Towards Future Reliable Pervasive Healthcare with Adherence Strategy Engineering

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ABSTRACT

Despite more than a decade with a focus on creating technical solutions for supporting self-care efforts and securing increased patient autonomy, data quality remains to be a challenge, especially when moving from the supervised clinical setting and into the unsupervised self-care setting. In the unsupervised self-care setting, healthcare professionals cannot actively monitor and guide their patients' use of medical devices nor track the use of prescribed medications, diets, and rehabilitation exercises. This lack of compliance with given medical advice and procedures results in reduced data quality of healthcare measurements and a diminished understanding of treatment effects, leading to faulty diagnoses of patients and resulting in treatment errors. If we wish to realize the future pervasive healthcare vision of reliable automated decision making systems, freed from the involvement of healthcare staff, we must have reliable high quality data as a basis. Thus, we must become able to identify and overcome data quality issues. The aim of this position paper is to discuss data quality related issues in pervasive healthcare and suggest how to meet these challenges in the future. Specifically, the paper addresses data quality issues stemming from a lack of patient adherence, and provides recommendations on how to move the field forward by using adherence strategy engineering as a design strategy.

CCS Concepts

Human-centered computing: Ubiquitous and mobile computing; Ubiquitous and mobile computing systems and tools.

Keywords

Pervasive healthcare; pervasive computing; self-care; adherence; adherence aids; adherence verifiers; adherence engineering

1. INTRODUCTION

Within the last two decades, the combined ubiquitous and pervasive computing communities have engaged intensively in the healthcare domain, experimenting with novel technology and user interaction techniques for enhancing healthcare. Ubiquitous computing originates from Weiser and his colleagues at the Xerox Palo Alto Research Center (PARC) [1-3]. A key contribution from Weiser and his PARC colleagues were the concepts of calm technology [3] and context-awareness [1] aiming at providing a better user experience as well as broader access to data and services [2]. Pervasive healthcare as a separate field emerged in the late 90's based on pervasive computing methods and technologies [4-8]. Since its beginning, the pervasive healthcare community has worked towards transforming existing healthcare systems to meet the challenges of the major demographic shifts faced by the developed world [5,8]. The potential for change has been investigated with a focus on prevention and early detection strategies to detect the early onset of illness and other care requiring conditions before they progress in severity and become more difficult and expensive to treat [5,8-10]. Other approaches involve reducing staff time and resources by supporting increased patient-autonomy and self-care, and thus stretching the resources and capabilities of existing healthcare organizations and staff, by empowering patients to be more autonomous and less dependent on healthcare staff, eventually leading to full patient autonomy [9,11]. Thus, one of the future visions of the pervasive healthcare community is to enable patients to self-manage their conditions, effectively reducing the role of the healthcare professionals to consultants when, and if, needed through novel technologies and methods [9] .

However, the state of the art healthcare technologies currently used in the healthcare area were to a large extent not designed to support such self-care patients [12]. Thus, this move from the present supervised care system to the unsupervised care-system of the future is facing uncharted challenges that have not been sufficiently addressed in the literature. One of the major challenges faced is arguably the data quality issues arising as a result of this move. This position paper investigates these challenges and the potential for overcoming them through relevant methods and technology from the pervasive healthcare field and beyond. Furthermore, the aim of this positon paper is to discuss data quality related issues in pervasive healthcare and suggest how to meet these challenges in the future. Specifically, we shall address data quality issues stemming from a lack of patient adherence, and provide recommendations on how to move the field forward by using adherence strategy engineering as a design tool, employing context-aware technologies for the tagging of healthcare data and more calm guidance of the patients.

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One of the challenges faced when designing self-care systems, compared to traditional medical technologies for hospital use is a change in the way data is being measured and interpreted, as well as a necessary cost-benefit compromise on the quality of the equipment being used. Cheaper equipment developed for home use and self-care patients may be less accurate and precise as compared to hospital equipment. Also, more errors are bound to happen when data needs to be sent via several uncontrolled hardware and software nodes to the clinical system for interpretation [12]. A blood pressure monitor operated by a healthcare professional in the clinic is less error-prone as compared to a telemedicine system used at home [13].

