informed, and take an active role

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in decisions about their health and treatment [8, 9]. Patient self-management can be initiated by the healthcare provider or the patients themselves and adopt continuous monitoring of relevant disease or lifestyle-related parameters originating outside the healthcare facilities. In this paper, we focus on self-management initiated by the patients, specifically on the design and development of a mobile app for food nutrition information, as part of diabetes self-management. The overall aim is to contribute with insights that can help improve and innovate self-care practices and quality of life for patients with diabetes while also addressing the need for more research on app design and development related to data-driven decision-making and digital self-management in general. The research question is: *How can a mobile application be designed and developed to support nutrition choices for patients with diabetes, and what are the implications for patients and designers?*

The remaining part of the paper is structured as follows: first, we outline related research; we then describe research methods (case description, design method, user tests and analysis); followed by the research findings and analysis; finally, we discuss the implications and end with a conclusion and outlook for future work.

2. Related Work

Digitalization within healthcare settings has been ongoing for decades. The electronic patient record (EPR) has been vital when examining historical aspects, and the healthcare sector has invested heavily in information systems, such as the EPR, as support for healthcare practices [10-12]. The digitalization efforts in healthcare have mostly been large-scale, and focused on national standards and strategic infrastructural changes that aim to integrate various digital solutions. The EPR has been the most significant challenge since the early 2000s [11], but in recent years there has been a shift in focus from the EPR as a working tool to other parts of healthcare. In that category, there is a newfound interest in understanding how mobile applications (apps) can assist in small decision-making processes related to healthcare in general and towards patient self-help or self-care in particular.

Previous work on e-health and remote care shows that digital artifacts like apps have become integrated into patient self-care practices, extending the meaning of what healthcare represents and increasing the agency of patients in their own healthcare journey [13-18]. A large body of literature has focused on healthcare performed as a part of call centers, where the care is viewed primarily in terms of distributed care [14-16, 18]. Many studies on e-health are, according to Kahn [19], before-and-after studies that rarely shed light on patient-centered outcomes, whereas fewer studies have focused on the digitalization process through design, looking more closely at the role of patients. There are a few attempts to be proactive and use the power of apps to create new self-care trajectories that can help with everyday decision-making for the patients. In this context, a socio-technical perspective is important to understanding the interplay between technical aspects of app design and development, along with the social aspects of collaborative design that include stakeholder engagement and active participation in the design process [7, 20, 21]

This brings us to augmented intelligence. In recent years there has been a shift towards promoting digital tools, such as apps that rely on machine learning algorithms and their potential to revolutionize various parts of patient care. However, some parts of the self-care process will and should not be enhanced by such efforts. Instead, intelligence augmentation (IA) might be more suitable than artificial intelligence (AI) for specific areas. IA is commonly defined as computers and digital artifacts enhancing human intelligence through their design and is not meant as a replacement of any sort [22]. Instead, IA artifacts are intended to augment the learning process, aid the patient, and support the journey towards self-care. With the use of apps and other digital artifacts comes a vast amount of data, and the data analysis is within care, commonly done by humans. The interpretation of the data might someday be made by AIs, but today, traditional self-care like dietary recommendations and timing for diabetes as an example, is an analog practice of coaxing information by reading food packages, packaging the food, and through trial and error, building up a knowledge base of what foods spike blood sugar more than others [23]. The patient-generated health data becomes a part of the clinical decision-making process and can be seen as a practice where intelligence augmentation through data and data produced in and for healthcare contexts calls for analytical skills both by the patient and the nurse to engage in the sense-making process together. While the data in the world is increasing and people are increasingly relying on data-driven decision-making, some application areas within healthcare are lagging and raise the question of what should be kept analog [8]. That shift is the change that we focus on in this particular paper. By critically examining the role of quantified self-apps, and highlighting the importance of socio-technical design, we seek to contribute with an in-depth understanding of how an app can help patients be independentby augmenting their decision-making process.

3. Research Approach

The research setting is in Iceland, and the aim of the project was to make a mobile application that could make it easier for users to look up food nutrition information and especially useful for those who need to consider the intake of carbohydrates, sugars, fats, etc., such as a patient with diabetes, food intolerance or allergies. Agile methodology was used during the project to break down the long-term goals into smaller tasks. The period of 12 weeks was divided into sprints where each sprint had a specific aim. Daily standup meetings were held in the mornings, and every second week of each sprint, a "retrospective" was held, where the sprint was discussed, what went well and what went worse. Gitlab was used to keep track of project status, requirements and coding. This section first describes the technological environment for developing the app, first front-end, then back-end and database connection and how it was implemented, followed by a description of user tests, data gathering and analysis.

