

IoT eHealth Applications for Chronically Ill Patients: Requirements and Design Principles

Tilo Mentler

Department of Computer Science
Trier University
of Applied Sciences
Trier, Germany
mentler@hochschule-trier.de

Henrik Bundt

University of Lübeck
Lübeck, Germany
h.bundt@alumni.uni-luebeck.de

Nicole Jochems

Institute for Multimedia and
Interactive Systems (IMIS)
University of Lübeck
Lübeck, Germany
jochems@imis.uni-luebeck.de

ABSTRACT

Chronic diseases are a global burden affecting billions of people, causing millions of deaths per year and excessive costs for healthcare systems. Smart and ubiquitous eHealth applications supporting patients in their everyday life could have a major impact on patients' quality of life and treatment outcomes. In this paper, we present results of an online survey with 320 participants (188 chronically ill patients, 132 persons related to chronic diseases in various ways, e.g. relatives) in order to gain insights into expectations and concerns of patients with chronic conditions towards eHealth solutions based on Internet of Things (IoT) technologies. 175 of them finished the questionnaire completely. In addition, interviews with 8 physicians on patient-doctor-relationships, therapy processes of patients with chronic health conditions and opportunities for improvements through IoT-based eHealth services were conducted. By thematic analysis of the results, requirements were identified that future applications need to fulfill to achieve acceptance and long-term usage. Accordingly, we present six design principles for IoT-based eHealth applications for chronically ill patients.

CCS CONCEPTS

• Human-centered computing~Human computer interaction (HCI) • Human-centered computing~Interaction design • Human-centered computing~Ubiquitous and mobile computing

KEYWORDS

Chronically Ill Patients; eHealth; Internet of Things; Usability, User Experience; Treatment Adherence

1 Introduction

According to estimates by the World Health Organization (WHO) chronic diseases (e.g. cancers, cardiovascular diseases, asthma, diabetes mellitus, Alzheimer's disease) "are the leading global cause of death and are responsible for 70% of deaths worldwide" [1]. Previous studies have shown that they strongly affect quality of life both of patients and of their relatives [2, 3, 4, 5, 6].

As individual behavior (e.g. diet, physical activity, use of alcohol, smoking, treatment adherence) has a major impact on health conditions and disease processes, tremendous efforts including health promotion measures at home and at work have already been made to intervene at this level [1, 7]. Nevertheless, chronic diseases will "continue to be an important public health challenge in all countries" [1].

Apart from emergency care and immediate treatment, e.g. bypass surgery in case of a heart attack, chronic disease management is characterized by long-term efforts involving patients' self-care, ambulatory care, and hospital care. In this regard, at least two major challenges can be identified:

- What is needed – and according to [8, 9] is missing in healthcare systems all over the world – is a "[care] model that involves coordinated inputs from a wide range of health professionals over an extended period of time and that places patients at the centre as co-producers of care to optimize health outcomes" [10].
- Self-management abilities of patients can be affected by several factors (e.g. age, duration of disease, education level, single status) [11]. Especially, medication adherence is poor. According to estimates, up to 50% of patients do not follow prescribed procedures [12, 13].

E-Health, in terms of the "use of information and communication technologies in support of health services" [14], has been called a "promising solution" [15] for improved chronic disease management and "a way to change the traditional [health care] approach to person-centered care" [16].

Especially the "Internet of Things (IoT)" [17], here in terms of home appliances, everyday objects and novel interaction devices (see Fig. 1) equipped with network connectivity and health-related software components (e.g. activity trackers, blood pressure monitoring smartwatches, smart pill boxes), has the

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"potential to give rise to many medical applications" [18], e.g. supervising chronic diseases or ensuring compliance [19,20].

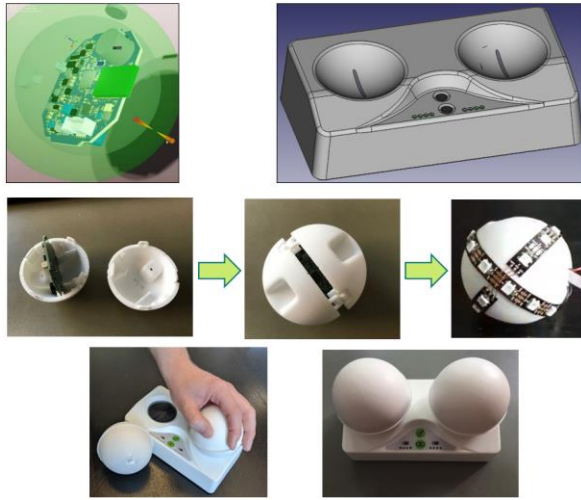


Figure 1: Stages of development of a Ball-shaped Interactive Rehabilitation Device for patients with limited verbal and sensomotoric skills [21]

However, acceptance, usability and user experience are crucial aspects - especially with respect to long-term users like patients with chronic conditions. Designers should be - as Wolters [22] states - "in the search for the minimal effective dose of technology".