2. CHALLENGES IN SELF-CARE

When a patient is required to self-care unsupervised, either in the clinic, or at home, the patient is no longer personally guided and monitored by a treating physician or nurse, but is left on his own to perform the measurements, do rehabilitation exercises, or take the prescribed medication [13]. As a consequence, the quality of the self-care actions are no longer guaranteed by a healthcare professional, but relies on the patient's training and abilities, and on the level of technology support provided [12]. Healthcare professionals thus have to rely on their patients' ability to follow the prescribed treatment plan and guidelines [14].

Merriam-Webster's Medical Dictionary gives the following definition of reliable: "giving the same result on successive trials" [15]. For instance, a reliable blood pressure measurement device will persistently measure the same blood pressure readings under the same circumstances, while a reliable activity monitor would accurately track rehabilitation efforts of a patient.

However, the measurement itself is not only dependent on the medical devices and sensors used. As discussed by Varshney [5], there are several technical factors determining the reliability of a pervasive healthcare solution and pervasive healthcare solutions are required to be reliable throughout all of these layers, including the infrastructure and system layers, in addition to the mentioned sensor and device layers. However, while traditional systems engineering efforts used in pervasive healthcare have focused on the technical aspects, it could be argued that the patient may introduce an unacceptable level of bias to the data quality when moving to the unsupervised setting [13].

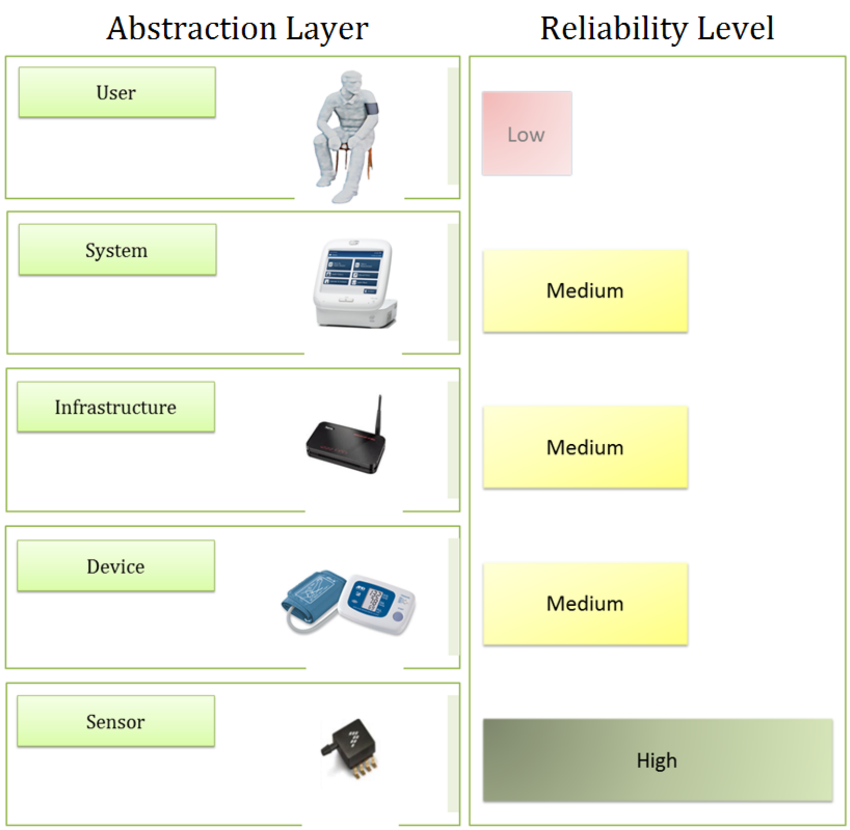


Figure 1. Five abstraction layers of reliability of a healthcare monitoring system are shown on the left side. On the right side the reliability level of the layers are categorized. First, sensors (in the sensor layer) will work equally reliably in the supervised and unsupervised setting, next healthcare devices, infrastructure and platforms, healthcare systems and applications, are all more likely to fail due to reduced control and quality of the infrastructure when moving to the unsupervised self-care setting. However, the weakest link is arguably the patient, as human beings are unpredictable by nature, and their motivation, willingness, and ability to perform as instructed and according to best practice is subject to change over time, resulting in the healthcare system seen as a whole, including the patient as the key component, becoming unreliable and producing unreliable data, leading to diagnoses errors.

