Beyond Self-Monitoring: Understanding Non-functional Aspects of Home-based Healthcare Technology

Erik Grönvall, Nervo Verdezoto
Department of Computer Science - Aarhus University
Aabogade 34, 8200 Aarhus, Denmark
{gronvall, nervo}@cs.au.dk

ABSTRACT
Monitoring of health parameters in non-clinical settings is one strategy to address the increasingly aging population and age-related disabilities and diseases. However, challenges exist when introducing self-monitoring activities in people's everyday life. An active lifestyle can challenge the appropriation of healthcare technologies and people with comorbidity may have diverse but co-existing monitoring needs. In this paper, we seek to understand home-based health monitoring practices to better design and integrate them into people's everyday life. We perform an analysis of socio-technical complexities in home-based healthcare technologies through three case studies of self-monitoring: 1) pre-eclampsia (i.e. pregnancy poisoning), 2) heart conditions, and 3) preventive care. Through the analysis seven themes emerged (people, resources, places, routines, knowledge, control and motivation) that can facilitate the understanding of home-based healthcare activities. We present three modes of self-monitoring use and provide a set of design recommendations for future Ubicomp designs of home-based healthcare technology.

Author Keywords
Self-monitoring; home-based healthcare technology; case studies; personal health management.

ACM Classification Keywords
H5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

General Terms
Design; Human Factors; Management.

INTRODUCTION

Ubicomp technologies for healthcare are becoming more widespread, both in clinical settings and at home [28]. However, as reported by Arnrich et al. [2] two major challenges in pervasive healthcare are: 1) the shift from disease management to individual care management (e.g. from a centralized, reactive, information focus to a more pervasive, user and assistive focus); and 2) avoiding or delaying critical health situations (i.e. preventive care). Available off-the-shelf self-monitoring technology can support the aforementioned shift from managing illness to maintaining wellness through preventive care [28]. Technologies for self-monitoring include both wearable and non-wearable sensors, fill-in forms and guides for managing health and illness. Such technologies can provide integration with mobile and web applications [28] and allow people to collect and reflect upon their own personal health [18]. Examples include blood pressure monitor devices, Fitbit mobile Apps and devices (e.g. Flex, Zip) and Microsoft HealthVault. These technologies aim to improve quality of life by empowering people to take an active role in their own health management [10, 27]. However, most of these technologies have not been designed with a sufficient understanding of people's needs and home-based practices [1, 19, 21]. Consequently, there is a risk that the amount of care management work increases instead of supporting and integrating care activities into everyday life [32].

Three home-based self-monitoring projects have served to investigate peoples' illness and preventive health practices and self-monitoring needs. The cases of self-monitoring are: 1) pre-eclampsia (i.e. pregnancy poisoning), 2) diverse heart conditions, and 3) preventive care. The cases have served to analyze socio-technical challenges and dynamics of self-monitoring practices in non-clinical settings.

Now we will present related work and our three cases. Then, our cross-case analysis emphasizes the relevance of non-functional aspects (people, resources, places, routines, knowledge, control and motivation) of self-monitoring to build local care awareness at home. Finally, we present three modes of self-monitoring use and suggest design recommendations for home-based healthcare technology.

RELATED WORK

This section presents challenges of home-based monitoring focusing on user acceptance and how monitoring systems are inserted into everyday life. We also describe people's care management routines in non-clinical settings.

Challenges of Home-Based Monitoring Technology

How technology can support a patient's transition from the hospital and back home has been widely investigated [1, 5, 13, 17, 21, 32]. Challenges can emerge as care and rehabilitation move into private homes and people that suffer from comorbidity or weakened by age are expected

UbiComp'13, September 8–12, 2013, Zurich, Switzerland.

http://dx.doi.org/10.1145/2493432.2493495

to engage in self-monitoring of their health. Challenges include the acceptance of technology in private homes [13], to find space, or a place, for the care technology within the home [4] and within everyday life [5] and how patients can transport and install medical and rehabilitation devices in their homes [13]. Challenges also include the reliability of self-measurement [3], clinical barriers to early detection (e.g. lack of knowledge about people's everyday life), and individual barriers to early detection (e.g. underestimation of health variability, fear of diagnosis labels and stigmatization [31], privacy [21], lack of understanding clinical terms and health parameters) [22].

Many older adults do not perceive that healthcare technologies can significantly improve their lives [15]. However, Clemensen et al. [10] report a positive influence in quality of life, safety, acceptance and empowerment when home monitoring fits into a person's everyday life. Older adults prefer technology that enhances personal and decision-making abilities over surveillance technology [21]. Designing for healthcare technology adoption, features such as simplicity, a person's ability to control the technology and its perceived benefits should be considered [15, 27]. People tend to accept being a 'patient' at the hospital but when returning home (now as citizens) they have more preferred roles such as spouse, sportsman or parent [13].

Care Management outside the Clinic

Care management is complicated in both clinical and non-clinical settings. Home-based care involves both temporal and spatial arrangements and people apply home-made strategies to manage for example their medications [23]. Through boundary work people render objects invisible/visible and integrate/segment healthcare activities [31]. Indeed, care management in peoples' everyday lives is highly context dependent (e.g. their home, activities, specific needs and desires) [1, 5, 8, 9, 23, 31]. The home-setting is an example of a complex and distributed information space that has been less studied as a place for care in comparison with the clinic [28]. Also Chen [9] shows the importance of patients' health information use at home and how patients engage in self-management and self-learning activities during chronic care. There is a need to better understand healthcare activities across care settings [28], but also how technology can support home-based care activities and its integration into everyday life [5, 32]. Care activities can be both private and collaborative. A care network (e.g. family, friends, etc.) may get involved in everyday care of for example frail, older adults [11, 17]. The lack of understanding of home-based care practices where the individual living at home is the expert rather than the healthcare professional [5, 8, 9] can result in no, or even negative, effects on a person's care management and life.