Our contribution considering the research question how IoT-based eHealth systems must be designed to improve perceived benefits and long-term acceptance by patients can be summarized as follows:

- We report results of a study with 188 chronically ill patients and 132 persons related to chronic diseases in several ways, e.g. relatives, on intuitive expectations and concerns towards IoT-based eHealth solutions. 175 of them finished the questionnaire completely.
- We report results of interviews with 8 physicians - both general practitioners and specialists involved in treating chronically ill patients.
- We present six design principles for IoT-based eHealth systems based on requirements identified by thematic analysis of patients' and physicians' feedback.

After summarizing related work (see section 2), the study design is described in detail (see section 3). Finally, requirements and design principles derived from the study results are described and discussed (see sections 4, 5, and 6).

2 Background and Related Work

In the following section, previous research on digital technologies for chronically ill patients as well as design principles for IoT and eHealth solutions is summarized.

2.1 Technology and Chronically Ill Patients

Research groups all over the world have identified patients with chronic diseases as a user group that could profit from sophisticated information and communication technology solutions - especially at home and related to self-care (cf. [23]).

On the one hand, specific applications or systems have been developed and evaluated, e.g. mobile applications for managing treatments [24], tangible health-related educational toys [25], wearable devices for self-reporting pain [26], wireless monitoring [27], virtual reality applications for meditation exercises [28] or an integrated physical and virtual pillbox [29]. On the other hand, more general issues like communication, cooperation, privacy and security have been studied, e.g. usage of social media platform and online communication tools by chronically ill patients [30], communication boundaries between patients, healthcare providers and caregivers [31, 32, 33], health-related information sharing [34] and privacy in smart home environments [35].

Furthermore, design challenges for ubiquitous computing in the context of chronic diseases have been identified, e.g. "the open-ended and uncertain nature of chronic care, the wide inter- and intra-variability of patients' conditions and attitudes towards the disease, and the need for more symmetrical interactions and consultations with medical experts" [36].

In this regard, Barricelli et al. [37] emphasize the need for further research on "method[s], techniques, technologies, and design approaches for improving the level of patients' engagement in therapy management in order to contribute to a higher efficacy and effectiveness of the cure and to a higher patients' satisfaction".

2.2 IoT and eHealth Design Principles

Apart from software engineering considerations (e.g. [38]), design principles for IoT and eHealth applications with respect to user interfaces, usability and user experience have been proposed by several researchers. For example:

- Jones et al. [39] introduced "accessibility", "adaptability" and "iterability" as "design principles for health wearables" that account for handling of data and connectivity. They provided questions "designed to explore these criteria", e.g. "Can users add and edit data if they choose?" or "Can users store personal copies of their data?"
- Kientz et al. [40] developed 10 heuristics to evaluate "persuasive health technologies", e.g. "not irritating or embarrassing", "use of positive motivation strategies" or "customizability". The 13 researchers and students with "experience in user-centered design" developed them by reviewing and evolving existing guidelines.
- Based on the results of projects in different healthcare settings, especially with elderly and pregnant women with diabetes, Ballegaard et al. [41] suggest "design for continuity" and "design for understandability and learning" as eHealth design guidelines. While the former is related to augmenting technologies that are already

present in most peoples' life instead of developing new ones, the latter is requested to match patients' abilities and view them as active parts of managing their conditions.

