Building Digital Health Systems to Support Treatment Administration: A Preliminary Case Study

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Abstract. The emergence of Digital Health Systems (DHS) has had an impact on the understanding of the diagnosis, treatment and cure of diseases. In the case of chronic or long-term illnesses, these systems may improve the disease follow-up. However, these target scenarios also raise specific challenges. For example, due to the long-term nature of treatments, it may be harder for patients to maintain active use of the technology assets, being this aspect key to leverage DHS potential. From a review of the literature, this article analyzes the aspects surrounding patient adherence, to compile a concept model to drive DHS design. The concept model is applied over a DHS focused on patients under a specific health condition (kidney disease) that implies a long-term treatment (peritoneal dialysis). Under this treatment, clinical follow-up and medication adjustment require patients to track daily practical aspects and register health status, to dynamically manage daily life and disease. The availability of granular information also helps clinicians to optimize the judgement of treatment's effectiveness and counter effects. The result is a DHS that relies on a mobile application and a secure backend server accessible to the professionals in charge of patient management. It is focused on simplifying patient's data gathering, data continuity and completeness, and meaningful data retrieval and visualization for the parties involved (patient and clinician). The article explains the design process, with adherence in mind, and, as partial validation, an analysis of the user experience of four 'lead' users (volunteer patients and practitioners), with a review of the adherence results on the patients' side.

Keywords: Digital Health · Mobile Health · patient · application · adherence · usability · usefulness · abandonment

1 Introduction

The management of health conditions has changed with the emergence of digital health systems. Worldwide regulatory agencies are approving digital strategies to diagnose, monitor and support the treatment of diseases [1]. Digital Health Systems (DHS) are designed to improve consumer health and disease management through the use of digital

A. Cunha et al. (Eds.): MobiHealth 2022, LNICST 484, pp. 220–232, 2023.
https://doi.org/10.1007/978-3-031-32029-3_20

technologies. These tools have the potential to impact strongly on the management of chronic or long-term conditions, both for patients and clinicians. Chronic diseases are defined broadly as conditions that last several months (>3) or longer, and require ongoing medical attention or limit activities of daily living or both. Cancer, heart disease, stroke, diabetes, and arthritis are some of the most frequent chronic conditions.

To maximize the benefit of DHS, it is important to assess their impact, as well as the barriers and enablers to adoption. Over the last decade, research has tried to show the potential of digital healthcare systems. For example, a number of proposals, [2–7], focused on managing heart disease (arterial hypertension, cardiometabolic diseases, etc.) through sensors and apps tailored to incentivize behavioral change, compile different studies on how these technologies impact on patients' health status. These studies include traditional trials with control and intervention groups that shows the second group (the one using the application) overperforming the first one (with regular management) in terms of health outcomes.

This article explores how to design a DHS to provide a sound value proposition, both for patient and clinician, when managing a long-term condition. The main objective is to understand the specific needs that DHS for chronic disease management should tackle, to support patients in their treatment and practitioners in their follow-up and accompanying processes. Although DHS may be built on different tools, in this case we will center on DHS involving, in brief, a mobile application for the patient, a backend for data storage and processing, and a dashboard for the practitioners to access data. Then the mobile health (mHealth) component is a cornerstone of the system. The diversity of chronic conditions will undoubtedly modify the type of functionalities and goals that the DHS must address, but the objective includes abstracting and generalizing some main design guidelines that may be horizontally applicable.

The paper structure is as follows. First, in Sect. 2, gathers a review of key concepts, state of the art, and cause-effect elements related to adherence and mHealth systems, as patient-oriented mobile tools are the ones guaranteeing data input. On this analysis, we present a concept model to drive design of DHS and exemplify it through the system presented in Sect. 3, which is focused on peritoneal dialysis treatment management for kidney disease patients. This type of patient must record the volumes of infusions and drains they perform daily, apart from recording health indicators such as weight or blood pressure to manage e.g., food and liquid intakes. In Sect. 4, the proposed DHS has been built and validated with a small group of users. Being a preliminary work, Sect. 5 analyzes conclusions and further steps.