Self-Monitoring Technology for Individual Care Management

A range of self-monitoring systems have been developed to support people's active involvement in their wellness and disease management [17, 28]. These systems include monitoring of vital signs, diseases, treatments and mental disorders [2, 20, 28, 32]. Simultaneously, self-monitoring of health parameters for wellness or lifestyle management has been tightly coupled with behavioral change such as losing weight and physical activity awareness [28]. An integration of these technologies with a Personal Health Record (PHR) can facilitate the collection [27] and self-reflection [18, 20] of health information at home. However, most systems focus on one particular illness, treatment, lifestyle problem or user-group (e.g. older adults) [13]. In addition, if guidelines for measuring bio-values (e.g. home blood pressure monitoring [3, 14]) and contextual information [14, 28] are not considered in self-monitoring designs, the quality of the measured values cannot be guaranteed.

As exemplified this Related Work section, we must better understand how self-monitoring activities are situated in people's everyday life. The three case-studies enabled self-monitoring activities at home with the aim to support people's health management [28]. Instead of focusing on a specific population or self-monitoring device, we investigate home-based care practices. We include both healthy and frail people to get a broad understanding of non-functional aspects in everyday self-monitoring activities. This understanding has implications for future personal and home-based healthcare technology designs.

METHODOLOGY AND CASE STUDIES

We undertook an exploratory case study approach [24, 30] that emphasizes the study of close-real life situations and how they unfold in practice. The three cases were purposefully selected (purposeful sampling [24, 30]) to reveal socio-technical challenges and dynamics of self-monitoring practices in non-clinical settings. Figure 1 provides an overview the cases and their involved main actors, devices, locations and internal relationships.

Initially, we undertook an *exploratory* case study [30] of the pregnant women with severe pre-eclampsia (pregnancy poisoning). These pregnant women monitor their condition at home instead of being admitted, or constraint to do daily visits to the hospital. Our work developed into a *multiple* case study [30] by adding two different cases (heterogeneity sampling suggested by [24]) to further challenge and extend the socio-technical conceptual framework derived from the initial case study (as suggested by Yin [30]).

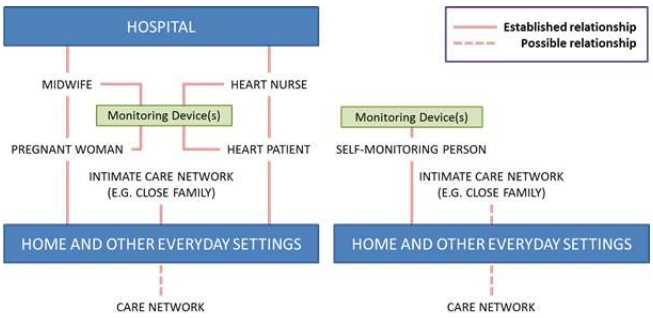

Figure 1. The cases and their socio-technical configurations.

Then, we describe the data analysis followed by a report on our findings and the common elements across the cases that conforms the socio-technical conceptual framework. The socio-technical conceptual framework helps us to investigate both home-based illness and preventive self-monitoring practices across the cases (see Figure 3).

Self-monitoring Cases

Our initial two cases investigated self-monitoring needs among 1) pregnant women with pregnancy poisoning and 2) frail older adults with different heart conditions (see Figure 1 - left). In the first case, the women performed self-monitoring activities during a specific period of time (from weeks up to months) until childbirth. In the second case, heart patients (mainly older adults) used diverse self-monitoring devices to monitor their condition until it stabilized or for the rest of their lives. The third case considers healthy older adults that should perform voluntarily preventive self-monitoring (see Figure 1 - right).

Self-monitoring of pre-eclampsia

We examined a project, investigating the impact self-monitoring had on pregnant women diagnosed with pre-eclampsia (i.e. pregnancy poisoning) or, in some cases PROM (Premature Rupture of the Membranes). The project was conducted by a consortium, including a university hospital that recruited and equipped pregnant women with both off-the-shelf and project-specific monitoring systems. One of our project-interests was how these women integrated, perceived and managed their measurements as part of their everyday lives and potential positive/negative outcomes of the monitoring activities. We followed the women at the hospital, as they received and learned to use the monitoring equipment and later in their homes. Each morning the women measured weight, blood pressure, pulse and CTG (i.e. the fetal heart and uterine contractions). They also measured the protein-level in the urine and compiled an online questionnaire (e.g. if they experience headache or not). Due to the time-consuming CTG measurement (done by placing sensors on the woman's belly - see Figure 2 right) the daily measurements took about 45-60 minutes to complete. The system sent the results to the hospital midwife for evaluation. The midwife sent a mobile phone text-message to the women if everything was OK. If not, the woman had to visit the hospital and repeat the measurements in a more controlled environment. If a woman with pre-eclampsia is not tele-monitored, she may have to visit the hospital every day or be hospitalized.

We made interviews with six of the pregnant women and their midwife. Our work included semi-structured interviews (an interview guide was developed based on early fieldwork at the hospital) and fieldwork in the pregnant women homes. The interviews focused on how the women used and placed the monitoring equipment at home, how they integrated their measurements into their everyday lives, motivation, experiences of use, the (nature of the) contact with the hospital, pro and cons with monitoring. We also developed a questionnaire handed out to women at the genecology and pre-eclampsia ambulatory waiting rooms at the hospital. The questionnaire took about 15 minutes to compile. The questions were informed by the outcome of the early interviews and fieldwork. Among other things the questionnaire addressed the women's personal relations (e.g. availability and nature of a care network), their contact with the healthcare system, their condition and their perception of, and attitude towards tele-monitoring. A total of 66 compiled questionnaires were collected during 1 1/2 month. The answers helped us to update the interview guide and validate results from the qualitative study. The workshops dealt with 1) the healthcare professionals' perspectives and requirements on home-based monitoring, and 2) the pregnant women's needs regarding home-based monitoring, how they have adapted their everyday life and how they relate to their condition through the monitoring.