While some researchers study guidelines for specific user interface details, e.g. how to visualize single health data streams (persons' weight over time) [42], others look at best practices for dealing with broader socio-technical issues, e.g. how to facilitate usage of eHealth applications [43], or design challenges with respect to certain conditions, e.g. dementia [44] or cancer [45]. Based on a case study with 28 participants (14 cancer patients, 14 persons without cancer in a control group) Das et al. [46] conclude "that designers of online healthcare systems need to take into consideration the unique challenges of being ill and/or using medication". We agree with this conclusion but would like to extend it in two ways:

- Considering the basic nature of tasks participants had to perform in the study of Das et al. [46] (e.g. accessing the internet, sending a message, receiving a message), we are convinced that the aforementioned conclusion applies to designing eHealth applications in general, not only web-based systems.
- In addition to considering patients' conditions, thoughts must be given to technology-related issues. It is a debatable point requiring further research whether general eHealth design principles can be applied to IoT-specific solutions.

3 Methods

Based on a human-centered design approach, the aim of our study was to gain insights into the intuitive expectations and concerns of patients with chronic conditions towards IoT-based eHealth solutions. In the following sections, the applied research methodology and study design are described.

3.1 Online Survey

Following an initial literature review on patients with chronic conditions as well as specific eHealth and IoT applications (cf. the previous section), a questionnaire was constructed in order to get detailed information about the living conditions of chronically ill patients, features they would request of an IoT-based eHealth-system and how they imagine its usage in their everyday life.

The questionnaire consisted of six parts as shown in Table 1 and 37 questions – 25 of them concerning patients' therapy experiences. If suitable, free text answers were preferred over Likert scales for qualitative insights. To prevent that patients gained a wrong understanding of technical issues or had a certain device or application in mind, they were not introduced to IoT- or eHealth-related concepts in detail. Instead, they were informed that the questionnaire – especially in part E – was about digital technologies supporting therapy in their home environment in any way.

Table 1: Parts and sample questions of the patients' questionnaire

Part	Sample questions with ID and answer options (translated from German)
(A) General questions	A1: What is your sex? (male, female, other (free text))
(B) Computer Experience	B3: Do you use applications or devices for health tracking? (yes, no) B4: As how useful do you perceive that usage? (not at all, very little, a little, intermediate, much, very much) B5: As how laborious do you perceive that usage? (not at all, very little, a little, intermediate, much, very much) B6: Why do you feel this way? (free text)
(C) Chronical Illness	C1: Do you suffer from a chronical disease? (yes, no) C2: Which disease? (free text)
(D) Therapy Experience	D6: What about the personal contact with your physician is especially important to you? (free text) D7: How much time per trip (h) do you spend travelling to and from your physician? (free text) D8: How high are your expenses (€) per trip to and from your physician? (free text) D9: What other efforts do you have for travelling to and from your physician? (free text) D11: What measures are usually taken when you visit your physician? (free text) D14: If you have a prescribed medication, how often do you take it? (I have no prescribed medication, as often as prescribed, more often than prescribed, less often than prescribed, not at all) D15: Why do you divert from the prescribed dosage? (free text)
(E) Expectations	E1: Which features would you like to have in such a system? (free text) E2: Which concerns would you have regarding such a system? (free text)

97 German patient organizations and self-help groups (e.g. German Diabetes Society, German Parkinson Society) as well as 10 German-speaking online communities (8 disease-specific forums and 2 disease-specific Facebook groups) were contacted and made aware of the online survey based on the LimeSurvey system. Representatives of these groups were contacted and asked to pass the survey on to their members and sub-groups.

320 persons participated in the survey and 175 of them finished the questionnaire completely. 199 of the participants were male, 68 females; the rest did not specify the gender (sample question A1). The age of the participants ranged from one to 80 – however, it can be assumed that answers which stated such a noticeably early age came from parents or relatives of ill children. The average age of the participants was 41.75. 38 participants left their E-mail-address for future contacting.

We would like to point out that 132 persons participated although they stated not to suffer from a chronic disease (C1). Some of them, like in the case of the 1-year old participant, might be relatives, or are related to chronic diseases in diverse ways, e.g. as caregivers. While we did not expect persons with no or non-chronic diseases to participate in our questionnaire and had to separate their answers from further analysis in this study, their involvement provides an indication of greater interest in the topic of IoT-based eHealth services.

The 188 participants of the online survey with chronic conditions suffered from various illnesses, and some of them even from multiple diseases at once (C2). The 3 most represented chronic diseases were diabetes (30 patients), Crohn's disease (22 patients), and asthma (12 patients). Most chronic diseases were represented by only one or very few patients (e.g. cystic fibrosis, dysthymia, Parkinson's disease). In total, 69 different chronic diseases were named.

