The *ActiveAgeing* Mobile App for Diabetes Self-management: First Adherence Data and Analysis of Patients' in-App Notes

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Abstract. The up-to-date treatment of diabetes often includes the adoption of technology (eHealth) to support patients' self-management. This contribution features first data on patients' usage of *ActiveAgeing*, a mobile app supporting daily self-management. Over 6 months, 15 elderly patients with type 2 diabetes (T2D) and 11 young women with gestational diabetes mellitus (GDM) received daily reminders to perform treatment activities, registered capillary glucose within the app, and added personal notes to explain abnormal values. While no differences emerged between the groups' glucose registrations, T2D patients were more likely to add notes. Sentiment analysis with the software Watson on T2D patients' notes and some selected notes are reported. Discussion highlights that notes may be used not only to explain abnormal data, but also to express emotions and confide personal information. eHealth presents opportunities not only for self-management, but also to empower and enrich trust between patients and health providers.

Keywords: eHealth · Self-care · Diabetes · Adherence · Personal notes
Patient engagement

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1 Introduction

Global increase in the aging population, especially in Western countries, brings along a significant demand of care for chronic health conditions [1, 2], therefore requiring the elaboration, development and implementation of innovative ways to sustain care. Such instruments should not only be efficient and high-quality, but also cost-effective. This scenario sparked the rise of eHealth, or the use of new communication technologies to support healthcare [3, 4]. Indeed, technologies embedded in chronic patients' everyday life could assist them in disease management; for example, dedicated platforms can be used by patients to register and monitor treatment adherence (e.g., taking medications, adopting a more healthy lifestyle) [5–7], while computer mediated communication (CMC) and social media may be extraordinarily helpful in supporting communication between patients and different health care providers [8, 9], or even between patients themselves in order to encourage peer education and positive social influence. In addition to eHealth implementations to support treatment adherence and effectiveness, eHealth solutions have been proved useful also in the promotion of patient engagement [10, 11]. Specifically, new technologies are effective in terms of making patients more aware of their health status; equipping them with emotion-regulation resources to manage depression, stress and adverse emotional states; and, during advanced steps of the patient engagement process [12, 13], helping patients to recover their hobbies, passions and life goals despite the presence of a chronic disease.

In the field of eHealth implementations, diabetes, being one of the most common conditions has a huge interest. Indeed, diabetes has significant impact on patient's everyday life. First, this disease requires numerous factors to be constantly monitored (e.g., glycemic values, weight, adherence to medications); secondly, it also notably affects quality of life because the disease management necessitates for specific, daily activities to be timely performed (e.g., insulin administration, diet changes, frequent medical consultations).

In this context, numerous technologies have been developed in order to empower patients' daily disease management, however, only few have been tested. The present contribution includes an analysis of the first implementation of *ActiveAgeing*, a mobile app for diabetes self-management.

1.1 The *ActiveAgeing* Application

Among currently available mobile applications for the control of diabetes, few seem to include specific educational functions. It is often not clear what kind of interactional and clinical model they are based on, nor if they have been tested for beneficial effects on users' self-management skills and self-efficacy levels [14, 15].

The design of the *ActiveAgeing* application (henceforth, AA app) takes into account the tenets of the Chronic Care Model [16], the conditions for patient engagement [11, 12] and the clinical goals for patients with diabetes [17]. Among these goals, self-management skills are very important, as they guarantee that patients – through their healthy behaviors – will be able to maintain optimal control and avoid long-term

complications as well as manage acute situations of mild hyperglycaemia or hypoglycaemia. Indeed, acute episodes can seriously affect patients' quality of life and represent a significant burden for healthcare systems. Self-management skills are supported by a correct understanding of the problem, the awareness of the solutions available and the possibility to put them into practice; in other words, by critical thinking skills. However, patients with diabetes have infrequent and short outpatient clinic appointments and only during the consultations do they have the opportunity to critically think about their condition, correlate behaviors with parameters and discuss possible solutions for very specific management problems, and receive feedback by their doctors.

Thus, the AA app was developed as a tool to be integrated within the therapeutic alliance between doctors and patients and aiming at increasing patients' awareness of their condition and their decision-making autonomy. To reach these goals, the app needs to be used by doctor and patient in a complementary way.

