The MaXi-project: User-driven innovation in Ambient Assisted Living – towards an experimental needs analysis of services.

Fusion of user-driven innovation, model based "ICT-intelligence", Personal Health Systems, and LivingLab experimentation in the design of ICT-support for every day living with a chronic disease.

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***Abstract* — The main purpose of the MaXi-project is to conceptualize and design, user-driven, coherent, pervasive ICT-support *for patient responsibility* understood as *patient response ability* for everyday living with a chronic disease. The focus is on architecture and models for delivering individual-, personal- and situational- context-sensitive knowledge-services through Near Field Communication such as RFID and special-purpose mobile devices with interfaced sensors and actuators.**

Several times a day a diabetic has to evaluate the dynamic action and balance of treatment, carbohydrate intake, and physical exercise to try to keep blood glucose within tight limits What is needed to make this an Ambient Assisted Living activity – also from an end-user (diabetic) perspective?

SETUP: Several structured-user-workshop results are translated into concepts, which are then implemented in the remote fishing/holiday village of Skagen (Denmark) - as a citywide Living Lab using state-of the art ICT. Information from commerce, the tourist-association, hotels, restaurants, and personal health data are used to feed the model. Diabetics and their families are then invited to come and live with and evaluate the concepts.

Keywords: Participatory design, Personal Health Systems, computer models, diabetes, patient support, clinical decision. pervasive computing, ubiquitous computing, pervasive healthcare, Ambient Intelligence

I. Introduction

In St Vincent, Italy (1989) [1] major stakeholders, including WHO, agreed on how good quality of diabetes care should be understood. This agreement also implied a "division of tasks" in the teamwork between healthcare systems and the object/subject of care – the individual diabetic person. The health care system – irrespectively of its organisation and financing model - should control and treat the overall diabetic state, and work on trying to avoid late complications by offering education, advice, screening for late complications, and secondary prophylactic treatment of such complications. The patient's part of the teamwork is mainly the "round the clock" balance of food, exercise and treatment to keep blood glucose within tight limits.

The aim of the MaXi-project is to create coherent ICT-support for the patient part of the diabetes management teamwork – thus enhance *patient responsibility* in the meaning of *patient response ability*. This aim is pursued through a participatory design process between diabetics and professionals (in health and ICT).

In this paper we mainly report the user-needs analysis for the conceptual design process and give an overview of the methodology and technologies employed in the project.

II. Diabetes

Diabetes is a serious illness for which there – at present – is no cure. In 2006 the global number of adults with either type 1 diabetes (T1D) or type 2 diabetes (T2D) was 246 million or 7.3% of the world's adult population [2].

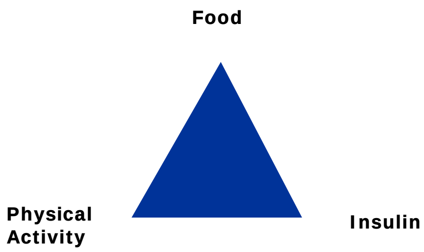

Figure 1: "The diabetes triangle". The clinical model of diabetes management. In practice this model behaves far more plastic and dynamic than the triangular shape envisages.

Being diabetic, especially for T1D, requires from a medical perspective strict control of your blood glucose level obtained by balancing within a triangle of food, exercise and insulin (treatment) (figure 1). Patient decisions within this model of thinking takes place throughout the day, but especially around meal-times or in relation to physical activity.

The patient's experience of short time unbalance in the "triangle of diabetes" could be hypoglycaemic episodes, which gives various physical and psychic symptoms and may lead to unconsciousness. Manifest hyperglycaemia can lead to an internal poising-like condition known as diabetic coma, which may lead to death. Chronic moderate hyperglycaemia implies an increased risk for earlier and more severe late complications of diabetes.

III. Materials and Methods

Overall two full cycles of the experimental sequences is planned. In the first cycle – running a year from October 2007 standard off-the-shelves hard- and soft-ware components are employed. In the second, running a year from October 2008, we plan to engineer special-purpose prototypes of hard- and software components aimed specific at the user-needs and the domain - using software defined radio, hardware-software co-design and rapid design methods. Each sequence has four phases: (1) enduser (diabetics) needs analysis, (2) conceptualization (3) Living Lab experimentation, and (4) evaluation.

End-user involvement: Eight families were selected among the members of the Danish Diabetes Association (www.diabetes.dk) by questionnaires, mainly assessing their engagement in technology and willingness to participate in their spare time in the user workshops, interviews, and the Living Lab experiments. A structured sequence of workshops, interviews, home visits, games, postcard, and text-messing from the daily situations encountered were used as physical and visual artefacts to communicate the user's needs to the project.