3.2 Interviews

To understand physicians' work and role in the context of chronic diseases, semi-structured interviews with physicians were conducted. The goal of these interviews was to learn about the patient-doctor-relationship, the therapy process of patients with chronic health conditions and to find opportunities for improvements through IoT-based eHealth services.

Potential interviewees were contacted via e-mail and telephone calls, whereas the latter turned out to be much more effective. It proved quite difficult to acquire physicians as interviewees due to their tight time schedule. Out of about one hundred forty contacted physicians and health professionals, eight gave a positive response (see Table 2). So, a total of 8 interviews was performed.

An interview took about forty-five minutes on average. Six of the interviews were conducted at the interviewees' workplace and two on the phone. A consent form about the recording and analysis of the obtained information as well as a short questionnaire about the interviewee's specialization, experience and usage of technology preceded the interview.

Table 2: Roles and Working Experience of the interviewed participants

Participant	Role	Experience
P1	general practitioners	25 years
P2	general practitioners	22 years
P3	general practitioners	31 years
P4	general practitioners	30 years
P5	orthopedic specialist	50 years
P6	neurologist	23 years
P7	neurologist	28 years
P8	heart surgeon	15 years

The interviews started with an opening question about the interviewee's background and work. The following part of the interview consisted of these questions:

- How do you stay in contact with your chronically ill patients?
- How often are you in contact with your patients?
- Which electronic devices do you use for your everyday work?

The main part of the interview concerned patients, their health conditions, and treatments (13 questions in total), e.g.:

- How much time is spent for the preliminary discussion?
- How much time is spent for the actual examination / treatment?
- Could some of the data be collected by the patients themselves if they had the proper devices?

Furthermore, the interviewees were asked about their collaboration with other health care professionals on the treatment of their patients. The aim of these questions was to determine any obstacles or difficulties that occur in the treatment of chronic patients and to find out which features and aspects of an IoT-based eHealth-service could help to improve the treatment of the patients. The interview concluded with the request of the interviewee to add anything he or she has in mind, which had not been talked about yet, or to add any other comments or questions.

3.3 Data Analysis

We conducted a quantitative analysis of the data from the online survey as well as a qualitative analysis of the free text answers of the online survey (B6, D6, D9, D11, D15, E1, E2) and the interviews of the physicians.

Therefore, the interviews were audio recorded and transcribed resulting in a single transcript and the free text answers of the patients were summarized in a single document. Afterwards we conducted an iterative thematic analysis by clustering and coding to identify and synthesize themes within the data.

This process was iteratively done by the authors and resulted in the five expectation on IoT-based eHealth systems: being more informed, being involved, staying in touch, having less mental, financial and physical effort as well as feeling safe and taken care of.

4 Findings

In this section, we summarize patients' and physicians' feedback with respect to everyday life and medical treatment as well as expectations on IoT-based eHealth solutions.

4.1 Everyday Life and Medical Treatment of Chronically Ill Patients

In summary, it can be said that patients' chronic conditions and medical treatment have a major impact on their everyday life and their social environment.

More than one-third (39.42%) of the chronically ill patients see their physician at least once a month or more often. 80.58% perceive these check-ups as much or even very much expedient, and 28.95% perceive them at least as medium useful. On the other hand, about half of the patients (50.28%) experiences them as middle to very laborious.

For most participants of the online survey, the check-ups and examinations usually take place in their physician's practice (84.57%). 40% visit a clinic regularly (and obviously, there is a group of patients that visits both), 1.17% get visited by their physician at home, 1.14% chose "other location". Between those personal check-ups, many stay in touch with their physicians via telephone. 14.85% use email at least once a month to communicate with their physician.

The kinds of efforts patients have for visiting physicians are numerous (96 participants answered question D9, only 6 of them stated to have no efforts):

- 19 participants have to find someone to look after pets or kids ("My older daughter (5) has to stay at the kindergarten up to 10 hours on these days").
- 15 participants have to take a day off from school, university or work.
- 12 participants have to coordinate their work shifts with coworkers.
- 8 participants stated that they have to get the regular amount of work done in less time to leave early.
- 8 participants rely on others to take them to physicians or clinics and back home.
- 7 participants have to take measurements up front or afterwards (e.g. blood samples, collecting relevant information which can take up to an hour according to one participant, going to a pharmacy).
- 7 participants depend on public transport or specially equipped taxis.
- 6 participants have strains during or after the treatment and feeling exhausted and stressed.
- 4 participants have to fill out special forms to be allowed to leave workplaces for appointments.
- 3 participants have to be accompanied by others for several reasons (e.g. treatment effects).
- 3 participants have to find a place to stay overnight (hotel, friend's home).
- 3 participants stated that they have to pay high parking prices ("costs for underground carpark 4.00€/h => often more than 2.5 hours").

