

Assistive Technologies for Homecare: Outcomes from Trial Experiences

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Abstract. The ubiquity of mobile devices and the pervasive Internet raised a new paradigm in care models, based more on contacts than on visits. However, the effects of assistive computerised systems on practitioners and patients remain understudied, and their promise of increasing self-care, acceptability, and accuracy of healthcare monitoring mostly untested. Similarly, evidence remains controversial concerning the effectiveness of providing support to caregivers of Alzheimer's disease patients, through technological devices integrated with existing care services. This paper aims to contribute further results and evidences gained from experimental trials, related to two different solutions: an electronic pain monitoring system, and a technological kit to support Alzheimer's patients caregivers. The positive outcomes suggest to further extend similar studies, to better clarify the role and realistic expectations on the use of ICT in healthcare.

Key words: remote monitoring, electronic diary, dementia caring, sensors, acceptability, compliance

1 Introduction

The ubiquity of mobile devices and the Internet raised the paradigm of new care models based more on contacts than on visits [1]. In fact, the ability to interact with the system *anywhere, anytime, anyhow* offers invaluable opportunities to healthcare delivery. Moreover, mobile devices showed significantly advances in storage capacity, battery efficiency, portability [2] and ability to access

Internet-based resources [3], that increased their suitability to healthcare delivery systems. Remote clinical systems enable patients either to report complaints, almost immediately as the generating events occur, or to address retrospective symptoms. However, several challenges are raised from these systems, namely the adherence of patients, healthcare personnel supervision, usability and user experience, and data management in terms of availability, accuracy, analysis and outcomes. In addition, most of these systems were designed to interact directly with patients without evidence of reliability and accuracy. Thus, the effects of assistive computerised systems on practitioners and patients remain understudied, and their promise of increasing self-care, acceptability, and accuracy of healthcare monitoring, mostly untested.

Similarly, evidence remains controversial concerning the effectiveness of providing support to caregivers of Alzheimer's disease (AD) patients, through case management, counseling, training, technological devices, and the integration of existing care services. Due to its epidemic spread, AD represents a significant challenge for the health care and social service systems of many developed countries. According to the estimations provided by The World Alzheimer Report [4], there were 35.6 million people living with dementia worldwide in 2010, and, according to forecasts, this figure will reach 65.7 million by 2030, and 115.4 million by 2050. The situation is further exacerbated by the fact that AD affects not only the patients, but also the family caregivers, on whom the main burden of care falls, putting them at higher risk of stress, anxiety, mortality and lower quality of life [5]. In 2009, 3% of EU-27 population cared for a relative several times a week, and the value of their care was estimated to range from 50 to 90% of the overall costs of long-term care [6]. New Information and Communication Technologies (ICT) - based services designed to enhance the home and living environments have the potential to improve the quality of life and well-being of AD patients and their caregivers, and to provide access to qualified care [7, 8]. They also generate savings which contribute to the sustainability of the care systems [9]. The use of technological devices as alternative or complementary form of support, specifically for caregivers of AD patients, remains an open research area, to which the UP-TECH project discussed in this paper aims to contribute. The UP-TECH project has been carried out as a multi-component randomized clinical trial (RCT), integrating previous evidence on the effectiveness of AD care strategies, in a comprehensive design, to reduce the burden of family caregivers of AD patients, and to maintain AD patients at home [10].

On the other hand, we evaluated the feasibility of a computerized system, named ePain Monitoring [11], among a clinically referred population of adults with mixed acute post-operative pain conditions. The system was developed to allow remote monitoring of pain, and encompasses an electronic pain diary, a web-based Personal Health Record (PHR), and a web service (WS) to take advantage of distributed computing, integration of applications and ubiquitous access [12, 13]. The paper is organized as follows: Sections 2 and 3 present the two case studies, in terms of technologies and system design. The case studies are

evaluated, and results from experimental trials discussed, in Section 4, whereas Section 5 draws the main conclusion of the work.

2 Case Study #1: The ePain Monitoring System

2.1 Background

Electronic pain diaries (EDs) have been developed as computerized versions of paper pain diaries (PDs). EDs enable patients either to report complaints close in time to the event generating pain, called Ecological Momentary Assessment (EMA), or to address retrospective pain, i.e. pain recall over some period of time. Pain is described through multiple facets [14–18], either physical (location, intensity), and emotional (depression, anxiety) ones. For this reason, the pain monitoring program may include self-monitoring of pain, adherence to prescribed medications, regular exercise, and weight control. In summary, the monitoring of chronic pain patients leads to many challenges across technology (e.g. to collect and send data), clinical settings (e.g. duration of treatment, momentary pain or recall pain), and multi-dimensional assessment (e.g. questionnaires, scales).