Conceptualization: The user needs were conceptualized in two ways in the prototype:

- ICT-support for the user's normal "tools" for coping with diabetes: Planning, co-operation, remembering, finding, and informing.
- ICT support for direct estimation of the dynamics of the "diabetic triangle" balance on the basis of input from service-providers (e.g. restaurants, supermarkets, diabetes clinics) and devices (e.g. accelerometers, blood glucose meters)

ICT-tools: Various programming environments will be used. For the "diabetic triangle" a model- and rule-based "in-house" Data Interpretation and Model Management System (DIMMS) will be employed. Various short range wireless technologies will be used for data communication between devices and user-interaction terminals.

Living Lab experimentation: We plan to setup a living lab in the remote fishing- and holiday- village of Skagen in the north of Denmark in September 2008 and 2009 for the two planned iterations. The village will be provided with the necessary ICT-tools and infrastructure for the experiment. The eight families are invited for an experience in a different environment, where they are not familiar with food and exercise possibilities. This setup is chosen to test the patient response ability – both technically and from a user perspective.

Evaluation: The MaXi-project is a user-driven technically proof of concept of a potential method to enhance patient response ability to the daily coping of a chronic disease. The project is not a clinical trial. The evaluation is therefore qualitative of user-experience, technical performance, and pervasiveness.

IV. Results

User coping strategy: Diabetes of one or more of family members (both children and adults) was a problem that the entire family had to cope with. The specific family-activities around the "diabetic triangle" could be generalized into the following coping strategy elements: finding, planning, cooperating, remembering, informing (figure 2), Cooperation could also mean negotiation within the family or with yourselves. Direct calculations of the triangle was not possible - due to lack of data in a suitable format and context, and user-manageable models for the interaction of insulin, exercise, and food – including the dependencies of food composition.

***Figure 2:Fammily coping strategy elements** of" the diabetic triangle" (shown in the centre of the figure).*

Design Implications: Our analysis of the user-needs with respect to design points towards the following:

1) Designing for diabetics is more than designing for one group of users. Children and adolescents have different interests, problems, and focus on activities than adults; this is independent of who have the disease. Collaboration in the family is essential despite the different design needs.

2) Designing for coping with diabetes is more than designing for calculation of food, treatment and exercise. Several activities are interrelated and impossible to practice without the others. This means that IT-support for everyday living with diabetes must support a variety of activities.

3) Designing for coping with diabetes is more than designing for specific locations. It is both designing for somewhere and designing for everywhere. Distinctions have to be made between 'activity-based IT-support' and 'locations-based IT-support'.

4) Designing for coping with diabetes is more than providing digital expert generated information. While expert generated information only support the activity of calculation (at the theoretical level of action) user generated information support the surrounding activities and management of unknown quantities. Expert generated information is widely used if the disease is newly diagnosed. Peer generated information is used, when you are more experienced with the disease.

5) Designing for diabetics is more than designing for diabetes. Information relevant in relation to diabetes is not special but 'just' information which could be of relevant to many. Diabetics aim to blend in rather than to stand out.

6) Designing IT for diabetes means interoperability of more systems than the diabetic's home computer and the diabetes-clinic-information-system. Ideally - it means a personal context-sensitive 'on human-data-integration' from several sources.

7) Most tools and devices for diabetics are very academic and clinical in the design and function, and hence unexciting to the user.

V. Discussion

There is often consensus between professionals and user about the everyday coping with diabetes, hence through management of "the diabetic triangle". But as the professionals use the direct model in their line of thinking, the users also employ a set of general activities, modified according to location, activity and personal context: informing about their needs, planning, remembering, finding information, and co-operating (negotiating) within the family.

The aim of the MaXi project can in this perspective be expressed as designing concepts and special purpose technologies that can assist both the diabetic's current strategies in unfamiliar surroundings and activities - like on holiday - and can make the direct calculations more operational in the daily coping with the chronic disease.

The two approaches to ICT-supported advice to the diabetic share some common prerequisites:

- Integration of (digital) information from various segments of society – healthcare-, service-, tourism-, device- (sensor, actuator), pharmaceuticals-, and ICT-industry.
- Coherent design and function – supporting the total chain from sensor trough "ICT-intelligence" to actuator
- Support for personal context as well as location, and activity specificity.
- Support for age and family-role.
- Design for "blending in" rather than "standing out" at least for invisible conditions like diabetes.
- Design for "life" not for "disease".
- Sustainable privacy and security giving the user full benefit and control of the data-flow.

The first iteration in our living lab in September 2008 will be impaired with respect to the ideals expressed in the preceding paragraph, since we have to use standard, discrete hard- and software technologies.

ACKNOWLEDGEMENTS

The research reported from in this paper is part of the maXi-project (www.maxi-projektet.dk) which has received generous financial support from the Danish Enterprise and Construction Authority. We acknowledge the work of Christian Nøhr, Anne Marie Kanstrup, and Pernille Bertelsen of Aalborg University. Thanks to the participating families and the Regional Diabetes Association of North Denmark for providing contact with the families.

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