- 1 participant requires special equipment to leave home (a mobile oxygen apparatus).

One participant summarized the efforts as follows: "tide- and weather-dependent journey by ferry; rent a car; bus or train; 1-2 nights' stay onshore". Another one stated: "You are speaking of one physician. However, I have several physicians. Some of them 2 hours away". Therefore, the patient's illness directly affects their everyday life and their social environment, i.e. their colleagues, friends, families, and partners, in numerous ways.

According to the participants of this study, the average time it takes them to get to their physician and back home is 4.38 hours and the average waiting time in the physician's practice or clinic is about 37 minutes (D7, D8). While many participants did not specify any costs for them to visit their physician or declared them to be 0.00€, the average costs of those who did state an amount are 11.28€. The highest costs a patient claimed to have were 160.00€ (D8).

48% of the participants of the survey use tools to help them managing their disease and therapy (B3). Mostly, they use PCs and Laptops or smartphones and different applications to plan and protocol their treatments. In addition, paper-based utilities were named prominently in the online survey, like notebooks, diaries, and folders for printouts. Those who use Desktop PCs or Laptops mostly use office software like Microsoft Excel to protocol measurement values of all kind and to determine trends in their development, e.g. blood pressure and blood glucose, or medication doses, but also to plan their daily schedules with calendar software. Some, mostly patients with diabetes, use special software like Carelink and SiDiary, or companion software for health devices like Abbot's FreeStyle Libre blood glucose meter. Additionally, the PC is used to scan admission notes, laboratory results and other documents relevant to the patient's disease or therapy for digital archiving. Most of those who mentioned smartphones as a device used to manage their illness did not specify the kind of apps they used. Among the named type of apps were GI-Monito by WellApps and apps to protocol different parameters like weight and consumed calories. Some also use fitness or health apps that are not necessarily suitable for medical application and several participants use more than one app concurrently.

68 participants answered question B5 (As how laborious do you perceive the usage of health tracking devices?). Five of them stated "much" or "very much". Exemplary remarks (B6) were:

- "It is funny in the beginning, and then at some point it becomes cumbersome."
- "I am a mother of 3 children and all 5 [mother, father, and children] have different allergies or diseases. Even if I record only one part, it takes a lot of time in total."
- "Values are utopian sometimes. It challenges me to reach the goal soon, although I have lain down all day."

4.2 Physicians and Chronically Ill Patients

Most of the interviewed healthcare professionals (P1-P5, P7) run a practice themselves. Two interviewee (P6, P8) work in a clinic. Additional to regular working hours, this employment includes standby service at night or on holidays. All those interviewees

who worked in an own medical practice stated that they visit immobile patients at home or at nursing homes. One interviewee (P4) worked about twenty percent as a chief physician in a clinic's standby practice, about the same amount of time at a geriatric psychiatry station and in palliative care, besides the work in his own practice.

General practitioners tend to be patients first contact on all kind of issues, even those of psychological nature and doctors in rural areas have an especially broad spectrum of tasks. But there is also an extensive cooperation between general practitioners and specialists of clinics. The interviewed general practitioners declared that about a third to half of their patients has a chronic health condition. Most of these conditions are related to the heart and circulatory system, the musculoskeletal system or diabetes. Majority of patients with chronic diseases were said to be older than 50, but some even younger than 30, primarily patients with diabetes. This correlates with the results of the online survey with chronic patients. Most of these patients stay with their general practitioners lifelong and most transitions take place when a patient moves, or a physician retires.

In general, the interviewees perceived the frequency at which they see their chronic patients in person as enough. However, some patients who tend to avoid the contact with their physicians and visit them less frequently or later expected or must be pushed to make an appointment. Others visit their doctors more frequently than necessary, be it because of boredom and lack of social contacts or anxiety and insecurity. These frequent visits are often nonessential and bind valuable time and resources.