2.2 System Design

A ubiquitous ED based on web technologies and mobile devices has been designed encompassing a smartphone, a web service, and a Personal Health Record (PHR), as sketched in Figure 1.

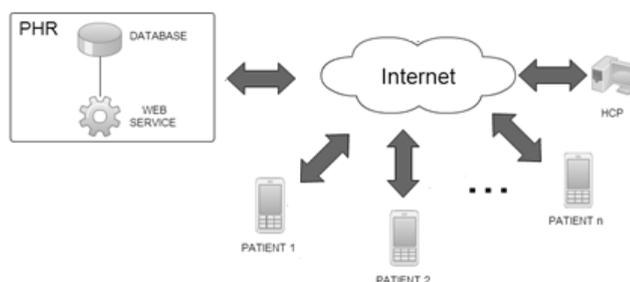


Fig. 1: ePain system architecture.

Each patient interacts with the system using a smartphone with capabilities to collect pain symptoms, communicate with the remote PHR and finally, to show alerts and advices generated by the system. The smartphone-system communications are based on a web service which offers, among others, a function to send the EMA and a function to detect if there are any updates related with the treatment protocol, in terms of medication, periodicity, or expected values.

At last, all the data are computed on a PHR and presented to the Health Care Professionals (HCP) as a structured information.

3 Case Study #2: The UP-TECH Kit

3.1 Background

Dementia represents a major burden for industrialized societies as, for example, the Dementia UK report estimates [19]. Enabling patients with dementia to live independently in their homes, is thus an imperative both from the individual and the societal point of view. However, promoting ageing in place for AD patients should not represent a strategy to shift the burden of care from the formal services to the informal caregivers, with supervision constituting the largest proportion of the caring effort. Part of the difficulties and stress related to AD caregiving might be prevented by leveraging the potentials of new ICT solutions, and by developing innovative support services for AD patients. However, the market availability of such solutions is far from optimal and there is a general consensus that ICT potential should still be fully exploited across Europe.

The UP-TECH trial was focused on the design, prototyping, and installation of an assistive technological kit (named UP-TECH kit), at each user's premise, in order to investigate the level of acceptance of assistive technologies among AD people, and also the impact of the technological facilities on caregivers. The kit is designed to unobtrusively monitor early stage AD patients, who are still able to stay at home, but need to be assisted, usually by a relative (spouse, husband, son), or a caregiver. The aim of the kit is to support caregivers in monitoring the AD patient. Following a 6-month recruitment period, 438 patient-family caregiver dyads were enrolled in the trial and randomized into one of three study arms, as detailed in the study protocol [20].

3.2 System Design

As shown in Figure 2a), each UP-TECH kit consists of a central management unit (CMU), to collect the data wireless transmitted by a set of sensors located in different positions inside the home (see Figure 2b)), and to process them. The selection of the sensors to be installed in patients' homes was based on specific AD requirements, and on a user-centered design, in order to primarily address the needs of patients and their caregivers. Among the requirements expressed by AD patients' caregivers, we can mention: i) the need to check if the monitored person leaves his/her bed during the night, and how long he/she stays out of the bed; ii) the need to check how much time the monitored person spends in the lavatory; iii) the need to check if there is water on the lavatory floor, that can increase the risk of falls; iv) the need to monitor the entrance door and the main windows to check if the patient leaves the room or the house, especially in the night hours. To such an aim, a focus group involving family caregivers (n=9) was organized, and the selected peripheral nodes to be connected to the CMU

include: a sensor to detect the presence of the subject in the bed; a sensor to detect possible flooding or liquid on the floor; a sensor to detect smoke or gas leaks; one or more magnetic sensors to detect opening/closing of a door or window; an automatic courtesy light. Sensors are commercially available devices; to provide the wireless communication link with the CMU each sensor is equipped with a proper electronic board operating in unlicensed subGHz bandwidth, with a proprietary protocol. In case of events detected by the CMU, like smoke presence, water leak, unexpected door opening, prolonged absence from bed, the control unit sends an alarm to the caregivers' mobile phone via a 3G connection. The UP-TECH kit was designed to work reliably 24 hours a day/7 days a week; the CMU was designed to be located in places not accessible to the patient, in order to avoid the risk it is removed or damaged. During the trial, the kit was installed by an expert technician with the support of a so-called study case manager [20], who also trained the caregivers on its use.

