

- CALL FOR PAPERS -

Pervasive healthcare in the home: Supporting patient motivation and engagement

A workshop at Pervasive Health 2010

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For more information, please refer to the workshop website : <http://www.ph-home.org/>

ABSTRACT

Currently, care and rehabilitation practices move, to a greater extent, out of hospitals and into private homes. This accelerating trend challenges healthcare systems and their patients. Heterogeneous settings such as private homes together with the diverse nature of the inhabitants and their conditions create both technical and usability constraints and possibilities that can inform development of home-based care and rehabilitation applications. This workshop likes to investigate and discuss challenges, requirements and possibilities related to home-based healthcare applications, seen from a patient perspective. For example, how do we design for acceptance and engagement among patients and their families living with these systems on an everyday basis? How can barriers related to patient engagement, motivation and the feeling of 'being cared for be handled by developed systems in heterogeneous environments such as private homes? Or, how can User Driven Innovation (UDI) and Participatory Design (PD) be used to create systems that are aesthetically and functionally accepted by persons subject to homebased healthcare and rehabilitation?

About the workshop

This Workshop will be a one full-day workshop. We expect high-quality, non-previously published work to be submitted. Accepted papers should be four pages long, and formatted according to the format of the main conference, Pervasive Health 2010. The workshop will be a mix of traditional presentations and discussions. Position papers should include a statement of no longer than 200 words containing a research question related to the submitted paper. The research questions will be

published on a discussion group on Facebook before the workshop to stimulate an on-line debate. The debate will inform the discussion at the workshop. The objective of the workshop is to bring together researchers, designers and practitioners – to present, discuss and contribute to a framework related to the design of pervasive healthcare, from a patient perspective.

The workshop likes to contribute to the design of pervasive healthcare applications and systems for the home. The focus will be on studies and applications that discuss a home care environment and outcome of such work, addressing individually or in combination socio-technical aspects of healthcare in the home, technological aspects of healthcare in the home, and methodological challenges of how methods such as UDI and PD can be used to develop tools and applications that embrace the challenges related to motivation and engagement. Both theoretical investigations and work based on empirical efforts are welcome. Examples of successful and less successful projects alike are invited creating a framework related to the design of successful applications for self-managed care in private homes.

Topics addressed in the workshop include, but are not limited to:

- Challenges with and new methods of UDI/PD in home-based healthcare
- Mismatch professional/patient understanding
- Responsibility for own treatment
- Aesthetics in the home and functionality
- Adapting solutions to each home and patient (physically and digital)
- Close family, Relatives, Community and their roles
- Integration of treatment in the daily life
- Home/hospital collaboration
- Patient vs citizen (patient role)
- Mobility
- Collaboration

Short description of the motivation and objectives

Current trends within the healthcare sector are that patients spend less time at the hospital, that healthcare expertise and treatment are centralized at bigger hospitals and that there is a growth in number of chronic diseases. These factors create the foundation for increased self-care, home-care and a shift from a passive to an active patient role. Assistive healthcare technologies for the home, trying to support this development need to consider, at a minimum, requirements related to (i) the patient's home, (ii) the technology and (iii) the healthcare sector. This workshop likes to explore how motivation and patient engagement in a home-based treatment programme can be supported, developing systems that take these three topics into consideration.

The patient and the home

Even if studies have shown that patients in some cases experience a higher sensation of 'quality of life' during home treatment in respect to hospitalization [1], known barriers exist. It is challenging to transfer a hospital-based treatment directly into a home-setting, due to the diverse properties of the settings. Indeed, the home as such is not designed as a place for care, and people often prefer to

keep their sickness invisible in their homes [2]. The role of the patient shifts while in the home or at the hospital. At the hospital, the patient only has to care about being 'a patient', while at home, 'the patient' shall also be e.g. the husband/wife, the worker, the sportsman, the neighbour [3]. Consequently, patient motivation and engagement decisively influence the success of home based treatment schemes. In particular within rehabilitation research, these concepts have been thoroughly elaborated (see e.g. [4, 5]). Furthermore, in rehabilitation, home based programs appear to have better adherence rates than centre based programs [6]. However, within 'traditional' treatment schemes, these concepts are less developed theoretically, and reports are more likely to concern the practitioner-centric 'compliance', claiming for instance, that compliance problems occur more often in home-based care than in a controlled hospital environment where for example a nurse both issues and supervises the intake of a medicine [7]. Regardless of the terms chosen, compliance or motivational issues derive from many reasons, often of complex human nature [8]. routines to support this exists, [9] presents a study that exemplifies how elderly creatively develop tools and routines to make medicine intake fit into their everyday lives. To develop diverse healthcare systems for the homes, we must understand these and other requirements, seen from the patient's perspective.

Technology

In pervasive health scenarios focusing on the home, technology is often used as leverage for implementing new home based treatment schemes. Thus, new technologies are introduced in the same process that moves the treatment scheme to the home. However, technology in itself poses challenges to the success of home based treatment. While some technologies are commonly acknowledged as 'empowering' for the patients [10], especially elderly patients may also experience alienation on account of the technology [11]. A different approach than attaching new technologies to the treatment is to make efforts towards integrating the solution into existing technologies and infrastructures. This approach has been shown able to sustain the aesthetic environment in the home [12], improve the patient's mobility and help de-stigmatize or 'put the condition in the background – for instance by allowing the patient to consult medical records by use of daily remedies such as the mobile phone [13]. However, regardless of strategy, the technology applied (e.g. applications, interfaces and the infrastructure) must answer to a list of both hard and soft requirements existing in a private home. The challenge is to introduce technological healthcare systems in the home that not only fulfil requirements from a medical protocol but that also answers to the wider range of requirements existing in private homes, emerging from the setting and its inhabitants.

Healthcare sector

As a tool to provide healthcare, assistive technologies that will aid in out-patients' everyday care should respond to health protocols and be able to provide meaningful support. What is the role of for example the doctor, physiotherapist or home-visiting nurse in the setup, configuration, administration and monitoring of e.g. use, alarm situations, collected data and logs?

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