As the most time-consuming but crucial aspects of a consultation, the interviewees named the evaluation of patients' verbal reports and the discussion of psychological problems. In addition, the examination of clinic reports or admission notes and the integration of numerous drugs prescribed by other physicians into the patient's medication plan were said to be very laborious. While the former requires the personal contact between patient and doctor, the latter might bear potential to be improved by an IoT-based eHealth solution.

Almost all interviewees declared the personal contact in face-to-face conversations to be of critical importance to them. The possibility to directly respond to the patient's situation and to ask context related question, the factor of nonverbal communication and the social experience can hardly be replaced.

One interviewee (P8) even avoided typing notes on a keyboard during the anamnesis to not appear absent to the patient and took notes on paper instead, which were later translated into the Electronic Health Records system. Thus, the paper notes were more detailed than the ones in the practice system. It is also particularly important for physicians to get a comprehensive impression of a patient's situation, including psychological aspects, the social environment, and employment situation. This is necessary, to fully understand the patient's situation and to build a trustful patient-doctor-relationship.

However, some topics are difficult to discuss in a conversation with a patient. Both the interviewed physicians and the participants of the online survey stated this. According to the

asked physicians, these topics primarily include issues related to sexuality, incontinence and other intimate or less socially accepted subjects. These topics are much easier for the patient to discuss if the physician addresses them.

According to the physicians involved in this study, another challenging task is to find out if there is a psychological cause for a physical symptom. It is also challenging to find out whether patients follow their medication and therapy plan, since there is no way for the physician to verify the patients' statements besides their personal intuition and experience. In the same way, it is impossible to tell if a patient holds back potentially essential information because he or she thinks they are irrelevant or does not recall them at that moment. Patients are also quite different in their preferences about the handling of negative and potentially upsetting news about their health conditions. While some ask their physicians to tell them about any negative development directly, others prefer to be informed more thoughtfully. Most of the time, it is up to the physician to tell which approach is the right one for each patient.

4.3 Expectations on IoT-based Systems

As a result of the online survey for chronically ill patients and the interview with physicians, main topics that are concerning patients regarding IoT-based eHealth technology are:

- privacy and data security,
- reliability and accuracy,
- the possibility to access their own data and to exchange it with their physicians,
- thereby being informed about their health status and knowing that their physician is so as well,
- and getting additional information about their disease, medication, and therapy.

Furthermore, patients want IoT-based eHealth systems to reduce their effort in dealing with and managing their disease by automating certain tasks or by reminding them of appointments or tasks like taking their medication. Overarching all these aspects, patients want any kind of eHealth technology to seamlessly integrate into their daily life and to adapt to their individual needs, and they want to feel safe and taken good care of when using such technology.

From all this gathered insight into the needs and wishes of patients with chronic diseases, five key goals and motivations become apparent. In the following, exemplary samples of free text answers from the online survey are provided followed by the description of the patients' and physicians' needs that they indicate:

1) Being informed:

[E1] "Direct connection to the physician (data transfer) and easy communication, instant availability of results, straightforward way to make appointments."

[E1] "Documentation and collection of my daily status and symptoms. Information about when I should contact a physician or instant notification of my general practitioner if there are any unusual events."

[E1] "Telling me what drugs and food to take in the event of any complains."

The participants want to be continuously informed about their own health status and have access to their health record. They also wish to get information about their disease, medication, and therapy. Furthermore, they want to be informed about news and trends regarding their disease and new forms of treatments. The physicians also want to know about the health status of their patient, and they are especially interested in information about whether patients follow their medication and therapy plan.

2) Being involved:

[D6] "Discussing further actions together."

[E1] "A good balance between automation and the possibility to make own decisions."

Patients want to take an active part in making decisions about, and planning of their treatment. They want their physicians to cooperate with them and to take their needs and concerns seriously. The physicians are also interested in collaborating with their patients, but therefore they need more information about the wishes and needs of their patients.

3) Staying in touch:

[E1] "Remote check-ups (which my physician already provides), additional video connection like skype would be nice."

[E1] "Maybe a system to transfer doctor's letter and laboratory findings securely (!)."

Participants wish to have an easy and convenient way to contact their physician for asking questions and getting advice. They also want to have access to a shared data set as a common knowledge base. However, patients want to maintain a good patient-doctor relationship, despite the usage of ICT. For the physicians, the building of a trustful patient-doctor-relationship is also particularly important. Therefore, they must stay in touch with their patients and have as much information as possible to fully understand the patient's situation.