2 Understanding Adherence in mHealth

A key issue in mobile health is adherence to mobile applications enabling data gathering; the workings of Digital Health Systems assume that users will provide an adequate amount of data, that will be as recommended and intended by clinicians [8, 9]. If the application on the patient side does not collect the expected amount of data, the system will not achieve the optimal results. Obviously, adherence should not be the same on a stand-alone mHealth system (only relying on an app and an automated service) than on a system counting on clinicians' feedback on the other side. But trying to isolate the app from the rest of the system, in general, adherence can be understood because of perceived usefulness and usability. If the application causes fatigue, the user may be less eager to use it or even abandon it (therefore, improved usability is conceptually correlated to better adherence). Moreover, if the user perceives benefits from using an application (perceived usefulness), s/he will have an incentive not to abandon it. Ideally, it will also be an enabler to perceived usefulness: the user adheres to the app because s/he finds it useful, and the DHS can provide meaningful feedback and advanced features because complete personal data logs are available due to the regular app usage.

How to improve adherence to a health mobile app is still a challenge. Mobile health apps make use of a variety of design incentives to engage the user. Some of the main mechanisms are user status tracking and performance feedback [3, 4, 6, 10, 11]. Also, there are popular mechanisms to adhere users such as personalized goals set-up, reminders and prompts or gamification with rewards delivery, as it can be seen in [12–15]. Additionally, strategies aiming at behavior change, such as motivational messaging or social sharing functionalities are common [14, 15]. Table 1 summarizes the list of strategies/design features in literature that may be considered. The mechanisms from 1 to 4 are mainly related with adherence in its literature. On the other hand, from 5 to 17 are mainly related with usefulness, but most of these are also associated with adherence (e.g., community support, gamification or performance feedback) or usability (e.g., data personalization or connection to devices). The mechanisms more related with usability are 18–27 and these are rarely mentioned as such in the development of the applications, although they are present in almost all the proposals.

It is not just important to get to know the existing mechanisms, but also the way users rate them. As show at [12, 14, 15], the mechanisms most highly valued by patients are mainly monitoring, personalized goals set up, access to health information and notifications/reminders. On the other hand, the lowest rated mechanisms are rewards and social comparison (nevertheless, the prevalence of these techniques in this type of system is very common). In the next Section, we will organize mechanisms into an adherence concept model.

3 Adherence Concept Model to Build a Patient-Oriented App

As previously stated, adherence, usefulness and usability are closely related, impacting one over the others. We can assume that, to foster high adherence, the application on the patient side must be perceived as a valuable tool (being able to provide the promised benefits) effortless to use [16]. The same requirements can be posed for clinicians-oriented tools, as the DHS is at least a two-sided platform, but patients' data are key to activate the full system. So, the model next is focused on identifying key aspects when designing the patient app side of the DHS, which will oversee obtaining data from the user to provide the right service.

The adherence strategies compiled in Table 1 have been organized into four non-exclusive groups, depending on its objective:

O1) Incentivize Data Entry. In this group, we refer to all the strategies to get as many data as possible, such as notifications and reminders delivery (to remind of pending

Table 1. Adherence strategies considered in literature for mHealth.

ID	Strategy	Short description	Studies
1	Send personal data	Allow the sending of data related to the Patient's health status or experience with the application	[2–4, 6, 10–12, 14, 15]
2	Display personal data	Display simple views of collected patient data, allowing the patient to access them whenever s/he wants	[2–4, 6, 10–12]
3	Communication with the sanitary	To create a simple communication channel between the patient and the healthcare staff	[2, 6, 11, 13]
4	Reminders, notifications	Use of alerts to remind the patient to interact with the application, submit data, keep an appointment, etc.	[2–4, 11–13, 18]
5	Health information	Provide access to information about the targeted health problem that is useful to the patient	[2, 4, 6, 12, 14, 18]
6	Community support	Creation of channels of communication between patients to share experiences and support each other	[13–15]
7	Social comparison	Show data from other patients (with the possibility to establish a ranking) to motivate the user to improve	[4, 14, 15]
8	Personalized goals	The application or the user can set goals to be achieved with the intention of motivating the user	[3, 4, 12, 14, 15]