The app receives input data from two sources: (1) the doctor, who performs the setup together with the patient when the app is installed on the patient's smartphone. In this phase, individualized parameter ranges are set and lifestyle information is provided; (2) the patient, who records clinical parameters according to the schedule recommended by the doctor. The data are saved on a web platform that is accessible to both doctor and patient through the patient's phone number and a password, set by the patient. The app then functions by comparing the data recorded by patients with the data entered during the setup phase and by providing immediate feedback in the form of textual messages, graphs and symbols. The messages provide reward, encouragement, they bring the patient's attention to parameters that are not within the set ranges, provide suggestions for coping with a potentially risky situation and suggestions for finding the causes of such situations. It is in particular in this last case that the app points out the possibility to take notes about what could have caused a certain parameter to be out of range. Notes can be inserted by typing in a dedicated space whatever patients feel is relevant. Apart from realizing an important tracking function that is very useful when the values are then discussed during the visit in the outpatient clinic with the doctor, the act itself of writing comments about such values can have an impact on the capacity of patients to actively reflect and think about their own health condition.

1.2 Objectives

The AA app has been used by two groups of individuals, namely elderly with established type 2 diabetes (T2D) and young pregnant women with a new diagnosis of gestational diabetes mellitus (GDM). These groups, intrinsically different for age and sex, were compared for adherence measures.

To address the research question, "how do patients use the notes function within the app, or, what information and meanings do they convey through it?" we analyzed the available patients' notes.

2 Method

2.1 Sample

Results discussed in the next section refer to patients recruited between 01/01/2017 and 31/08/2017. In total, 26 patients accepted to participate and were enrolled in this study: 15 T2D patients with a median age of 69 (range 65–73) and 11 GDM patients with a median age of 37 (range 34–40). They were recruited in two different hospitals in northern Italy. Specifically, GDM patients were recruited at San Raffaele Hospital (Milan, Italy), while T2D patients were recruited both at San Raffaele Hospital (Milan, Italy) and at ASL TO3 - Pinerolo (Turin, Italy). The study was approved by the Ethics Committees of both participating institutions (Protocol No. 105/2016 DRI006 and 0005047, respectively).

Inclusion criteria for both groups of participants were: diagnosis of diabetes, clinical parameters that showed difficulties of self-management, non-satisfactory clinical profiles, therapeutic prescriptions (tablets or insulin), and ability to use a smartphone. All participants spoke and read Italian fluently.

2.2 Procedures

Patients meeting the inclusion criteria were recruited by endocrinologists during a regularly scheduled consultation, after receiving all relevant information about the study. In this phase, clinical parameters were collected by the endocrinologists, who also proposed and discussed the app setup with patients. In a second phase, patients signed a written informed consent and met with the researchers from Università Cattolica del Sacro Cuore of Milan (Italy) to install the app and be instructed about its functioning. Apps were set up according to the endocrinologist's recommendations discussed with patients during the consultation.

2.3 Data Preparation and Analysis

The present paper reports three kinds of data: statistical analyses on adherence; sentiment analysis on patients' in-app notes; and, selected patients' in-app notes with a significant anecdotal value.

First, adherence data have been computed to compare T2D and GDM patients. Each patient had a specific treatment plan to follow depending on his/her diabetes diagnosis. Each patient had also a specific self-monitoring of blood glucose (SMBG) regimen to follow according to endocrinologists' prescriptions. By comparing the total number of SMBGs each patient should have performed and the actual number they recorded in the app, the researchers were able to compute for each patient a percentage value of actual measurements against ideal measurements. This value has been labeled 'Adherence' as a measure of patient's commitment to self-monitoring via the mobile app.

The second analysis focused on in-app notes; these were intended as a resource for patients to add more information regarding abnormal capillary glucose (e.g., too high or too low glycemic values), illness state or lifestyle. Considering the total number of

notes present in the database, a new variable has been computed for each patient: 0 = patient added zero notes; 1 = patient added 1 to 5 notes; 2 = patient added 5 to 10 notes; 3 = patient added 10 to 15 notes; 4 = patient added more than 15 notes. This variable is intended to give information about the patient overlooking, just trying, occasionally or frequently using, or being seriously committed to the notes function.

Moreover, as some T2D patients included a high number of notes within the app, it was interesting to analyze what kind of information was present in them. However, in-app notes were not adequate to perform rigorous textual analysis; as previously said, some patients added no notes or a very low number of them, while others made an extremely assiduous use of this function; moreover, notes are extremely variable in their content, in that sometimes they are composed by just a couple of words, while other times they include elaborate sentences, vivid descriptions and narrations. Therefore, the researchers decided to employ a sentiment analysis. Sentiment analysis software are able to analyze texts in order to extract emotional lexicon and its frame of reference, as well as to attribute a global positive/negative value to the text and quantify existent discrete emotions [18]. For the present study, the researchers employed the IBM software Watson (https://www.ibm.com/watson/), which includes advanced features for Natural Language Processing/Understanding and Sentiment Analysis [19, 20]. In order to use the software, the researchers have translated patients' notes in English maintaining the highest possible adherence to literary meaning; then, T2D patients' notes with more than one sentence available in notes were included in the analysis (GDM patients' notes were generally too rare and brief and the researchers decided they were not adequate for sentiment analysis).