Self-monitoring of heart diagnoses

We examined a project, investigating the impact self-monitoring had on (mainly older) adults with severe heart conditions. The project was conducted by a consortium including a university hospital that recruited and equipped heart patients with both off-the-shelf and project specific monitoring systems. Our interest in the project was on how the heart patients integrated, perceived and managed their measurements as part of their everyday lives and potential positive and negative outcomes of the monitoring activities. All patients had a severe, possibly life threatening diagnose and they should make daily bio value measurements to monitor their health. The heart patients measured their weight, blood pressure and pulse. Some patients also conduct ECG measurements. The patients were instructed to perform measurements and fill out an online questionnaire (e.g. if they felt a tendency to faint or not) each morning. The system then sent the data (using 3G) to the hospital for evaluation. If the hospital-nurse discovered something not being as expected, she contacted the patient.

We followed seven heart patients at the hospital and in their homes. Similarly to the previous case, our work included semi-structure interviews and fieldwork related to the patients' monitoring activities. The interviews were recorded and transcribed. The interviews touched upon similar questions as the interviews with the pregnant women. A questionnaire was also handed out to heart patients at the heart ambulatory to better understand how these patients perceive their illness, its impact on everyday life and self-monitoring. 83 replies were compiled during 1 1/2 month. The answers helped us update the interview guide and validate results from the qualitative study.

Figure 2. Case participants performing self-monitoring.

We also did workshops and field studies with two nurses enrolled in the project. The workshops dealt with the healthcare professionals' perspectives and requirements on home-based monitoring. The nurses also demonstrated the software used to handle the patient-generated data.

Self-monitoring as preventive care

We conducted a project to investigate healthy older adults' attitudes towards preventive health monitoring. The study engaged eight older adults to discuss their perspectives on health and preventive health monitoring as part of their everyday lives. Participants were recruited from an activity center. The older adults participated in workshops to explore why, how and when they could best perform and integrate blood pressure self-monitoring in their everyday lives (see Figure 2 left). Their everyday routines and activities were identified and rules related to successful blood pressure measurements (e.g. do not eat 30 minutes before the measurement and sit and rest without talking five minutes before a measurement) were put into relation to their daily activities and rhythms. Participants were also asked to do blood pressure measurements at home (both morning and evening) for three days in a row within a one-week timespan.

A web questionnaire was developed to better understand how people perceive and use preventive self-monitoring technology. We collected 165 questionnaires (responders' age: 22-83 years old). Questions were related to motivation in health management and lifestyle changes, the need of information about the current health condition, sharing of health data, what 'general' self-monitoring technologies do people have at home and the notion of assistance and surveillance in home-based health monitoring. Further details regarding this project can be found in [14].

Data Analysis

Apart from the investigated participant (e.g. care receivers and healthcare professionals), each case also included a multi-disciplinary group of researchers (e.g. computer scientists, ethnographers and Participatory Design (PD) experts). Minimum one of the two authors worked with each case and hence participated in the case-specific data generation and analysis. In this paper, the initial analysis focused on the first case (i.e. the pregnant women), before starting the comparative analysis across cases. The initial analysis was guided by an open coded approach conducted by each author with a computer scientist and PD background. Non-functional aspects of self-monitoring technologies were identified as the main concept from the initial analysis and thereof represent the main concept for further exploration. The initial themes that emerged around this concept were: people, resources, places, routines, knowledge, control and motivation (see Figure 3). These themes constitute the initial lenses for the socio-technical conceptual framework that we used to further investigate the temporal and distributed nature of health related self-monitoring activities in everyday life.

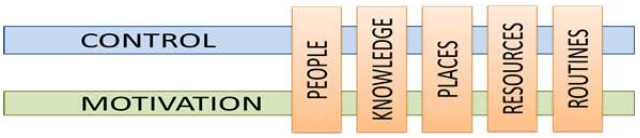

Figure 3. Identified themes in home-based self-monitoring.

We sequentially added the second and the third case and performed a comparative analysis across these cases. To allow comparisons, a more focusing coding of the aforementioned non-functional aspects was performed based on data from the additional two cases. Data was grouped into themes to facilitate the search of instances of the non-functional aspects and relate them to the current literature of home-based monitoring. The occurrence of the themes across the heterogeneous cases indicates consistency and reveals the shared themes.

The three cases provide a heterogeneous self-monitoring population with different ages, interests, and health conditions. This heterogeneity provides the maximum variation [24] that allows us to comparatively extract shared themes by focus on the non-functional aspects of self-monitoring technology. The themes were 1) present in all three cases and/or 2) identified as a particular challenge or aspect of health monitoring at home. As suggested by Yin [30], the three direct replications of the themes support an analytical generalization. Additional interviews were held with four additional persons to discuss illness and wellness devices (respondent validation [24]).

CARE MANAGEMENT SITUATED PRACTICES

Our cross-case analysis revealed seven specific themes (people, resources, places, routines, knowledge, control and motivation) related to home-based self-monitoring (see Figure 3). Previous work shows the importance of some of these themes in the home setting (see Related Work [4, 5, 8, 11-13, 23, 31]). All themes were present in our studies and together they established a socio-technical conceptual framework that facilitates an understanding of 1) the non-functional aspects in self-monitoring technologies, and b) the dynamic complexities of situated practices within self-monitoring and the interrelation of these practices in non-clinical settings. These themes will now be presented.