(*continued*)

Table 1. (*continued*)

ID	Strategy	Short description	Studies
9	Motivational messages	Texts aimed at encouraging the user to continue to improve and get involved in their health	[14, 18]
10	Gamification	Use of game elements to motivate and engage patients in health-related contexts	[12, 13]
11	Performance feedback	Provide patients feedback and data about their progress, to motivate to improve or to change behaviors	[3, 4, 10, 11, 13–15, 19]
12	Risk assessment	Establish indicators to measure and report on the patient's condition. Then, process the data collected to detect risk and alert the patient and practitioner	[2, 3, 7, 10, 11, 19]
13	Data personalization	To be able to adjust the data requested or displayed to users' preferences	[3, 7, 11, 14]
14	Emergency button	Button that allows the patient to call emergency services with a single click	[2]
15	Relaxation exercises	Used to enable the patient to assist in the process of lifestyle change	[14]
16	Export personal data	Option of downloading a document with the data history	[19]
17	Connection to devices	The application can be connected to a health measuring device for easy data collection	[2, 7, 10, 11]

(*continued*)

Table 1. (*continued*)

ID	Strategy	Short description	Studies
18	Minimalist design	Avoid displaying large information on the same screen, avoiding empty information and trying to avoid scrolling	[17]
19	Intuitive design	E.g., buttons that look like buttons, that the flow between windows is understood	[6, 17]
20	Coherent order	In a view it is recommended to order the displayed information from most to least important	[17]
21	Language adapted	Avoid technical terms, language adapted to all types of patients, using vocabulary that they understand. It is recommended to use the second person, to take a friendlier tone	[6, 17]
22	Clarity of instructions	Provide guidelines for using the application, in the form of an information menu and/or a video tutorial at the beginning of its use	[2, 3, 17]
23	Accelerators, shortcuts	Enable fast application interaction	[17]
24	Undo actions	For example, allow the user to delete data sent in case of a mistake	[17]
25	Error prevention	Try to prevent the user from making a mistake, for example by using confirmation messages to avoid pressing a button by accident	[17]

(*continued*)

Table 1. (*continued*)

ID	Strategy	Short description	Studies
26	Avoid free text entries	If used, given the option to delete everything with a single click	[17]
27	Appropriate colors	For example, excessive use of black tends to cause rejection, or the components shown should contrast with the background	[17]

tasks, to alert of inactivity or to directly request to send data) or connection to electronic measurement devices (thus, encouraging the user to retrieve data by simplifying the collection procedure). By collecting the maximum amount of user data, the system will be able to offer an optimal service. Regular and timeliness data collection is key to apply, in general, machine learning techniques that enable personalized models and detect anomalies or even predict risky states. When dealing with chronic conditions, these functionalities may be part of the value proposition of the DHS system.

O2) Facilitate the Application Use. We group together those strategies mainly related to enhance usability. In mHealth terms, usability refers to the effort required to use the application (greater usability also allows for greater perceived usefulness). Among others, we include traditional principles, such as using a simple language, tracking system status, avoiding errors and facilitate their management (indicating how to solve them, allowing undoing actions, etc.), quick interaction, minimalism or no empty information [17]. These mechanisms prevent user fatigue and the user from abandoning the application because it takes too much effort. Additionally, for long-term users, specific short cuts and customizable views may coexist with learnable functionalities.

O3) Extend Information. They are basically strategies related to enhance usefulness perception through information (e.g., displaying personal data or curated information about the disease) or to create a security context for the storage of their data and the way they are handled (e.g., allowing data export, risk assessment or communication with doctors). In the case of chronic conditions, the system should support reliable information retrieval in different stages of the disease evolution, from getting familiar to it, to learning to detect changes and risk, while also optimizing contact with practitioners.