Finally, some selected in-app notes by patients will be reported and their anecdotal value, useful to understand patients' experience, will be briefly discussed.

3 Results

The three types of results will be reported in three subsections.

3.1 Adherence Data

A t-test has been performed comparing T2D patients and GDM patients on the Adherence variable. Although T2D patients (M = 81, DS = 75.5) were generally more adherent than GDM patients (M = 58.18, DS = 31.5) in registering glycemic data, the analysis reached no significance: $t(1,25) = .933$, $p = .363$. It has to be noted that the number of SMBGs required for individuals with type 2 diabetes was on average 4 per week and the observation period spanned several months, whereas the SBGMs required for individuals with GD were at least 4 per day and the observation period was limited to 3 months.

For what regard the number of in-app notes, as this variable is based on an ordinal scale, a non-parametric statistic (Mann-Whitney test) was used to compare T2D and GDM patients. T2D patients were significantly more likely than GDM patients (M = 1.66, SD = 1.6 vs M = 0.36, SD = 0.5, respectively) to leave personal notes within the app ($Z = -2.160$, $U = 43.500$, $p = .041$, $r = .42$).

3.2 Sentiment Analysis

Indeed, the researchers noticed that, although the majority of the notes included information about food and life activities (because notes were especially intended to explain abnormal glycemic values), there were occasional references to emotional states and personal confidences (see next section for notable examples of patients' notes). Table 1 features individual patients' total number of words in the notes and the corresponding sentiment and emotional values attributed to them by Watson's analysis.

Table 1. Patients' total number of words in notes and corresponding values attributed by Watson's sentiment/emotional analysis. On numbering: patients were originally listed in the database based on the presence of notes, for this reason their numbering is consequential. Patient 7 has been excluded because he added just one note of a couple of words.

Patient	Total words	Sentiment (Positive/Negative)	Joy	Anger	Disgust	Sadness	Fear
1	27	0.88	0.80	0.01	0.01	0.07	0.04
2	133	0.29	0.48	0.08	0.53	0.15	0.06
3	70	−0.75	0.52	0.08	0.09	0.18	0.07
4	30	−0.16	0.61	0.11	0.10	0.13	0.06
5	170	−0.28	0.47	0.11	0.47	0.15	0.48
6	73	0.60	0.66	0.05	0.09	0.08	0.06
8	156	−0.77	0.24	0.15	0.52	0.58	0.19
9	69	0.29	0.48	0.08	0.53	0.15	0.06

It is important to take into account that these data should be interpreted with caution. Their inclusion in this study is not meant to constitute a rigorous analysis of patients' emotions, on the contrary they are intended as clues about the actual presence of emotional contents in patients' notes. Indeed, all patients obtain notable scores in joy in that the majority of notes are written with a positive and proactive attitude; also, explicitly happy and humorous comments are present. Occasional scores in sadness and fear are probably related to explicit statements about illness and the disease, while disgust scores may be related to the numerous food words associated with shame/regret for having eaten too much and therefore having negatively influenced glycemic values.

3.3 Patients' Selected Notes

Reporting some patients' notes is interesting to understand how this function of the app has been actually used and intended by the patients. Table 2 includes some selected notes from the app database, along with reference to patients (Italian original text and English translation).

Note (a) represents the majority of notes present in the database; this is how most of the patients' notes look like. As users were invited to include notes when glycemic values were above the limit suggested by the clinician, most of the notes feature possible justification for high values, therefore they describe food intakes prior to measurement.

Table 2. Selected patients' in-app notes.

Reference in text	Patient, note number	Content (Italian, English)
(a)	Patient 2, note 11	"A mezzogiorno ho mangiato insalata, due uova, un panino e una fetta di crostata e un bicchiere di vino" "At noon I ate salad, two eggs, one sandwich and a slice of pie and a glass of wine"
(b)	Patient 1, note 1	"È la prima volta che la misurazione si mantiene quasi su valori std. Infatti 136 al mattino non rispecchia i miei valori precedenti. Sono contento!" "It is the first time that the measurement is almost on standard values. Indeed 136 in the morning does not mirror my previous values. I'm happy!"
(c)	Patient 9, note 5	"Ho mangiato in mattinata perché mi sentivo vuoto" "I ate during the morning because I felt empty"
(d)	Patient 4, notes 1, 2, 5, 7	"Pranzi in Valle d'Aosta un po' pesanti" "Inizio ferie al mare" "Fine ferie" "Colpa delle ferie" "Lunches in Aosta Valley a little heavy" "Starting holidays at the sea" "Ending holidays" "It's holidays' fault"
(e)	Patient 9, note 7	"Vado in ferie torno il 30/05" "Going on holidays will be back on May, 30"