3.1. Programming environment and development process

There were known difficulties in navigating the nutritional value of food in distribution on the Icelandic market, indicating that it is vital for diabetics and others who need to closely monitor nutritional value to have digital aides by their side. The app was not developed in collaboration with a specific company, but the data that is the backbone of this project was provided by Matís (https://matis.is/en/). The data was delivered in the form of a .csv file that contained over 1300 different foods along with their nutrition information. The front-end was written in JavaScript, using Airbnb programming rules due to previous use and good documentation, and ESLint was used to review and ensure that they were enforced. The back end was written in Python and used the pep8 rules and pylint addition to Vscode to refactor the code. The app was developed/programmed in ReactJS / React Native, which made it possible to break the code into many small parts, each with its own task. CSS was used to design the code. The Expo CLI was used for testing, where the small program could be tested on both computers and smart devices.

The back end was split to separate users and data. Users could log in with an email address. The data was stored in a PostgreSQL server hosted by Amazon AWS (Amazon Web Service). On that basis, the main data on Matís food products were housed: nutritional value, vitamins, light description of contents, etc. Other information generated during the run, such as user settings and food that the user chose to save, were also set in PostgreSQL, the foundation. To retrieve data from the database and send to the front end was python websocket server built, but when the script started to take shape, it was decided to move the functionality from it to the Apache server hosted by AWS. WSGI (Web Server Gateway Interface) plugin was added to Apache to allow it to send results from python code as http answers. This decision paid off because the Apache server could serve several people at once was more convenient to use and was much faster.

In the first version, the food was classified into its own food category and had a special origin, and the food also had data on the contents, which are vitamins, minerals and nutrients. Whereas in the second version of the database, the food is classified into its own food category and has a special origin. The content of the food has been compiled under the name Nutrients, and in addition, there are users who have saved food and optional harvests. The excel file was provided through PostgreSQL database by Apache2 server with mod_wsgi plugin that runs Python to be a monkey for the script. Firebase is used to store user data and handle user authentication. Expo converts React JavaScript code into native smartphone widgets (see fig. 1).