4) Having minimal mental, financial, and physical efforts:

[E1] "Reduction of check-ups / driving."

[B6] "Blood glucose values get transmitted automatically, so I spare myself the cumbersome diary."

[E2] "Taking the medication has become such a routine, that you cannot remember if you already took them or not."

Patients want to be relieved of certain physical or mental burdens. These can be the need for long or expensive journeys to their physician, laborious or uncomfortable treatments, or tedious routines. Other examples are the need to remember their medication, check-ups, and other treatment related

appointments and obligations. However, patients also wish to not always need to have their illness on their mind and want it to take a less predominant role in their life. Moreover, participants expressed the abstract desire to feel more independent and get support in their daily lives. For physicians, the personal contact in face-to-face conversations is of critical importance. However, they also have many patients that visit them more frequently than necessary. This could be reduced by well-designed IoT-based eHealth systems.

5) Feeling safe and taken care of:

[D6] "It is important to me that my physician always knows about my state, so he can help me as much as possible."

[E1] "Alarm function, reliability"

Patients want to feel safe and looked after. They want their physicians to be informed about their current condition and to be notified of important incidents. When it comes to the use of an eHealth system, they also wish to have all relevant health data at hand to get an accurate impression of their status by themselves. Moreover, they would like the ability to quickly report an emergency when necessary. The physicians also want to have a good patient-doctor-relationship and be informed about the current health status of their patients. They want to reduce time-consuming aspects that could be improved by IoT-based eHealth systems and therefore have more time for important face-to-face communication.

5 Design Principles for IoT-based eHealth Systems

As it became clear in the analysis, the main topics that are concerning patients regarding eHealth technology are privacy and data security, reliability and accuracy, the possibility to access their own data and to exchange it with their physician, thereby being informed about their health status and knowing that their physician is so as well, and getting additional information about their disease, medication and therapy. Furthermore, patients want eHealth systems to reduce their effort in dealing with and managing their disease by automating certain tasks or by reminding them of appointments or tasks like taking their medication. Overarching all these aspects, patients want any kind of eHealth technology to seamlessly integrate into their daily life and to adapt to their individual needs, and they want to feel safe and taken good care of when using such technology.

As another key finding, it can be determined that patients wish for an eHealth system to help them with disease and therapy management, serves as a central source of information and data hub, and that enables them to conveniently stay in contact and cooperate with their physician.

Based in the findings from the analysis the following design principles for IoT-based eHealth systems are suggested to make sure that it supports the previously determined user motivations

as much as possible, resulting in a high user acceptance and compliance rate:

1) Patient Involvement and Feedback:

An IoT-based eHealth system should help to involve the patients in the treatment of their disease. Therefore, it should support data exchange and communication between patients and their physicians and facilitate shared decision making regarding the patients' therapy. It should also provide feedback about the therapy's efficiency and effectiveness to help the patients recognize their achievements and thereby make the benefits of the eHealth system comprehensible.

2) Information and Awareness:

An IoT-based eHealth system should provide the patients with access to all relevant information the system has about their status, disease, and therapy. The amount of detail and abstraction may vary depending on the nature of the information, the kind of system, or the application context, but should allow the patients to increase their awareness of their current condition. However, it should be avoided to continuously remind the patients of their chronic illness, for example by presenting information only when requested by the patients or by allowing them to filter any alarms or notifications according to their preferences and needs.

3) Trust and Confidence:

An IoT-based eHealth system should inspire trust in the correctness and objectivity of the presented information by providing its sources and making the process of information acquisition transparent to the patients. Therefore, it should provide patients with confidence in using the system by making it self-explanatory and tolerant to errors and false inputs. However, it should make recognizable to the patient what the purpose and functionality of each component of the IoT-based eHealth system is and which benefits it contributes. It should also convey to the patients that the system is designed to be safe and robust.

4) Safety and Assurance:

An IoT-based eHealth system should make the patients feeling safe and taken care of, for example by providing them with a convenient way to contact their physician to ask question or to report unusual events, and by giving feedback when the physician received the message. In addition, it should assure them that their physician always stays informed about their current state and cares for them, e.g. by notifying the patients each time their physician checked and approved their condition. The patients must always know that their physician is still their main caretaker.