As seen in Figure 1, at the lowest layer, the biomedical sensors used must be reliable, guaranteeing the required precision and accuracy under all circumstances of typical use. Next, at the device layer, the healthcare device using the sensors needs to operate reliably, interpreting and conveying sensor input to the user, and must be able to operate for prolonged periods without malfunctioning or requiring calibration for supporting unsupervised use. At the infrastructure layer, the execution and communication infrastructure platform needs to be robust and reliable, allowing for data to be securely and reliably communicated to where it was intended, assuring that software and hardware components continue operation with as few exceptions as possible, handling communication and operation failures seamlessly [5,16]. A monitoring system might consist of several subsystems and components: one or more biomedical devices, a home gateway computer, a remote server, and a clinical decision support system application at the hospital. Such an ecosystem needs to operate reliably across all subsystems at the system layer. It must be able to receive data from the device, store the data on the gateway computer, and reliably convey data and notifications to relevant stakeholders in a timely and secure manner. At the system layer there may be multiple points of failure, which must all be addressed adequately. This includes local area communication with the biomedical sensors, internal hardware and software system components communication, as well as remote communication with servers at all communication layers; often relying on wireless area networks such as 3G or 4G networks with the well-known challenges to stability and reliability in such networked systems [5,17]. Finally, at the highest level of abstraction the patient needs to follow (adhere to) given advice and recommendations for correct device and system usage at the User layer. The user (e.g. a patient) must be willing and able to operate the system as instructed. If the patient is not willing or able to adhere the system might fail or even worse, it might provide biased data leading to erroneous diagnoses and treatment error [18-20].

In the following sections, a range of key concepts surrounding self-care efforts are further introduced and discussed, leading to a range of recommendations for the pervasive healthcare community.

3. PATIENT ADHERENCE

A patient's ability to follow prescribed guidelines and treatment plans is covered by the medical concept of adherence. The level of adherence relates to the degree to which a patient correctly follows given medical advice. Traditionally, the main focus has been on medical adherence, also known as compliance [20,21].
Medical adherence is defined as "the extent to which a patient acts in accordance with the prescribed dosing regimen" [21], in other words, the patient's ability to take medication as prescribed. The World Health Organization (WHO) in a report on "adherence to long-term therapies – evidence for action" argues in favor of expanding this definition to include diet and lifestyle changes and other relevant topics [22]. The WHO report proposes a wider definition of adherence as: "the extent to which a person's behavior – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider" [22].

The concept of patient adherence can also be used to denote the ability of a patient to correctly follow guidelines and recommendations on how to perform self-measurements using a healthcare device, as well as taking medication as prescribed or following a rehabilitation program [12]. Furthermore, interventions, measures, and means to increase adherence can be designated as "disease management relying on the focused application of resources in order to improve care and outcomes" [23,24].

To exemplify, several studies have shown that measurement errors occur frequently in the home when hypertensive patients self-monitor their blood pressure, potentially leading to over- or under-medication as a consequence [17,25,26]. Also, in a recent survey on medical adherence data, the authors found that less than half of patients receiving treatment for chronic conditions, including hypertension, would keep adhering to their medication after the first year [6]. Thus, patient adherence is arguably a main factor to consider when moving healthcare from the supervised to the unsupervised self-care setting.

4. IMPACT OF ADHERENCE ON DATA QUALITY

Being able to determine the adherence level of patients is arguably of equal importance to creating more reliable biomedical sensors, building more reliable medical devices, as well as devising more reliable healthcare infrastructures and platforms for the unsupervised self-care setting. If we cannot verify user adherence levels, then even the most accurate biomedical sensor measurements could be subject to excessive bias-levels rendering the resulting data set invalid [21].