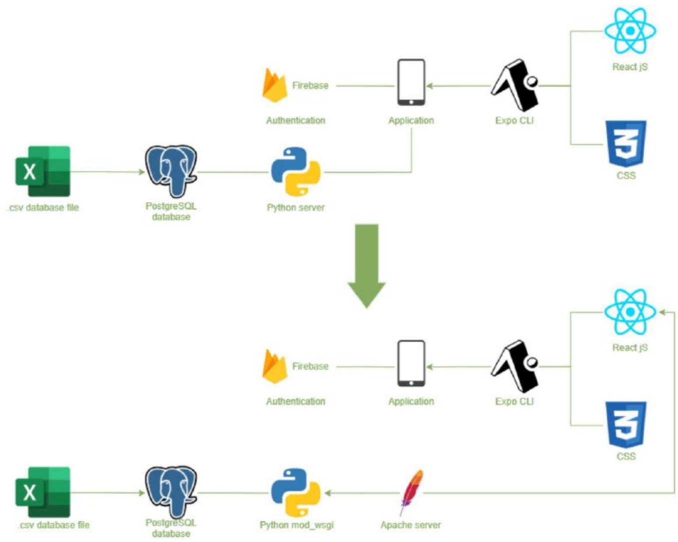


Figure 1: System diagram. Initial and final versions

3.2. User tests

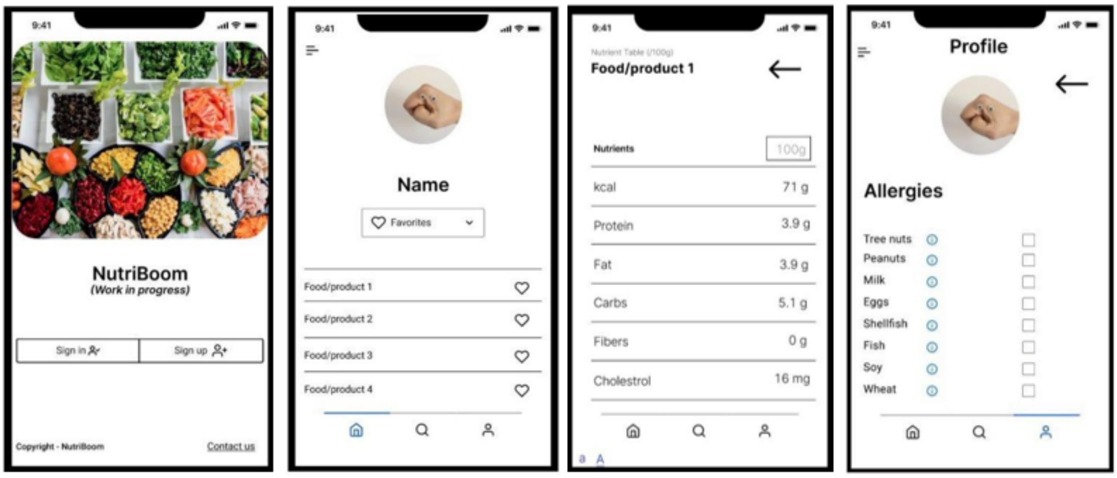
In Iceland, as in other countries, there are many types of foods available in different stores and searching for nutrition information is often not simple. It is possible to search online according to the ingredient descriptions of individual foods, but often that information is not in an accessible or easy-to-read form. This is problematic for many users, and this project aims to design and develop an app that publishes information to users on the nutritional value of food that is distributed on the Icelandic market in a way that is simple and accessible. To achieve this goal of a good design—i.e., that enables users to search for food and ingredients in a simple way and see key information such as nutritional value—user tests were conducted with the intended users of the app and redesigned based on the results of those tests. Each user test consisted of an introduction, a pre-interview focusing on background information and demographics (including questions such as age, gender, diet, health problems related to food, smartphone literacy and computer literacy); an assignment with tasks to do in the app; and a post-interview with questions focusing on user experience, suggestions for improvement and assessing user satisfaction.

A majority of the respondents were in the age group between 31-40 years, followed by the age groups 20-30 years and 61-71 years. There was a fairly even distribution between men and women as well as between iOS and Android. When asked about their computer skills (scale 1-10, where ten equals highly skilled), most of the respondents rated themselves between 5-8, but two users gave a rating of nine. Only two of the users said they had used a similar app before, almost none of them had dietary or health-related food restrictions, and when asked to determine their general knowledge of nutritional content, most users gave a rating between 5-10 (10 being the highest (See figure 2).

User	Age	Gender	Computer skills	Smartphone skills	Smartphone	Used in a similar way before	Optional food restrictions	Health related restrictions	Knowledge of Nutrition content
1	26	Male	7	7	Android	No.	No.	Reflux	2
2	26	Female	8	8	iOS	Yes	No.	No.	7
3	27	Male	5	8	Android	No.	No.	No.	4
4	32	Female	9	9	iOS	Yes (My fitness pal)	No.	No.	5
5	33	Male	8	8	Android	Yes	No.	No.	5
6	38	Female	5	5	iOS	No.	No.	No.	2
7	38	Female	7	7	Android	Yes, but will not use again	No.	No.	5
8	59	Male	5	5	Android	No.	No.	No.	7
9	62	Female	7	5	iOS	No.	No.	No.	8
10	66	Female	6	8	iOS	No.	No.	No.	7
11	67	Male	10	9	Android	No.	Avoid cheese	No.	5

Figure 2: Respondent characteristics

In order to be able to adapt to the needs of most users, it is not enough just to have the right functionality. Great emphasis was also placed on the design. Initially, a rough prototype was created, which was used for user testing and user interviews (example screenshots are provided in figure 3).



Screen 1: Landing page	Screen 3: Profile	Screen 4: Further information	Screen 8: Customization

Figure 3: Prototype screenshots

The usability tests followed a standard form created by the team to ensure that all tests were conducted in the same way, using the same data during the test. Each user test lasted about 30 minutes and was recorded. Due to restrictions in force due to COVID-19 was not considered advisable to take these tests on-site, and instead testing through either Discord or Microsoft Teams was deemed appropriate. The user shared a screen to allow the administrator to monitor the resolution of the to-do list, and the aim of these tests was to monitor and measure three main factors:

1. *Goal effectiveness:* Accuracy and enforcement that users achieve in pursuing a specific goal; Did the user complete the project? and; If not, what were the main obstacles?
2. *Efficiency:* Accuracy of the user in achieving his goal in the shortest possible time; How clear is this goal? and; How long was the user completing the project?
3. *Satisfaction:* Avoid inconvenience, aim for a positive attitude from the user; How did you like the system? and; How would you rate it?