O4) Support Behaviour Change. These are strategies which aim at changing the pattern of behaviour, such as: motivational messages, personalized targets, social comparison (encouraging healthy competition among users) or task reminder techniques. Achieving changes in self-behavior increases perceived usefulness of the technology. Chronic disease therapies may require specific training for patients, and interactive guidance to reach targets to improve their health condition.

As mentioned above, the identified objectives are not exclusive one against other, which means that, in many cases, each strategy is not only supporting a single objective. In most cases they can be related to two or more objectives, as shown in Fig. 1.

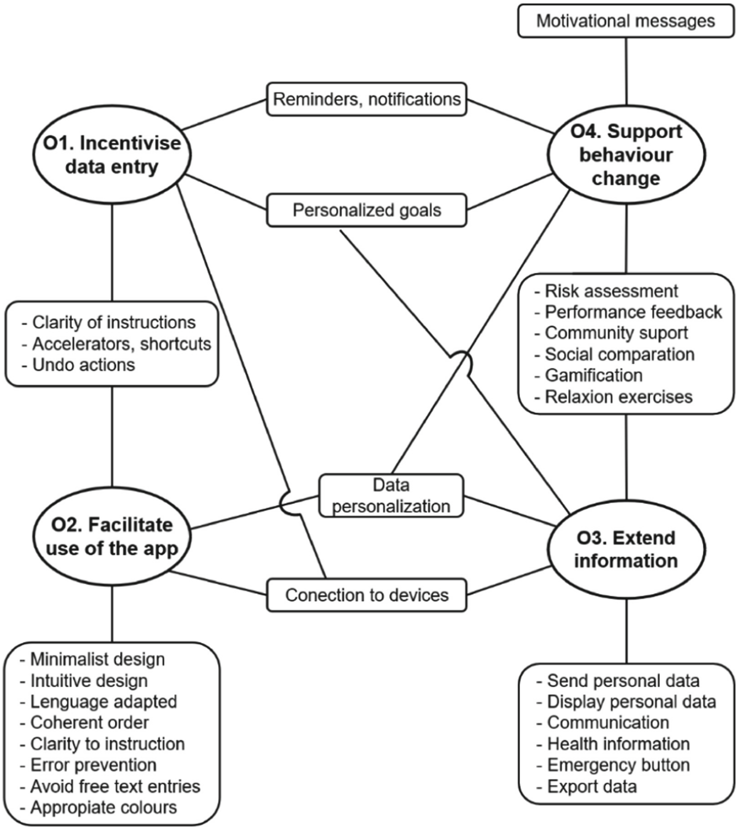

Fig. 1. Adherence concept model.

4 Preliminary Use Case: A DHS for Kidney Disease Patients

4.1 Design Stage

The concept model for adherence proposed in the previous section has been applied to build a DHS for patients with kidney failure following peritoneal dialysis. This dialysis is performed introducing a fluid into the peritoneal cavity through a catheter placed in the abdomen. To avoid the excess of fluids in the abdomen, patients need to carefully control the amount of fluid infused and drained throughout the day. Therefore, patients must record information about their treatment guidelines several times per day. Additionally, they must take note of some specific health status data, such as daily weight and blood pressure. This information is used by clinicians to adjust therapy, when necessary, e.g., due to hypertension or fluid retention issues. Many patients decide to use standard notes apps or traditional notebooks to track their evolution and to explain the records to their doctors at regular check-ups. So, the objective of the designed DHS is, initially, to facilitate treatment follow-up and health status awareness, while making it easier for the clinician to perform data-driven disease monitoring. In technical terms, the system has the following components: a mobile application, a backend server and two databases and a professional dashboard.