People

The reasons for doing home-based self-monitoring vary as do the people that benefit from such activities. We have observed that people take different stances towards their health, illnesses and measuring devices and how they integrate these in everyday life [5]. An *individual* that must make daily measurements for a long time to monitor a life-threatening disease is in a different situation compared with someone doing preventive check-ups few times a year. Aligned with [31], it is evident in all cases that the participants do not like to focus on their condition and keep their monitoring needs in the background (both mentally and physically). A woman with a heart diagnose with problems to move up to the second floor in the house said: *"…I slept down in the living room for a couple of months…*

I then told my husband, that I cannot stand it – that it should be a 'hospital room'. I don't want that". The care network can play an important role in home care management activities [11, 12]. Yet most participants only involve the *immediate family* and maybe their *closest friends* in their health management. We named these people the *intimate care network* (see Figure 1). The heart ambulatory questionnaire revealed that over 90% of the respondents involved the immediate family in their illness management. However, an *extended care network*, such as friends, distant family members or neighbors [11] rarely get involved - at any level. Only 12 (out of 83) discussed their health with the *extended care network* and six indicated that they do not include anyone in their health management. The questionnaire from the preventive case shows similar, but more restrictive data as most respondents preferred to only share health data with a healthcare professional and only 15% wanted to share health data with family and friends. The healthcare professionals also represent an involved (but remote) partner in the hospital-initiated cases.

Resources

Self-monitoring devices are main resources in personal health management. From the preventive case questionnaire, devices for measuring blood pressure and pedometers have a notable presence in people's home. However, we have noticed that some people attribute different meaning and function to different devices. One heart patient said: "*I can see a point in, having something* [monitoring equipment] *that is not related to something with the hospital…*". There seems to be a mental difference on devices that are perceived as general devices (e.g. a laptop), wellness devices (e.g. body weight scales and pedometers) and 'illness devices' (e.g. blood pressure and blood glucose monitors). For instance, people tend to leave wellness devices visible (for one-self and others) compared with devices more connected with illness around the home. The heart ambulatory questionnaire revealed that 53% would hide the blood pressure monitoring device but only 16% would hide the body weight scale. In a tele-monitoring project, four participants were individually shown pictures of diverse tools for health management (e.g. a blood pressure device, Nordic walking sticks, computer, body weight scale, thermometer). The participants preferred to leave wellness-related devices more visible and hide more illness-related devices. Also, a generic device such as a computer would keep its 'non-illness'-connotation when used for illness management – in this case tele-monitoring. For example, one participant did not like to have a special-made computer for tele-monitoring visible at home and prefer to use her personal computer instead.

Some participants in our three cases used calendars and notebooks as documentation tools [8, 9]. Others lacked a history log in the devices, but still did not kept a separate log. Also, measurement guidelines (e.g. a person should rest and not talk five minutes before a measurement) on how to perform a correct measurement becomes a resource (and possible constraint) in the self-monitoring activity [3, 14].

Places

Aligned with [23, 31], many participants in the three cases created or adapted a place for their measurements. However, the measurement guidelines provide different constraints on both the activity and place. The constraints are meant to ensure validity of the measurements. Our cases confirm the distinctions between public and private places when doing the self-monitoring activity [31].

If the measuring system is mobile, it can ease transportation and allow self-measurements outside the home, for example at work, during vacations or trips. However, the healthy older adults raised privacy concerns when we discussed the possibility to perform measurements outside the home. It seems that a bigger acceptance of self-monitoring occurs within the boundaries of the home for healthy people whereas frailty people tend to do it when it is necessary [31]. Still, they might not feel comfortable doing such measurements in all ambient and among all people and hence prefer to stay home instead of visiting friends or attending social activities. A heart patient that should visit a relative's birthday and stay the night said: *"…there I thought, should I bring it* [the monitoring system] *or not, no… you* [intending himself] *do not bring it*". However, some pregnant women brought their measurement system on vacations and were in general more open to perform monitoring outside their own homes. Consistent with [13], a higher acceptance towards self-monitoring has also been noticed if monitoring equipment can be freely positioned within the home. The questionnaires also show that many people are afraid that a tele-medicine system would be too spacious and could not "*just be placed anywhere*". A pregnant woman told us: "*Well, I have a need for, like, that it* [the monitoring system] *could fit…and not fill the whole room…I really like to have a nice home and so… If it had been a big machine…but now, when it can be put away into a box… Then one can bring it out when one should use it instead of that if should fill ones' life*".

Routines

As described by [5, 8, 12, 23, 31], implementing self-care activities into everyday life relates to how people actually live and organize their lives. In our cases we observed that people have the most stable routines in the morning. At a workshop in the preventive case [14], participants were asked to make floor plan drawings of their homes and then tag activities to the different locations and their individual order. By analyzing the drawings and discussing them at the workshop, it was clear that the morning routines were more homogeneous (from day to day, and among participants) compared with the afternoon/evening routines. While the measuring guidelines (as *resources*) support the reliability of the measurements [3] they can also challenge the integration or insertion of the self-monitoring activity in people's everyday life. There are specific rules on how one should behave, not only during, but also before a blood

pressure measurement for example. A person should not smoke, drink or eat in a specific interval before the measurement. It might sound trivial, but for some of our preventive care participants, just to consider measuring blood pressure twice a day (for a three day period) seemed impossible due to for example the breakdowns of routines [12]. They could do the measurements in the morning, but had severe challenges integrating their 'afternoon or early evening'-measurements in their everyday lives due to other (distributed) activities already planned in this time period such as bowling and playing bridge. These activities were something they did not easily want to give up, or reschedule. A participant expressed "*You can be completely worn down after meeting with a friend, but it brings me so much joy to do it*". These activities included other people – making rescheduling harder or even impossible. In the mornings, the measurements could more easily be integrated into the current *routines* and other people did not need to be included or know about the measurements. Exceptions did occur, as one heart patient liked to go fishing in the very early morning and do the measurements before that, something that was not technological possible. Indeed, finding a solution that 'fits all' is challenging in a heterogeneous patient group [8, 31] that might possibly have just one thing in common - their illness.