The tasks were submitted to the user one by one. A "think-aloud" method was used in which the users were encouraged to think aloud and describe what they were doing or expected to be able to do while performing the tasks. The administrator observed and noted the time it took to complete each task which was written down along with other comments and reflections from the observation. After completion of all user tests, results and comments were collected and summarized to draw conclusions and draft improvements in design, user experience and functionality.

4. Findings

The findings are presented according to the design process: identified user groups, artifact requirements and the prototype/user interface of the application.

4.1. User groups and requirements

When designing software, it is important to define user groups that can use it and prioritize them according to their intended importance (A, B, C, User Group A is the highest priority). Five user groups were identified: 1) General users where anyone can use the information (C); 2) Users with allergies as it is good for them to avoid certain foods; 3) Users with underlying diseases (e.g., diabetes) where it is imperative to monitor the nutritional content of the food consumed (e.g., carbohydrates); 4) Users with food intolerance, and 5) Users who need or choose to live on a special diet.

The user experience may be different, but it is important to identify the requirements and functionality that the system is expected to fulfill. The main requirements considered important and/or would improve the user experience is summarized by priority (A-C) in Table 1 below. Requirement A are the requirements of the developers considers that must be implemented in order to be able to deliver a usable product, B requirements are requirements that are not as important but improve the user experience considerably, they will only be implemented when all A requirements are ready. C requirements are requirements that the developers thought were good to have but are not necessary for scripts.

Table. 1 Requirements list

Requirement	Priority
The user needs to be able to search for food in a simple way	A
Users with dietary restrictions should be able to save a diet that is safe in itself	A
The user must be able to log in to the system	A
The user should be able to create an ID in the system to install diet plan	A
The user should be able to see the nutrients in the food	A
The user should be able to see information about food that contains something they may not eat	A
When the user is searching, provide suggestions on what products the user is looking for	B
The user should be able to filter the list by specific food category	B
The user should be able to record their diet to monitor their diet	C
Users should be able to see suggestions for food products that connects to users after	C
The user should be able to save food products for access to them in a simple way	C
User should be able to remove food from favorite his list	C

A summary of the user tests, and the time it took to complete each task in the assignment (compared to estimated time), is provided in table 2. Below is a list of comments and suggestions for improvements made by users during the tests. This is also an excerpt from the problems users encountered while dealing with tasks, highlighting the potential issues that the participants faced along with suggestions for solutions and improvements.

Table 2. Summary of user test results

Project no	The project	Average time	Estimated time	Difference
1	User logged in	34 sec	14 sec	20 sec
2	User registers health-related restriction	81 sec	30 sec	51 sec
3	User should edit email	18 sec	15 sec	3 sec
4	User should change personal information	11 sec	10 sec	1 sec
5	Look for specific foods	25 sec	14 sec	11 sec
6	Look for specific foods and add them to your favorites	38 sec	8 sec	30 sec
7	User enters food customization settings	23 sec	9 sec	14 sec
8	User enters allergy information	17 sec	6 sec	11 sec
9	User wants to edit profile picture	21 sec	14 sec	7 sec
10	User wants to remove food from favorite list	24 sec	4 sec	20 sec
11	Users want to view a list of their favorite foods	36 sec	15 sec	21 sec
12	The user receives information about the specific nutritional content dosage of food.	35 sec	16 sec	19 sec
13	User wants to contact administrators	23 sec	20 sec	3 sec
14	User returns to landing page	5 sec	4 sec	1 sec
15	User wants to be able to see "history"	22 sec	10 sec	12 sec

User comments and suggestions for improvements

- *Favorites were perceived as confusing,* it would be more understandable if the dropdown contained categories (e.g., meat, dairy products, fish etc.), and displays everything that belongs to that category. Favorites could be one of these categories. Users also found it difficult to find health-related restrictions to tick and to find dietary restrictions to label if applicable.