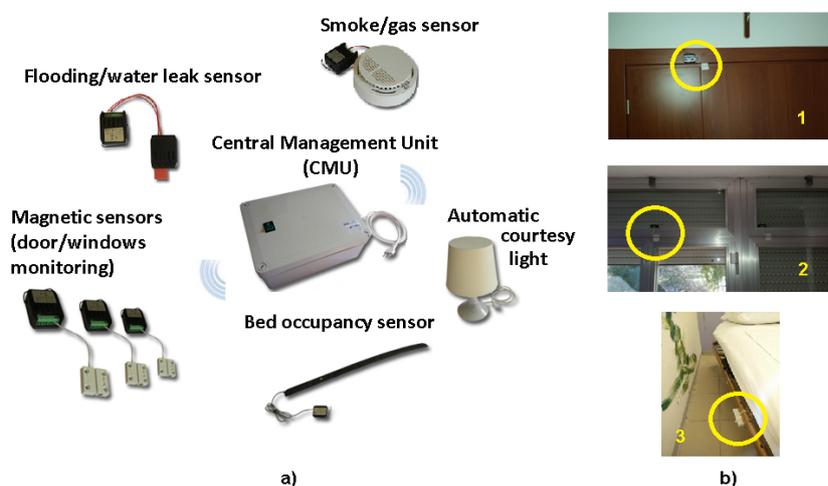


Fig. 2: The UP-TECH kit: a) CMU and sensors, b) home installation (1-2: magnetic sensors on window and door; 3: bed occupancy sensor).

4 Evaluation and Discussion

4.1 Case study #1

The proposed ePain Monitoring system was evaluated among a clinically referred population of adults with mixed acute post-operative pain conditions, in the Ambulatory Surgery Department of the Sousa Martins Hospital in Guarda, Portugal. The study included 37 adults patients submitted to surgical procedures from which a certain degree of pain is expected, or possible, during the

Table 1: Post-treatment questionnaire related to the experience on the usage of monitoring software

Questions	
Q.3.1	Do you consider that the application is easy to use?
Q.3.2	Do you consider that the training provided by the HCP was suitable?
Q.3.3	Do you consider that the application presents an attractive design?
Q.3.4	Do you consider that the terminology is clear and understandable?
Q.3.5	Do you consider that the font color and size are easy to read on screen?
Q.3.6	Do you consider that the response time of the application is fast enough?
Q.3.7	Do you consider that the alarm sound is easily audible?
Q.3.8	Do you consider that the application is suitable to access the medical indications?
Q.3.9	Do you consider that the application is suitable to improve the management of post-operative pain?
Q.3.10	Do you recommend the application?

Table 2: Post-treatment questionnaire related to the experience on the study participation

Questions	
Q.4.1	Do you consider that the information provided on this study was sufficient and enlightening?
Q.4.2	Do you consider that participating in the study was beneficial to improve your health?
Q.4.3	Do you consider that participating in the study enabled a faster access to information?
Q.4.4	Do you consider that participating in the study contributed to reduce the costs associated with treatment?

first post-operative days. Participants were recruited over a six-weeks period by the ambulatory surgery department. The protocol of the study was approved by the appropriate Ethics Committee, and the participants were enrolled after written informed consent. Participants aged from 18 to 75 years, and experienced a status I or II in the Scale of Risk of the American Society of Anaesthesiology. They had basic computer and mobile phone literacy. Of the 37 individuals assessed for eligibility, five were excluded: two had impairment that precluded using the mobile device, one was a non-Portuguese speaker, and two refused to participate arguing shortage of time. Thus, the participation rate was 86%. The final population consisted of 32 participants. All patient-reported outcome measures were obtained by asking the participant to complete a seven-point Likert scale questionnaire during hospitalization after surgical intervention, supervised by the HCP. At the end of the monitoring period each participant completed an additional questionnaire to evaluate personal adherence and experience with technology, in home based pain monitoring.

The analysis of the post-treatment questionnaires (see Tables 1, and 2) revealed a very strong correlation ($r_s = 0.844, p < 0.01$) between the adequate training provided by HCP (Q.3.2) and the easiness of use of the application (Q.3.1). The adequate training provided by HCP is strongly correlated to the suitability of the application in improving pain management (Q.3.9, $r_s = 0.675, p < 0.01$), to the positive recommendation of the application (Q.3.10, $r_s = 0.750, p < 0.01$), and to adequacy of the terminology used in the application (Q.3.4, $r_s = 0.626, p < 0.05$). Moreover, design (Q.3.5) and performance (Q.3.6) presented a very strong correlation ($r_s = 0.843, p < 0.01$). The audibility of the alarm sound (Q.3.7) is strongly correlated to the suitability of the application both to provide medical information (Q.3.8, $r_s = 0.667, p < 0.01$), and to improve pain management (Q.3.9, $r_s = 0.695, p < 0.01$), together with the recommendation of the application ($r_s = 0.666, p < 0.01$). In addition, this topic is strongly correlated with the suitability of the application to improve pain management ($r_s = 0.688, p < 0.01$), and very strongly correlated to design (Q.3.3, $r_s = 0.751, p < 0.01$) and use of terminology (Q.3.4, $r_s = 0.857, p < 0.01$).