Another aspect was to allow oneself to forget about the condition to continue with one's normal day [5]. One pregnant woman explained this, saying that after the morning measurement "*they* [she and her partner] *could forget about the condition until the next day"*. If the measurement had been in the afternoon, the whole day would be planned around this event and might create worry as they would not know if the values would be good or not.

Knowledge

Align with [5, 8], we have identified an important aspect of learning about oneself and one's condition directly connected to the act of self-monitoring. A central source of knowledge is the measured bio-values and how they unfold over time. Through the measured values people can start to reflect on the results and its correlation to their *routines* and day-to-day activities [5]. For example if a person has been drinking to little (or too much) water one day, the next day's bio-values may reflect this. A pregnant women told us "*...it helps us* [woman and partner] *that we feel that we can do something with the illness*" and another explained that "*...it's cool that you can do something yourself and not just go to the hospital and say: Fix me*". By rendering bio-values visible, that normally are invisible, the person is provided with a tool for learning through reflection to help understanding his or her own body and condition. A participant told us that: "*one learns more when you do it* [the measurements] *yourself instead of when a nurse does it*". The learning aspect can on instances go beyond the self-monitored person to also include people in the vicinity, such as a spouse. While creating awareness for the care network has been investigated by [11], an active support for the *intimate care network* learning was not present neither in the diverse cases, nor in the Related Work. By learning for example what makes a partner feel better or worse, one can provide better care and get a deeper understanding of why a person might be tired one day. A pregnant woman said: "*It creates a feeling of security, also because I do believe, when he cannot really feel the child, as I can… I can feel the child and so… I know now what to react on, but when he cannot even know, if she kicks or not, or if I gain sufficient weight, than he can see these values… and see that everything is ok…*". The gained knowledge includes not only an interpretation of bio-values but also how they effect and be affected by everyday activities. While self-monitoring provides an instrument for learning through reflection [20], none of the systems in the three studies were designed to facilitate learning and reflection for either the individual or people close to the patient (see people). For instance, the healthy older adults used different mechanisms (e.g. additional readings, grouping values, symbols) to support their understanding of bio-values.

Control

In the three cases, we have observed mainly four aspects of control; 1) the (perceived) gain in control for the person subject to self-monitoring; 2) the control that is distributed to people close to the monitored person; 3) the removal of control from the healthcare professionals (when applicable) and 4) control retained by the system.

First, an increased personal control can facilitate freedom regarding when and where to make measurements [13]. If one does not regularly have to go to the hospital and meet up at specific hours, one may better accept and integrate the measurements (e.g. creating routines) in everyday life. One heart patient expressed this stating that: "*I have nothing against surveillance if it is for 'good', where it can help you. They can monitor me as much as they like… If I just do not have to go to the hospital only once… If I only have to go to the hospital 12 times a year it is fine*". The personal level of control also relates to the control of one's life and the role of illness in that life [20, 31]. For example, some of the pregnant women have reported using their condition as an excuse not to do things they do not feel like doing (like go grocery shopping or meeting someone). Similarly, we encountered situations where a person manipulated values to prevent a trip to the hospital. For example, the pregnant women should urinate on a special paper strip that reacted to the level of protein in the urine. This value was manually read and entered into the monitoring system. The scale is analogue as the paper strip change color based on the protein level (similar to a litmus PH-test). The obtained non-discrete value allows for interpretation of the results (*knowledge*). This interpretation allows the women at times to prevent going to the hospital or not. Another strategy was to drink more water to adjust the urine protein level. One of the women said: "*so then I drank a lot of water, and then it* [the value] *was not that high, and I didn't have to be hospitalized…*". To increase accuracy, one might vote in

favor for a completely automated system. However, the individual can feel more involved, and learn more about their values when they manually input data. A pregnant woman said: "*Yes, one should of course do the actual work at home, at the hospital there is a nurse that does it all, so there one is a bit more tranquillized in the situation. Here* [at home] *you should do it all by yourself. But one has also more control and one also shows more interest; one should by oneself understand and know* (…)".

Second, some control was also given to (or taken by) people close to the monitored person. The bio-data became a tool, for example for the fathers-to-be to imply 'rules' on the pregnant women. As they worried about the child and the woman they could say, backed by the bio-values, that the woman should not do specific activities, rest more etc. A pregnant woman's partner told us: "*She decides all the time, but if I feel that, based on the results, that, if I see the results are not good I can say this to her, we can talk about it, it is not good to do* [an activity] *more*".

Third, a distribution of control became an effect of the self-monitoring. As described above, the patient gained control while the healthcare professionals lost some levels of control. Still, the healthcare professionals are remotely present in the two hospital cases. They were positive to tele-monitoring, but also stated that they did not like all patients to use it as 1) not all were suitable for it and 2) they did not like to spend all their time in front of computers but rather meet patients.

Last, a system takes control of some aspects of the patient's life when entering to the home. Aligned with [31], the removal of control was manifested by the physical properties of the devices (e.g. size, portability, power, 3G coverage) that constraint the *place* and people's *routines*.

Motivation

Motivation is highly individual and complex by nature. In the three cases, we have observed different types of motivation. First, a healthy person motivated by the desire to maintain health and wellbeing. Second, a heart-patient motivated by the desire to get well or achieve a better health state. Third, a pregnant woman motivated by the desire to maintain health and the wellbeing of her child. Last, the immediate family and friends motivated by the desire of improvement in a loved person's health.