- Suggestions for changes and improvements

    - Add the possibility to "switch" favorites by pressing the heart, and see it become empty or filled depending on whether it is in favorites or not.
    - Add the possibility to indicate that you are following a special diet, e.g., vegan, keto, carnivorous, etc.
    - Remove dietary restrictions from "Settings" and place it directly under the burger, as found be pretty deep on these settings and not default where to look.
    - Make it possible to add food and to see all food categories
    - A bar code or QR signal reader would be cool.
    - The "Location" setting is unnecessary
    - Explaining everything "My" is unnecessary and a bit personal. Change these names.
    - Profile photo is unnecessary?
    - Difficult to find "Last viewed" Redefine as "History" to follow naming conventions in the technology sector.
    - "Contact us" is located in a confusing place. Could be in footer rather.
    - Add the possibility to keep a food diary and calculate calories
    - Set the script to display certain information for a short period of time, which may be suitable for visitors in a visit that need to pay attention to diet.
    - Add a link to the Directorate of Health's website, regarding advice
    - Show pictures of the food
    - Can find "macronutrients" of food to be able to track oral intake. Helps with weight management.
    - Add "dark mode"
    - Would be willing to see if the food is environmentally friendly.

4.2. User interface

The result of all our work is JappL, a small program that informs the user about nutritional value food, whether the food may be harmful to the user or cause him inconvenience. We will go through the script and discuss each window individually, each of their goals is and where they lead the user.

The **landing page** (fig 5a) appears after the script launches for the first time. It is necessary to log in to be able to push it. If the user does not have access, they can register. User enters the registration screen by selecting "Sign Up". The menu (Fig 5b) open after the user has logged in. **List of food** products listed in the database are displayed. User can scroll through the list and select from it, or search for a name in a search bar located at the top of the screen. The applet returns the list filtered with the food products that contain the search string. The **user settings**, the user is prompted to turn on settings that let him know if the food he inspects meets the conditions that are turned on (fig 5c). If you click on the information ball, a window will appear showing more details information.

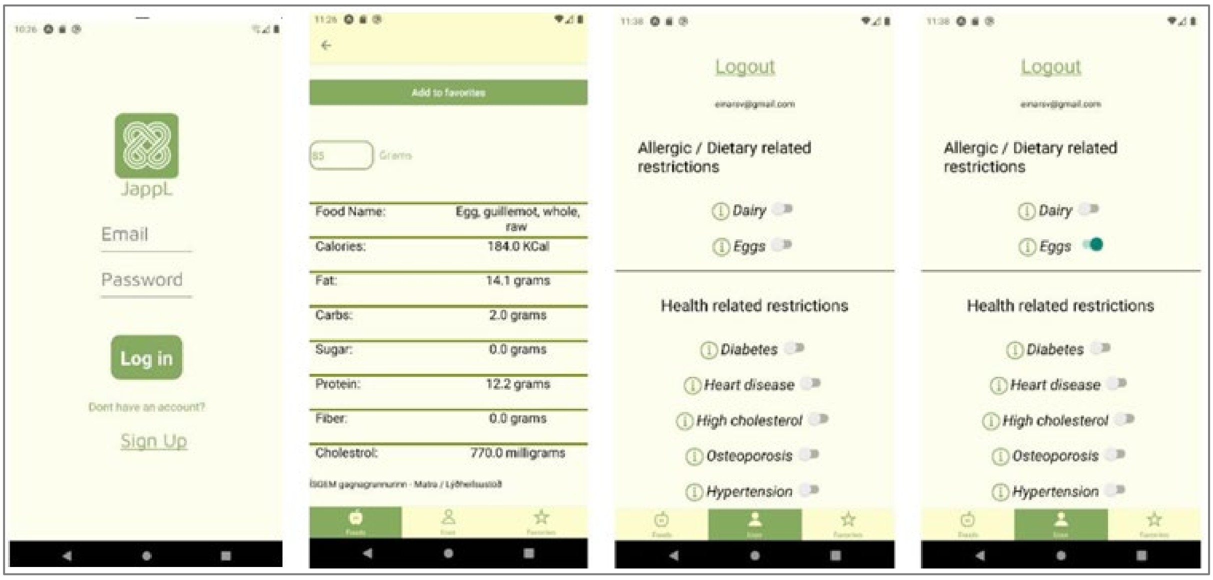


Fig. 5a-5c User interface

Notifications: After the user has entered the settings then lets the script let him know if the food that he is viewing the contents of something that might be dangerous to him. The applet shows this warning in the overall list as well in the food information card. If you click on the warning triangle in the info card, it will appear the reason why the user is warned. **Add to favorites:** The user is offered to add the selected food favorites. When you click on "Add to favorites" then the food in question goes on a list as slowly as possible is viewed under the "Favorites" tab. Located on the bar at the bottom of the page. As if the food is already a favorite, then offered user to remove it from this list.