To exemplify, a blood pressure measurement obtained without the patient observing the required rest time would misdiagnose most borderline hypertensive patients to suffer from hypertension thus requiring medical treatment which often implies adverse effects from prescribed medication, as well as increased insurance and treatment costs [19]. A cigarette smoked just before measuring the oxygen saturation of a chronic obstructive pulmonary disease (COPD) patient can bias the measured oxygen level, erroneously indicating higher oxygen saturation in the patient due to bias caused by the increased level of carbon dioxide in the blood, likewise leading to an erroneous diagnosis [22]. Finally, a Parkinson's disease patient taking his medication at the wrong time of day could experience more explicit symptoms as a result, and the treating physician will have no way of knowing whether this is due to wrong medication dosage, or insufficient compliance of the patient [23].

Substantial results have already been achieved in terms of increasing the reliability of healthcare sensors, devices, infrastructures, and systems [4,5]. However, previous work has only sparingly investigated user level reliability [21]. Thus, the user level reliability, measured as the ability of the patient to perform self-care activities correctly and adhere to given instructions, has not been adequately investigated in the literature, and remains to be a challenge for future healthcare systems.

If the vision of utilizing pervasive healthcare technology as a transformative tool for improving overall healthcare and making existing healthcare systems and organizations more efficient [5,8], then it is a fundamental prerequisite, that healthcare professionals will accept and embrace these novel technologies, and have trust in data originating from self-care activities. Thus, pervasive healthcare solutions operating in the unsupervised self-care setting must be sufficiently reliable to support the accurate and reliable diagnosis of patients for pervasive healthcare to succeed its mission.

5. ADHERENCE STRATEGY ENGINEERING

Interventions, measures, and means to increase adherence, fall under the category of disease management, relying on the focused application of resources in order to improve care and outcomes [12]. The way adherence is handled can be labelled as an adherence strategy [12]. An adherence strategy is defined as: "the means, measures, and interventions used to facilitate patient adherence during a healthcare process as part of the overall disease management" [12]. A healthcare process could include a series of individual actions, for example: taking medication, performing rehabilitation training, measuring and registering the blood pressure or blood sugar. In the self-care setting, adherence strategies have traditionally been based on manual or low-tech based measures such as patient training, paper instruction leaflets, and other [12]. However, more advanced adherence strategies exists, such as persuasive technologies, automatic reminder systems, and artificial intelligence systems [8,24]. When using adherence strategy engineering as a design tool, the main design components include adherence verifiers and adherence aids, both of which are based on context tagging of healthcare data techniques, which are presented in the following sections.