5) Independence and Relief:

An IoT-based eHealth system should relieve patients of tasks and burdens rather than adding new ones. Therefore the usage of the system should be integrate into the patients' daily lives as seamlessly as possible, for example by reducing the input

required from the users, by making it compatible with systems already in u, or by taking advantage of existing routines and rituals. Also the usage of the system should be independent from local or time limits, for example by allowing patients to access as much of the system as possible at any time convenient to them, and by avoiding local or technical constrains limiting the access to their data or the operability of the system.

6) Control and Supervision:

An IoT-based eHealth system should keep the patients in control of what the system does and what it does not. Therefore, the system should only collect personal data if the patients agreed to it beforehand and should enable them to withdraw this agreement at any given time. In addition, the system should make transparent to the patients which data are collected and stored by which device or system component and allow them to change that if feasible. It should inform the patients what tasks are automated and under which conditions they are executed and give the possibility to adjust the degree of automation to their preferences.

6 Discussion

The study we describe above was focused on design principles for IoT-based eHealth systems from a user-centered perspective. Subsequently, we pick up on critical issues related to this aim and outline future work.

6.1 Patients are People

We completely agree with Nunes et al. [23] that patients should not only been seen as patients rather than as persons with different roles and interests. Especially, many of them already make use of various information and communication technologies in their private and professional life. With respect to concepts like "bring your own device", the question arises how sensitive health-related data could be management side by side with harmless one.

Furthermore, the introductory statement "patients are persons" can be interpreted as "patients are not medical experts". It is at least questionable whether patients should get immediate access to all their data once it is available, or if there are certain kinds of information, like unpleasant diagnoses, that patients should learn from their physicians in person.

6.2 One Chronic Disease is Not Like Another

In our human-centered design approach, we focus on chronically ill patients. As our results of the online survey as well as the interviews with the physicians showed, there are many diverse illnesses, and some of the patients even have multiple diseases at once.

When we focus on design principles for human-computer-interaction the abilities of the user are one of the important aspects that must be considered. Regarding the diverse illnesses, chronically ill patients of course have differential abilities with respect to the use of technical systems and therefore distinctive

design principles are needed. Though the ones which are presented in this paper are on a higher level of abstraction and must be refined concerning the requirements of the focused user group, for example patients with cognitive or motoric limitations. Nevertheless, the design principles presented could help to implement IoT-based eHealth systems taking the fundamental requirements and wishes of chronically ill patient into consideration.

6.3 Limitations and Future Work

The demand of patients for an automated data exchange and coordination between themselves, their physicians, other health specialists and even health insurances raises questions about data security and medical confidentiality, which have not been considered in this study.

Likewise, ethical, and therapeutic questions to which degree the control over sharing functionalities and the access to Electronic Health Records and other sensitive data should always lie with the patient are beyond the scope of this research.

Both the online questionnaire and interview results represent patients and physicians who are part of the German healthcare systems. While chronically ill participants suffered from one or more diseases, they were able to access the internet and take part in an online survey. To place conclusions on a firmer foundation, other methodological approaches might be advisable (e.g. contextual inquiries in day-care facilities or possibilities to participate while at a doctor's office).

Since only 8 out of about 140 physicians and health professionals gave a positive response to our interview requests, questions arise whether issues considered in this study are of limited interest to them right now in general or need to be elaborated in other ways.

Future work will address interaction and user interface design for IoT-based eHealth systems that are not equipped with large screens or full-scale keyboards. Furthermore, an ensemble of health-related and non-health-related devices and applications requiring sophisticated cross-device interaction paradigms will surround chronically ill patients.

In this regard, human-centered evaluation approaches for IoT-based eHealth systems need to be explored. While design principles like the ones introduced in this study could serve as a base for evaluations, suitable settings (e.g. living labs) need to be established and long-term effects need to be studied.

7 Conclusion

In this paper, we studied intuitive expectations and concerns of patients with chronic conditions towards eHealth solutions based on Internet of Things technologies.

Therefore, a human-centered design approach was taken to keep the patients in focus as the primary user group. An online survey was conducted to learn about the habits and struggles of chronic patients and physicians were interviewed to understand the context of a chronic patient's therapy, alongside an extensive literature review.

By thematic analysis of the results, we found answers to the question how IoT-based eHealth-systems should be designed to improve perceived benefits and user acceptance by patients for an increased long-term compliance. Six design principles were derived: Patient Involvement and Feedback, Information and Awareness, Trust and Confidence, Safety and Assurance, Independence and Relief, Control and Supervision.

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