The results of pro-active measurements may be noticeable first years after its initiation and this can effect motivation. In our cases, the healthy person supposed to engage in pro-active monitoring expressed less motivation compared with the other groups. In contrast, the direct benefits for a heart-patient or a pregnant woman doing monitoring at home were more evident. For example did they save trips to the hospital and could have a more active lifestyle as described above in *control*. Another participant said "*I've gotten an increased focus on taking care of my health so that my wife and I will grow old together –live healthy!*".

MODES OF SELF-MONITORING USE

Many of the themes are associated with specific properties of self-monitoring technology - the main resources to support self-monitoring activities in people's everyday life. For example, self-monitoring devices can have a visible or invisible position at home and people create, adjust and attach the monitoring activity to their routines. People engage in self-learning and reflection to acquire a sufficient knowledge through monitoring activities to perform health monitoring and to understand how their everyday life affects and get affected by the self-monitoring activity. Clearly indicated in our studies, people want to be in control of their own situation as long as possible and they might have different motivation for doing so. Self-monitoring devices are primarily designed to support the individual to play an active and collaborative role in his/her own self-care management. The analysis of the themes enables us to identify different use modes of Ubicomp technologies for self-monitoring.

Individual and Care Network Use

Especially in the two non-preventive cases it is evident that the technology is developed mainly for two people: the healthcare professional and the monitored person. Indeed, self-monitoring devices often lack a more situated support for the care network [11] (e.g. a monitored person may live with other people). While other people may not share a monitoring need, our cases show that people in the proximity of a monitored person may need better support and could be a better used resource in the care situation. An empowered care network member may for example provide better assistance to the monitored person and better learn and get knowledge about the overall situation. When shared, information about one's health is to a large degree connected with a feeling of security and safety. Some participants in the two non-preventive cases perceived a benefit if others know about their current health-status. This was generally not the case in the preventive care case. Most pregnant women include the becoming father by going outside of the system and sent SMS's or emails to inform him about her current health status. However, privacy is a main concern and the sharing of health data is a delicate matter. The monitored person should decide whom to include and how in their personal health management.

"Demo" Use

Another sort of inclusion-feature discussed in our cases, especially in the two cases with prescribed measurements, was the possibility to allow others [16] to try out and perform measurements with the device(s). To allow a partner, child or a group of friends to test a monitoring device can allow a more open discussion and understanding about the measurements and illness. In the illness related cases, this is not currently possible as all data is sent to the hospital and therefore must be performed at specific times and only by the patient. When role-based access control is not enough [16], something as simple as a demonstration-function where the device is used but does not transmit the values could prove useful. For example, a simple game-

function (i.e. gamification – not necessarily of the actual measurements but in a demo-mode) could help explain and demystify the measurements to children, or even make the measurement something fun in a group of friends rather than something one should hide or do alone.

Wellness and Illness Use

There seem to be differences on how people appropriate healthcare technologies into their everyday life. Some people care for example more about the appearance of their homes while others do not. There also seem to be a balance between what is practical in everyday life and hiding an illness. It also seems like the more severe one's condition is, the more one accepts. The participants have mentioned the aesthetics of the device as an important aspect to facilitate the appropriation process. For example should a monitoring system not communicate illness or be 'hospital-looking'. A similar aspect derives from the culturally embedded perception of a particular device. In interviews people have been more open to have a bodyweight scale visible in the bathroom at all times or training equipment such as Nordic walking sticks placed at the front door compared with monitoring equipment or special-made computers for tele-monitoring. Looking at pictures of diverse healthcare technologies, participants did not see any problem leaving a personal laptop also used for monitoring and communicating with the hospital 'in the open' as they can be placed anywhere. An image of a purpose-made 'hospital-looking' computer system would have been hidden away when not in use. Indeed, tools for wellness (or tools that do not communicate 'illness' or 'hospital') seem more easily integrated into peoples' lives compared with illness-related devices. Given the above mentioned, attention should be given to not only functional aspects but what a monitoring system or device communicate, both in use and non-use situations. This aspect of healthcare devices needs further investigation. The reason for why a devices is hidden or not or how it is perceived by a household is complex. But in diverse projects, people seem to prefer wellness devices and technology that 'everybody have' for example due to fear of stigmatization [31].

SUPPORTING MODES OF SELF-MONITORING USE

We have identified and exemplified different modes of self-monitoring technology use in which people take and share their measurements. For example 1) individual and care network use, 2) demo use and 3) wellness and illness use. Self-monitoring technologies should not be designed to support just one mode of use but offer flexibility and support a range of uses. This could be a way to lower stigmatization and normalize devices for self-monitoring, especially regarding illness-related monitoring. We will now discuss properties of self-monitoring technologies to support the described modes and care situated practices.

Individual and Care Network's Local Awareness

People engage in self-learning and self-reflection endeavors to get a sense of their current health status. Besides the efforts to provide design features to facilitate data collection during the maintenance and discovery phases of self-reflection [18], most self-monitoring technologies lack mechanisms to help people to make sense of their data. Here, data does not only include bio-values but also all the knowledge that can be gathered at home such as people's routines and contextual information. A proper combination of all these information can support a self-reflection process and provide local awareness for the individual and the intimate care network [11, 12]. People sharing the household (intimate care network) with monitored individuals in our cases have talked about the possibility to learn about the other person's illness and how to be able to assist this person through the reasoning and reflection that comes from sharing the measurements. Today this awareness and learning have been an emergent property in use, rather than a designed feature. As Bates [6] states most learning comes "through being aware and monitoring" as a result of the interaction with one's friends and the actual social or physical surroundings. We observed that the pregnant women were the only group actively sharing and discussing health data not only with their partners but also with for example their parents.