Differently, the other notes selected for the table show how patients sometimes used the app function to describe more intimate, confidential and/or emotional information. For example, note (b) accompanied a positive measurement, therefore it was an autonomous initiative by the patient (it was not suggested by the app). It includes a specific positive statement in that the patient wants to share his satisfaction for having reached a personal goal. Differently, note (c) features an ambiguous statement that may have an important emotional value. Indeed, both in Italian and English "feeling empty" may simply refer to feeling hunger, but it is an interesting choice of words that could also refer to sadness. Indeed, here the patient decided to not simply describe what he ate, nor to explicitly say that he was hungry, but he felt it was important to report a psychological sensation that moved him to eat outside of normal meal times.

The notes reported in (d) are quite interesting; the patient is basically using the notes app function as a small personal diary. He records the duration of his holidays with personal judgments instead of mere food or activities description, almost as if it was important for him to establish a personal dialogue with the clinician about what is happening in his life. Indeed, these notes constitute a small narration including context, events and emotional reactions.

In this sense note (e), wrote by the same author of note (c), is similar because it does not include justification of a problematic glycemic value: it is the last note of patient 9. Here, the patient is using the notes app function to say that his holidays are about to start. As the patient apparently foresees to be busy with holiday activities (or possibly prone to eat more than usual in the holiday context), he thinks that it is important to notify to the clinician about his life activities and maybe to justify why he will not write notes anymore during a busy period.

4 Discussion

This research compared patients with type 2 diabetes and gestational diabetes mellitus in their use of *ActiveAgeing*, a mobile application supporting self-care for diabetes. Statistical analyses show that there were no significant differences among T2D and GDM patients in the use of the app to register glycemic values, on the contrary both groups were generally satisfactorily adherent to the use of the app, thus empowering their self-care. Differently, T2D patients were significantly more likely to use the app's notes function, namely the opportunity to add personal written notes to glycemic/weight registration in order to explain anomalies. According to this result, T2D patients may be more engaged in the technology use in that they show personal initiative and the intention to help the clinician understand their health state. This could be related to type 2 diabetes' specific characteristics, i.e. a lifelong condition with high demands for daily self-engagement in care, with infrequent contacts with health professionals in a phase of life where other commitments might be reduced; on the other hand, women with GDM are pregnant and engaged in self and unborn child care, with frequent contacts with health professionals and an active daily life.

Secondarily, in-app notes by eight T2D patients have been analyzed. Watson's analysis showed that emotional aspects can be found in the notes, so their content cannot be reduced to "cold" reports of food intakes or care-related activities. Some interesting notes by the patients have been reported in order to highlight meaningful examples. It should be specified that such data cannot be generalized to a population, instead they should be considered as anecdotal information useful to understand the potentials of the *ActiveAgeing* app. Indeed, some patients showed a meaningful personal initiative by using the app function beyond its actual scope, which was adding details to possible abnormal glucose values (e.g., too high glycemic values). Sometimes, the notes function has been used to express emotions ("I'm happy!"), to write a "small personal diary", or to notify about life activities that may interfere with the app usage, as if it were a direct contact/appointment with the health provider ("I'm going on holidays, I will be back on May, 30"). Such examples show that the app's notes function could be developed further in order to constitute an actual tool for empowering the patient/doctor relationship, because patients actually use this affordance to express emotion and convey complex communicative intentions. Such a behavior actually transcends the concept of treatment adherence and hints at the one of patient engagement, or the proactive involvement of the patient in his/her own care plan [21, 22].

5 Conclusion

The present study showed that the *ActiveAgeing* app was generally successful in helping diabetes patients to monitor their own health. Preliminary data show that patients with type 2 diabetes were more likely to use the notes function to add details on their state, and also that they sometimes used such function to express emotions and convey complex communicative intentions. The main limitations of this study are related to the small number of subjects, and the different characteristics of the groups with regard to age and sex, which may act as confounding variables. Moreover, it

should be taken into account that the interpretations of T2D patients' in-app notes are purely anecdotal and should not be generalized to a population of patients, nor used to conclude strong inferences. Future studies on eHealth instruments should deepen the opportunities for empowering the communication between patient and clinician, in order to make use of self-care apps beyond their mere treatment adherence and health monitoring functions. Nevertheless, these should be tailored to specific patient group characteristics.

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