At the design stage, we aimed at understanding how patients performed data collection, what kind of language they used and what specific needs they had. To get better understanding on the disease and its management, we initially hold several conversations with clinicians. On these conversations, clinicians underlined that patients often adopt a very specific vocabulary to refer about their condition.

Prior to the DHS implementation, two volunteer patients under treatment were asked to complete a questionnaire to learn about their habits, and determine what needs they wanted to satisfy with the app. Their main concerns were forgetting to save data, losing data, saving data incorrectly and getting the wrong therapy (e.g., wrong time or dialysis fluid).

Thus, with this information, we used our concept model to better determine the DHS adherence strategies supporting patients' needs:

- The principal mechanism used to incentivize data entry (O1) would be notifications. Those are to be used to remind patients to send data and avoid inactivity. Patients also receive an alert for a new message from their doctor.
- To facilitate the use of the app (O2), we would try to embrace all the guidelines of the concept model: minimalist design (avoiding unnecessary information), coherent order (according to the most relevant data for the patient), language adapted to patients, intuitive, avoiding errors (using confirmation request to send data and indicating the type of error to help solve it), avoiding free text entries, reporting the status of the system (e.g., data saved correctly or loading), etc.
- Regarding extended information (O3), we would implement the capability of sending and displaying personal data (using simple and adapted questionaries, graphs, and tables), the capability to communicate with clinicians and the access to health information about peritoneal dialysis.
- To encourage behavioral change (O3, O4), we carried out a data analysis to obtain indicators of the patient's condition to report their evolution and to alert the doctor in case their therapy needs to be reviewed. The main calculations are the pressure variations or the total fluid in the abdomen variations.

We also followed an iteratively procedure to co-design the practitioner's dashboard.

4.2 Toward Validation: Some Early Usage Data

The developed system has been under validation during a short period of time, in two different stages. This validation should be considered preliminary due to the limited number of subjects involved, but it has enabled us to get some valuable feedback to determine next steps to take. In the first stage, the two volunteer patients and doctors were using the resulting DHS for a week time. Right after, they evaluated the usability and the usefulness of the functionalities under an adapted mHealth App Usability Questionnaire (MAUQ), from University of Pittsburgh [20, 21]. This questionnaire asks about how they feel about using the application, how challenging it is, if they would continue using it, or if they would recommend it. Overall, the scores for the 4 individuals were favorable, usability obtained on average 4.15/5 and functionalities obtained 4.625/5.

However, there were differences between clinicians and patients. The former's perceived usability scored on average 4.6, while the latter scored only 3.6. The main difference in the questionnaires is that patients rate the safety and reliability of the application lower. This may happen mainly because initially patients did not have the option of downloading the app from traditional app marketplaces. Additionally, patients complain about the inability to recover from certain errors, since the data sent cannot be modified. The following table shows the evaluation of the functionalities, distinguishing between patients (P1, P2) and doctors (D1, D2). As expected, users differ in their interests (Table 2).

Table 2. Surveys of functionalities.

Functionality	P1	P2	D1	D2
Save personal data	4	5	4	5
Display personal data	4	5	4	5
Therapy information	3	5	5	5
Communication from patient to doctor	5	5	5	5
Communication from doctor to patient	5	4	5	5
Notifications	5	5	4	4
Automatic filling of the data to be sent	4	5	5	5
Request sending confirmation	5	5	3	5

For both doctors, notifications are rated lower than other functionalities, while for patients it is one of the most highly rated mechanism for the application. The patient showing more criticism considers that displaying therapy guidelines is not that important, while both doctors (and the other patient) agree on its importance. We can also observe that one of the doctors (D1) does not perceive the usefulness of requesting confirmation on sending in the same way as the rest. These small discrepancies confirm the importance of considering both stakeholders (patients and clinicians) in the design of the system, as they may have different viewpoints over the same functionality.

After this initial pre-evaluation, certain styles were adjusted and new adherence strategies were included, such as the possibility of customizing personalized notifications. With this, a trial has been launched with 6 users, to carry out a more complete analysis of the benefits of the system. The information related to adherence collected during the trial from each user is shown in the following table (Table 3).