In all cases, the visualization tools were not designed to enable local awareness and learning, neither for the individual nor the care network. However, in some aspects the pregnant women perceived the monitoring system to be more beneficial for their partners than for themselves as it provides the partner with a tool that render what is for them 'invisible visible'. Although the visualization of bio-data (e.g. pulse, blood pressure and the child's ECG) can provide for example the intimate care network with an understanding of what is going on. Ubicomp monitoring technology designs could benefit by further acknowledging people in the direct vicinity of an individual doing home-based monitoring. Ubicomp technology can also help the intimate care network with learning endeavors and provide them with a sense of local awareness. For example, exploring ways to improve social connectedness through physiological data [26] or enhancing the PHR by creating common information spaces [7] to support and facilitate information sharing, reflection and learning for both the individual and care network in non-clinical settings.

Assess and Assist the Individual Health Locus of Control

As described earlier, there are different aspects of control and/or lack of thereof during non-clinical health monitoring. As care moves out of the hospital and into peoples' everyday lives there is a shift in control among the involved actors. When designing Ubicomp technologies for home-based healthcare, how to support or suppress the different actors' level of control over a situation can be an important system quality that might impact both the individual and the care network. While people might refuse to use over-protective or surveillance technologies [21], we have observed that technology have also helped to provide people with control in their everyday lives. It is important that the control of one's life remains with, or is returned to,

the individual. Our findings show that a person can gain an "internal health locus of control" [29] not only through reflective thinking [20] but also if the system allows some flexibility in when, where and how measurements should be performed. At the same time, the external health locus of control [29] associated with the healthcare professionals at the hospital decreases over the monitoring person and the measurements. This shift in control and how it affects the involved stakeholders and the overall care situation might differ when designing for frail people and not all people may be capable to handle a high level of control.

Especially among the pregnant women, we observed how they intentionally manipulated the reported values to get a higher internal locus of control of their life situation. However, frail people such as older adults might benefit from a setup where the control (internal and external) is shared among the involved actors or, in severe cases, put into the hands of others (external locus of control) such as for example the healthcare professionals. Furthermore, especially in the preventive case we also observed that healthy older adults might experience a chance-type health locus of control [29] as they think they are too old for health interventions. Furthermore, the fathers-to-be gained a multidimensional health locus of control [29] (i.e. internal and external) as they got access to the women bio-values. Also, they got in a position where they could take, or be permitted, some of the woman's control as they started questioning her decisions and habits. On some occasions this control were taken, and on other occasions given or negotiated as some women also expressed comfort in having someone taking 'tough' decisions for them.

In the described cases, we have seen examples of how an increased personal control has benefitted the individual performing home-based monitoring. Designing for an increased internal locus of control can indeed support appropriation and use of home-based monitoring devices for both frail and healthy people. Furthermore, designers of Ubicomp technology should not only consider the needs of the individual but also the role of the care network. In this sense, the individual and the care network should be seen as *proactive people* [25] of self-monitoring technologies. As described above, providing and maintaining the individual and care network's local awareness can help Ubicomp technology to assess and assist the individual health locus of control (internal, external or by chance). In doing so, the individual and the care network (intimate or extended if applicable) are able to gain health locus of control, share the responsibility [12] and identify atypical situations (e.g. cheating, obsession) in which a reinforcement (especially when chance health locus of control occurs) or a suppression of the health locus of control is preferred. This can avoid unintended consequences of a continued monitoring such as stress [19] provoked by the monitoring activity. Such stress can be perceived as a loss of internal health locus of control, in which the care network needs to become aware of, and gain more control over the situation.

Active Information Seeking and Reinforcement

The contextual information of measurements and the guidelines for bio-measurements play an important role in an individual's care management. To maintain awareness (individual or intimate care network) of the situation, people engage in active information seeking activities such as directed searching and browsing [6] to support their self-learning and self-reflection processes. We observed that a manual entry of bio-values supports the understanding of the current health condition. However, frail people might benefit from a setup where data is inserted into the system automatically. Participants that got feedback from the hospital about their measurements appreciated this as they were always looking for a response to get a feeling of security and safety during the day. Even though some of the current technologies on the market (e.g. Withings blood pressure device) inform the individual about the existing guidelines, they do not enforce the user to comply with these guidelines nor help to interpret the values. Ubicomp technologies can help by supporting the active information seeking, reinforcing the application of the guidelines, and capturing relevant contextual information. In this sense, capturing all this information together with the individual and care network's local awareness can help Ubicomp technologies to support the informational order [12] needed to perform self-monitoring activities at home. Knowing that all the necessary information is available at hand can motivate the individual to continue doing self-monitoring and support the intimate care network to get involved in the care activity. This can also be beneficial for the healthy (preventive) group as they can become more aware about the role and importance of the guidelines besides the meaning of their bio-values.

CONCLUSION

Although each non-functional aspect (people, resources, places, routines, knowledge, control and motivation) presented deserves further research, this paper provides a holistic perspective that we argue is important to consider when designing for home-based health monitoring. Through a cross-case analysis of three cases, we show the role of these seven non-functional aspects. We also identify and discuss three modes of self-monitoring use at home: the individual and care network use, the demo use and the wellness/illness use. Based on our findings, we suggest moving away from passive monitoring and surveillance to solutions that assess and assist the individual health locus of control and enforce active information seeking. By doing so, a sense of local awareness of the current health situation can be provided to both the individual and the care network through learning and reflection in non-clinical settings.

To our knowledge, these non-functional qualities have not been adequately discussed as a whole within the Ubicomp community. We hope the findings presented in this paper can inspire to future research and provide home-based healthcare technology designers with knowledge about the use of self-monitoring technology in the home setting. However, the presented findings are far from complete and

many challenges remain when designing home-based healthcare technology. We encourage the Ubicomp community to continue exploring and understanding socio-technical complexities involved when introducing home-based health technologies in people's everyday life.