5. Discussion

Healthcare is rapidly changing as advances in medicine and technology have enabled patients to be more actively involved and take an active role in decisions about their health and treatment. In this paper, we describe the design and development of a mobile app for food nutrition information as part of diabetes self-management, and critically discuss its implications for patients and designers. The analysis of our findings revealed three important aspects related to ethical considerations in the decision-making process

First, and in line with prior research on digital health, our study highlights that the use of mobile applications for self-care has the dual effect of both enabling and constraining patients in self-managing their disease in everyday life [24]. Whether initiated by healthcare or by the patients themselves, self-management and continuous monitoring mean the integration of digital technology, which has a bearing on the meaning of care and has influence on the role of both professionals and patients [6, 15, 16, 24]. As the responsibility of care is slowly shifting from the healthcare provider to the patients, where part of the decision-making is in the app, patients must have the ability, both in terms of access to their data and the skills and knowledge needed to make sense of it. This, to act in response to decisions and recommendations as part of self-management through mobile applications that may have a direct impact on their health and well-being. Our findings support prior research that calls for socio-technical perspectives to unpack the interplay between the technical and social aspects of app design and development when designing for specific purposes or practices [7, 20, 21]

Secondly, with increased use of apps and other types of digital artifacts comes a vast amount of data and the analysis of the data is within care, commonly done by humans. While AIs may in the future interpret the data, today, traditional self-care is a highly analog practice of coaxing information, such as in the case of diabetes management, through reading the packages of the food, and slowly, through trial and error, building up a knowledge base of what food spikes the blood sugar more than others [23]. The patient-generated health data becomes a part of the clinical decision-making process and can be seen as a practice where intelligence augmentation through data and data produced in and for healthcare contexts calls for analytical skills both by the patient and the nurse to engage in the sense-making process together. We argue that going from the analog practice based primarily on memory to a quantified self might not be optimal for all. Instead, we propose that some apps stay as augmented intelligence devices.

Thirdly, healthcare is known for its reactive character, meaning that when people get sick, they seek healthcare. In contrast, as mentioned earlier, this paper focuses on diabetes patients and their selection of eatables. While there exist a number of applications for nutritional information, most of them are targeted toward fitness, with integrated features for keeping a food diary and logging exercises. Few are designed to aid diabetes patients in their daily food choices. Design principles for others that would like to embark on the design of self-care app, in order to support diabetes patients and augment their intelligence: i) offer an interface where food producers have the opportunity to register their products the foundation; ii) allow users to add food to the database. Add a barcode scanner, where you can view the contents of a product with just one click scan its packaging barcodes; iii) add data from other databases. Loosely examined, institutions exist in most of our neighboring countries, we also found private information sources that offer similar information.; iv) provide a food diary, users can record food and shame size, the script keeps it that way keep track of the amount of nutrients that have been ingested.

6. Conclusion and Future Work

In conclusion, this study highlights the need for a critical view of the role of quantified self in general and diabetes self-management in particular. The new self-care practices, through the use of mobile applications, often designed, developed and used outside of the healthcare context, may be beneficial in many ways but also poses risks, and there is clearly a need for understanding underlying algorithms and potential biases that may affect users. In this context, socio-technical perspectives that consider the technological aspects of developing the app and the social aspects of stakeholder involvement and collaborative design are critical. In this paper, we describe the design and development of a mobile app for food nutrition information as part of diabetes self-management and critically discuss its implications for patients and designers. Our findings show that there are important learning aspects connected to self-management and that there are risks involved if too much, or too little, reliance is placed on the mobile app in the decision-making process. In conclusion, our findings show that there is a need for patients to learn how to balance between overreliance and mistrust in augmented decision-making, which calls for ethical considerations and a critical approach.

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