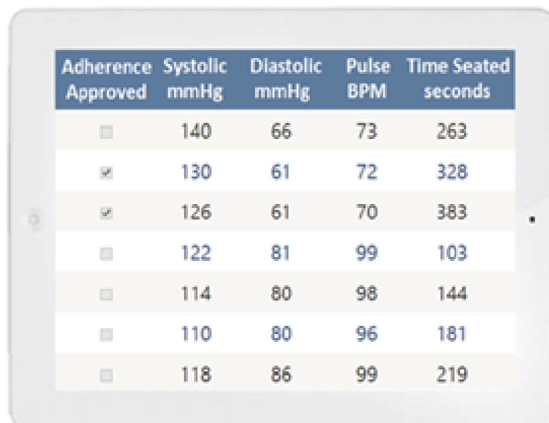
6. CONTEXT TAGGING OF HEALTHCARE DATA

Context awareness [25] is a key concept in pervasive computing and pervasive healthcare. Dey defines context awareness as: *"A system is context-aware if it uses context to provide relevant information and/or services to the user, where relevancy depends on the user's task."* [26]. Context-aware technology has been used to sense the environment in which the user acts to adapt its behavior accordingly. This is typically done through a range of sensors that can measure a relevant contextual parameter and convey the data to interested subscribers [5,16,27,28]. Context-tagging of healthcare data has been shown to be a feasible tool for achieving higher data-quality in unsupervised healthcare measurements [29]. Thus, identifying relevant context parameters appears to be useful as a method of ascertaining the reliability of a measurement. For instance, being able to measure the time and date of a patient having performed an exercise or taken medication is a way of context-tagging healthcare data. Likewise, context tagging blood pressure measurements with patient posture, stance, talking/not talking, rest time, and time of day, has been shown to correlate closely with the validity of the resulting measurements [30]. Thus, using context-tagging of healthcare data has been shown to be a relevant design strategy. If we are able to model all relevant context parameters, or at least all parameters that are feasible to measure with existing context-aware technologies, we would likely obtain an increased understanding of the individual patients' ability to self-care.

Contextual-tagging of healthcare data has been defined to include "traditionally used contextual-properties such as time and date, but also user-identification (the patient currently using the device), geospatial position (where was the measurement taken), environment-factors (noise-level, temperature, humidity), and use-context (wake-up time, time rested before taking the measurement, movement-level, stance, posture, food intake, toilet visit)" [12]. All of these data can be used to create a model of the adherence of the patient, also known as the adherence model [12], which again may be used to create adherence verifiers and aids, as further discussed in the following sections.

7. ADHERENCE VERIFIERS AND AIDS

Adherence verifiers are defined as being "for quantifying the adherence levels of a given healthcare process and the resulting data quality of the healthcare process" [12]. An adherence verifier will sense the actions of the patient, and verify them against a given usage model, e.g. taking medication or performing healthcare measurement at the right time of day and in the right order. Adherence verifiers are passive context tagging technologies and they do not them-selves present feedback or help to the patient. Data are always used in retrospect including for healthcare staffs quality control of the data [12]. An example of an adherence verifier is shown in Figure 2.



Adherence Approved	Systolic mmHg	Diastolic mmHg	Pulse BPM	Time Seated seconds
☐	140	66	73	263
☑	130	61	72	328
☑	126	61	70	383
☐	122	81	99	103
☐	114	80	98	144
☐	110	80	96	181
☐	118	86	99	219

Figure 2. This is an example of a basic adherence verifier as part of a clinical decision support system used at Aarhus University hospital for verification of the the "times seated" parameter as part of the adherence model of blood pressure self-measuring patients.

Adherence aids are tools and technologies that will help the user to better adhere to a prescribed treatment. These are often an integral part of the adherence strategy and multiple adherence aids can be used as part of an adherence strategy [12]. Adherence aids are defined as being "for providing context-dependent feedback to the patient during the healthcare process in order to improve adherence levels and increase the data quality" [12]. As such, adherence aids often require more advanced technology than adherence verifiers. This could include interaction devices for device and patient communication, including visual and audio guides, as well as other clues to achieve correct operation.

8. THE ASEF FRAMEWORK

The Adherence Strategy Engineering Framework (ASEF) is defined as "a conceptual and practical design space for developing and evaluating novel technology-based solutions to assess and improve patient adherence levels and quantify the quality of healthcare data obtained in the unsupervised setting" [12].

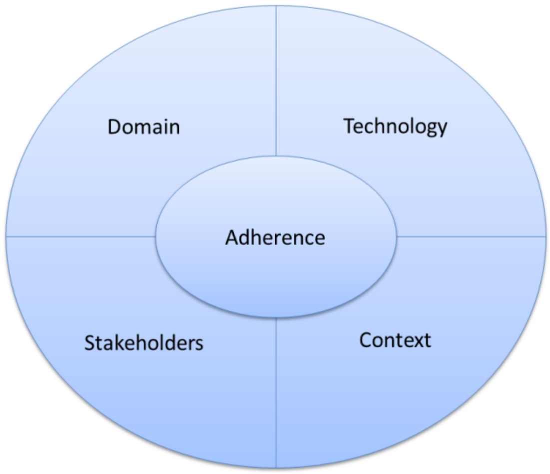


Figure 3. The five main elements of the ASEF framework. Each element represents important factors to consider when designing new adherence strategies. They can be viewed as separate perspectives that must be addressed when designing new healthcare technology support systems [12].