ACKNOWLEDGMENTS

We would like to thank the CfPH and especially the diverse participants from the LevVel and Tele-Skejby projects. We also thank all partners and colleagues that have contributed to the diverse projects and the data collection.

REFERENCES

1. Andreassen, H.K. What does an e-mail address add? - Doing health and technology at home. *Social Science & Medicine*, 72(2011), 521-528.
2. Arnrich, B., Mayora, O., Bardram, J., Tröster, G. Pervasive healthcare: paving the way for a pervasive, user-centered and preventive healthcare model. *Methods of information in medicine*, 49(2010), 67.
3. Ashiful, A., Zarifi Eslami, M., and Sikkel, K. Elderly and homecare tasks: A literature review on problems. In *Proc. eHealth 2012*, IADIS Press (2012).
4. Axelrod, L., Fitzpatrick, G., Burridge, J., et al. The reality of homes fit for heroes: design challenges for rehabilitation technology at home. *Journal of Assistive Technologies*, 3(2009).
5. Ballegaard, S.A., Hansen, T.R., and Kyng, M. Healthcare in everyday life: designing healthcare services for daily life. In *Proc.CHI 2008,* ACM Press (2008), 1807-1816.
6. Bates, M. Toward An Integrated Model of Information Seeking and Searching. *Graduate School of Education and Information Studies*, 2003.
7. Bossen, C. The parameters of common information spaces:: the heterogeneity of cooperative work at a hospital ward. In *Proc. CSCW 2002*, ACM Press (2002).
8. Chen, Y. Take it personally: accounting for individual difference in designing diabetes management systems. In *Proc. DIS 2010*, ACM Press (2010), 252-261
9. Chen, Y. Health information use in chronic care cycles. In *Proc.CSCW 2011*, ACM Press (2011), 485-488
10. Clemensen, J., Craggs, M.A., Marcussen, C. et al. Chronically Ill Citizens and Home Monitoring:"Nothing to talk about!". In *Proc. eTELEMED 2013*, IARIA (2013).
11. Consolvo, S., Roessler, P., and Shelton, B. *The CareNet Display: Lessons Learned from an In Home Evaluation of an Ambient Display*. In *Proc. UbiComp 2004*, Springer (2004). p. 1-17.
12. Dalgaard, L.G., Grönvall, E., and Verdezoto, N. Accounting for Medication Particularities: Designing for Everyday Medication Management. In *Proc. Pervasive Health 2013*, IEEE (2013).
13. Grönvall, E. and Kyng, M. On participatory design of home-based healthcare. *Cognition, Technology & Work*, 2012, 1-13.
14. Grönvall, E. and Verdezoto, N. Understanding Challenges and Opportunities of Preventive Blood Pressure Self-Monitoring at Home. In *Proc. ECCE 2013*, ACM Press (2013).
15. Heart, T. and Kalderon, E. Older adults: Are they ready to adopt health-related ICT? *International Journal of Medical Informatics (in press)*.
16. Kalpana, S. *Aging, Privacy, and Home-Based Computing: Developing a Design Framework*. Perv. Comp, 2012, 11(4), p. 46-54.
17. Korhonen, I., Parkka, J., and Van Gils, M. Health monitoring in the home of the future. *EMBS Mag., IEEE*, 22(2003), 66-73.
18. Li, I., Dey, A.K., and Forlizzi, J. Understanding my data, myself: supporting self-reflection with ubicomp technologies. In *Proc. UbiComp*, ACM Press (2011).
19. Lupton, D. M-health and health promotion: The digital cyborg and surveillance society. *Soc Theory Health*, 10(2012), 229-244.
20. Mamykina, L., Mynatt, E., Davidson, P., et al. MAHI: investigation of social scaffolding for reflective thinking in diabetes management. In *Proc. CHI 2008,* ACM Press (2008), 477-486.
21. Milligan, C., Roberts, C., and Mort, M. Telecare and older people: Who cares where? *Social Science & Medicine*, 72(2011), 347-354.
22. Morris, M., Intille, S., and Beaudin, J. Embedded assessment: Overcoming barriers to early detection with pervasive computing. *Pervasive Computing*, 2005.
23. Palen, L. and Ballegaard, S. Of pill boxes and piano benches: "home-made" methods for managing medication. In *Proc. CSCW 2006*, ACM Press (2006).
24. Patton, M.Q. *Qualitative research & evaluation methods*. 2001: Sage Publications, Incorporated.
25. Rogers, Y. *Moving on from Weiser's Vision of Calm Computing: Engaging UbiComp Experiences*. In *Proc. UbiComp 2006*, Springer (2006). p. 404-421.
26. Slovák, P., Janssen, J., and Fitzpatrick, G. Understanding heart rate sharing: towards unpacking physiosocial space. In *Proc. CHI 2012*, ACM Press (2012), 859-868.
27. Steele, R. and Lo, A. Future Personal Health Records as a Foundation for Computational Health. *ICCSA 2009*, Springer (2009), 719-733.
28. Tentori, M., Hayes, G.R., and Reddy, M. Pervasive Computing for Hospital, Chronic, and Preventive Care. *Found. Trends Hum.-Comput. Interact.*, 5(2012), 1-95.
29. Wallston, K.A., Strudler Wallston, B., and DeVellis, R. Development of the Multidimensional Health Locus of Control (MHLC) Scales. *HEB*, 6(1978), 160-170.
30. Yin, R.K. *Case study research: Design and methods*. Vol. 5. 2008: SAGE Publications, Incorporated.
31. Aarhus, R. and Ballegaard, S. Negotiating boundaries: managing disease at home. In *Proc. CHI 2010*, ACM Press (2010), 1223-1232
32. Aarhus, R., Ballegaard, S., and Hansen, T. *The eDiary: Bridging home and hospital through healthcare technology*. In *Proc. ECSCW 2009*, Springer (2009).