Table 3. Analysis of users indeed the trial.

Users	Total days	Active days	Dialysis days	General data	Msg to doctor	Msg to patient
U1	177	156	168	165	6	10
U2	115	115	117	266	3	3
U3	90	81	85	192	0	0
U4	82	82	85	111	1	1
U5	36	36	108	38	0	0
U6	25	16	17	18	0	1

As can be seen in the previous table, the levels of use of the application by patients are favorable. The average percentage of days those users have submitted data on their therapy is 90.36% (with a standard deviation of almost 14%). This shows that the patients of this small trial have been using the application almost constantly, which indicates very high levels of adherence. In contrast, it is observed that messaging is rarely used by almost any of them.

5 Conclusions

The concept model presented in the article is a summary of our experience when dealing with DHS patient adherence in a specific chronic condition, but it is still obviously a work in progress. The results obtained from the limited user trial show reasonable adherence, but the trial has an evident limitation in terms of scope, as few users have served as testers. In any case, the collaboration of lead users has made the system's design smoother. We are following compile some design guidelines that may be helpful for facing future designs:

1) Assuming a patient-centered design approach, that enable the designer to understand the management difference among patients' profiles (e.g., those that have been under treatment for a long time and those that are initiating it). We have concluded the importance of establishing a design procedure starting with the retrieval of relevant information about the patients' health situation and their specific data needs (e.g., type and frequency). Additionally, it is important to understand the current patient's practices, as it may be beneficial to mimic them and translate them into digital means, instead of creating a new methodology from scratch (e.g., for information logging). It is desirable to adapt language, vocabulary and even give specific customization mechanisms for patients, as patients on long-term treatments tend to develop their own terminology to refer to procedures, drugs and symptoms, and taking this into account in the app design can make it more friendly. Additionally, we have detected those patients on the same treatment can understand the application requests differently, thus it is crucial to support data gathering with accurate

and sufficient explanation. This information can disappear over time (or be hidden), together with newcomers training tips.

2) Devoting time to achieve a proper understanding of the disease evolution and its stages, in order to analyze the implication over the tools' features. The objective is to effectively translate this into dynamic application features both for the patient and the doctors.
3) Dynamic redesign with clinicians is needed to incrementally include tools that can get the most from the retrieved data taking their experience and practices as a base. For example, to make the dashboard acceptable for clinicians, it is helpful to conduct design reviews and consider their specific visualization requests and how to support them (e.g., data to show, key performance indicators, type of preferred visualization – tables vs. charts, risk detection, communication flow).
4) Analyze how the DHS is going to be integrated into the clinical pathway. This may lead to identify new administration features and user profiles. For example, in our case, the DHS enables asynchronous communication between patient and clinicians. This implies a dealing with the extra interaction in organizational terms.
5) The serious need of highly committed clinicians to promote the use of the service among their patients and colleagues. Clinicians' adherence is also important, as being a two-sided system, patients will only perceive full usefulness whether their health providers are paying attention to their data and requests and the communication is fluid.

A pending issue that we have not addressed in this version of the DHS is how to smooth or simplify data gathering by using connected sensors or even treatment machines data (e.g., in the case of ambulatory dialysis, the cyclers). Being desirable, the fragmented vendor ecosystem and the bundle with proprietary software platforms is always a hindrance. In any case, manual and continuous input of key data can increase patient awareness over the disease and health status, so it is important to find creative ways to leverage this continuous interaction. The DHS is a tool that may behave as an open window to the patient and the disease, so it may serve for multiple uses and evolve over time to provide support to the patient, always taking into consideration the preservation of data protection regulations.

Acknowledgment. Authors gratefully acknowledge the design feedback and participation on trials of volunteer clinicians and patients of Hospital 12 Octubre in Madrid, Spain, and sponsorship from REACT-CM MadridDataSpace4Pandemics Project and UPM Project RP180022025.

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