The purpose of the ASEF framework is to support adherence engineering efforts. It is divided into a range of elements including (see Figure 3): adherence, domain, stakeholders, context, and technology that are useful to consider as design perspectives when creating adherence aids and verifiers.

9. RECOMMENDATIONS

As argued in this position paper, current self-care methods and equipment are inadequate for securing valid measurements in the unsupervised setting. Therefore, either further training or active guidance should be provided to achieve a higher degree of adherence with existing self-care devices. Such extended training or guidance efforts would most likely strain staff resources and would still not allow the staff to identify patients who remain non-adherent despite the added training efforts. As an alternative, increased quality control could be achieved by letting trained staff supervise patients' self-care activities, e.g. over video as supported by some telemedicine solutions today [30]. However, while such increased supervision appears to be the gold standard, this would also increase staff costs and might have other implications.

As an alternative to training, guidance and video surveillance, we suggest using context-aware technology to detect and classify non-adherent patient behavior. Such context-aware surveillance would alert the treating physician or nurse to specific patients who have not adhered to the recommendations, thus identifying them for additional training and instructions using a suitable interface for the healthcare professionals. By tagging healthcare data, such as saturation or blood pressure measurements, with contextual data, the resulting data set could clearly mark data that would be fit to use, and other data that would be dangerous to use. Such augmented data sets could be automatically presented to the treating physician or nurse during consultation on existing client devices such as the consultation room computer or a mobile device depending on the setting. This would allow healthcare staff to take the necessary steps on an informed basis.

In addition, we suggest introducing increased tool support in self-measurement environments, to improve guidance to patients while self-measuring, e.g. correcting any non-adherent patient behavior in real time rather than retrospectively. These objectives could be achieved by basing such a system on the principle of adherence and extending these with proper adherence aids for context-aware automated guidance of the patient to avoid operating errors. Adherence aids should be considered the gold standard for improving patient adherence, and it could be argued that adherence aids should be prioritized in adherence strategy engineering projects [12]. However, adherence aids have proven to be more complex to design and implement than adherence verifiers and may appear as much more intrusive in the healthcare process. Relying e.g. on an audio based guiding system might be disturbing to others in a self-measurement environment, e.g. a waiting room or unnecessarily stigmatizing in the home of the patient. Adherence aids also risk causing additional "observer bias" during self-care activities, potentially leading to adverse effects not unlike the white coat effect, well-known from blood pressure measurements in the clinic, as the increased computer presence may induce additional anxiety and increase the BP accordingly [21]. While this phenomenon has not been adequately investigated so far, such challenges should be investigated further before designing new intervention methods based on novel adherence aids. In this perspective, using adherence verifiers appear to be the most suitable approach, not running the risk of introducing additional bias while at the same time providing healthcare staff with an evaluation of the data quality of the measurements. However, more work is needed on these aspects.

Research implications for the pervasive healthcare community include: i) consider to identify current and future self-care activities with a high risk profile of patient level data quality challenges, ii) consider to identify context-aware technology that could be used to detect any such problems, preferably proportional in terms of cost, privacy intrusion, and detection accuracy, iii) consider to investigate and formulate relevant strategies for adherence engineering, consisting of adherence verifiers and adherence aids to overcome these issues, including constructing relevant adherence models and designing and evaluating supporting context-tagging support systems.

10. CONCLUSION

This position paper has presented several examples of data quality issues. These include sensor and device level data quality issues, system level data quality issues, as well as user level data quality issues stemming from non-adherent behavior while self-measuring in the unsupervised self-care setting.

While both, sensor, device, and system level data quality issues can be identified through rigorous testing protocols and validation studies, user level data quality issues due to non-adherent patient behavior cannot. Instead, we need to build increasingly more sophisticated context-aware systems to capture all relevant aspects of non-adherence, in order to identify wrongful usage of the systems. This position paper has illustrated the consequences of such non-adherent behavior, and shown that context-aware technology can facilitate the detection of non-adherent behavior and use it to inform healthcare staff of potential bias to the measurements.

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