In summary, this study proved that the system tested, which combines a web-based PHR and mobile devices is feasible, and the majority of participants recommend the system and recognize that it is appropriate for pain management, it is user-friendly, and does not require advanced skills nor experienced users. Another strength of the study was to provide the evaluation of a purely mobile and web-based, no-contact intervention, to be used in the context of routine care. Such a no-contact intervention holds the advantage of being broadly available, which may be critical in order to provide access to healthcare to a large number of patients. The pain monitoring system could have major implications if accessed more widely, so as to enhance the potential societal benefits in terms of pain management and well-being [21]. Furthermore, the inclusion of PHR in the monitoring system enabled a reliable message delivery, required for emergency messages in a fully automated fashion, and scalable to support as many patients as possible, being on-line persistent data available to patient and HCP.

The PHR revealed its suitability to pain monitoring, providing ubiquitous and real-time access to patient's data, and it allowed an effortless definition and management of patient-oriented treatment rules, with minimal intervention from the therapist. The guidance of HCP at the beginning of the monitoring is crucial to patients' satisfaction, and experience stemming from the usage of the system, as evidenced by the high correlation between the recommendation of the application usage, and its suitability to improve pain management and to provide medical information. The absence of detected and reported errors related either to the application or to the PHR, suggest that the proposed system is stable and reliable.

4.2 Case study #2

A structured questionnaire was administered to patients and family caregivers at baseline, and at 2 follow-ups by trained research nurses. Patients' functional

status was measured by assessing Activity of Daily Living (ADL) and Instrumental ADL (IADL) capacity using, respectively, the ADL Hierarchy Scale, and the IADL Involvement Scale. ADL dependency was then summarized using the ADL Hierarchy Scale ranging from 0 (no impairment) to 6 (total dependence). The IADL Involvement Scale was also computed, which is based on seven IADL-related items, that are summed to generate an index that ranges from 0 to 48, with higher scores indicating greater dependency.

In the framework of the study, some specific items were also evaluated, such as: (1) if the patient suffered from behavioral disturbances; (2) the formal education level of the caregiver. The education level was categorized as: no title/low (primary school, or up to 5 years of formal education completed); intermediate (6-8 years); high (9-14 years); very high (university degree or higher, >15 years). During the deployment period, an ad-hoc designed form was used to keep a record of the caregivers that refused to have the kit installed, and the related motivations. All the data regarding the kit, collected during this phase, were merged with the clinical trial databases containing all the information collected by the research nurses, in order to assess the clinical outcomes of the RCT.

Descriptive statistics were used to evaluate differences between those accepting and those refusing the technological intervention. A two-tailed p -value of 0.05 was considered significant for all analyses. Out of the 144 dyads entitled to receive the technological intervention, 39 dyads (27.1%) refused the kit, while 23 dyads (16%) left the trial for different reasons (deceased, withdrew, institutionalized). Overall, the technology was installed in the homes of only 82 dyads (56.9%). The acceptance of technology was higher among those dyads who had the support of a non-cohabiting private caregiver (63.6%), and among those dyads where the patient (60.3%), or the primary caregiver (64.3%), were male.

An increased ADL dependency was strongly correlated ($p=0.003$) with non-acceptance of technology, either due to refusals or trial drop-outs. Younger patients were also more likely to accept the AAL solution (borderline statistical significance, $p=0.089$), as well as those receiving more hours of informal care from their caregivers, although the difference in this case was not statistically significant, due to high standard deviations.

5 Conclusion

The UP-TECH project aimed at providing a possible response to one of the effects of the AD epidemic, i.e. the impact on the quality of life of family caregivers and the related consequences. This target was addressed by focusing on the effectiveness of simple marketed technological devices combined with case management, and user-centered strategies. The outcomes of the project demonstrated that it is possible to design and deploy technologies that can help AD patients' caregivers, and they are intended to support both health care and social service professionals, and policy-makers, in addressing the increasing needs of AD patients and their caregivers, through ICT.

Similarly, the presented study proved that the ePain Monitoring system tested, which combines a web-based PHR and mobile devices, is feasible; patients are compliant to it, and considered its usage as user-friendly. The majority of the participants recommended the system and recognized that it is appropriate for pain management, being user-friendly, as it does not require advanced skills nor experienced users. Another strength of the study was to evaluate a purely mobile and web-based, no-contact intervention, for use in the context of routine care. Such a no-contact intervention holds the advantage of being broadly available, thus being critical to provide access to pain care to a large number of patients. The pain monitoring system could have major implications if accessed more widely, so as to enhance the potential societal benefits in terms of pain management and well-being [21]. Furthermore, the guidance of HCP at the beginning of the monitoring emerged as crucial to patients' satisfaction, as evidenced by the high correlation between the recommendation of the application, and its suitability to improve pain management and to provide medical information.

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