The use of information and communication technologies (ICT) for the assessment of patients with Alzheimer's disease and related disorders

KNOWLEDGE VALORIZATION

The goal of this valorisation chapter is to describe how the knowledge resulting from the research in this dissertation can be made valuable for clinical and social use. This dissertation investigated the use of Information and Communication Technologies (ICT) for the assessment of patients with Alzheimer's disease (AD) and related disorders.

Societal Relevance

With the prevalence of aging population the risk for cognitive impairment leading to dementia is increasing many folds. The health systems are struggling to live up to the challenge of effective care delivery and management of dementia primarily due to the support cost and the absence of a disease modifying treatment. The number of people living with dementia in 2011 was estimated in 35.6 million, and is expected to nearly double every 20 years, to 65.7 million in 2030 and115.4 million in 2050. For these reasons, early detection, treatment and management of dementia are now considered as a research priority. There is a pressing need for innovative research that will enhance quality care for people with dementia, decrease caregiver burden and reduce care costs. Some key challenges in dementia care are to assist the person to maintain its mobility and stimulate physical exercise as well as sustain communication and connection to family, caregivers and the environment through a personalized and customizable program. All these challenges require beforehand to be able to monitor and evaluate precisely and accurately the patient's behavior and symptoms remotely and continuously.

Currently, the inadequacy of existing methods combined with biased evaluations, points to a need for objective and systematic assessment tools and researchers aim to provide novel solutions. Clinical expertise and literature review indicates that ICT are not yet able to provide a direct diagnosis of AD and related disorders, but can supply additional

information for the assessment of specific domains (behavior, cognition, activity of daily living). This information can contribute with other clinical and biological data to earlier diagnosis of AD and related disorders. Several studies using ICT in the assessment of different domains show potential benefits of using ICT in clinical practice. It could help identifying earlier individuals that are more likely to develop dementia, clinicians can provide earlier timely care, treatment (pharmacological as non-pharmacological) and support, which will in turn reduce health care costs. Namely, drug research focuses at the moment to target patients at the very early stages of the disease when memory functions are still preserved. This means that the use of ICT could have a direct beneficial effect on the selection of people for the enrolment in clinical trials in the broader population, leading ultimately to a reduction of the total burden for society.

As soon as evaluation tools are available the results should be connected to assessment tools that will determine if the patient requires an assistance system that can provide help and coaching in a personalized way. ICT may be a solution in addressing these challenges by first providing evaluation and monitoring tools, with more objective and more frequent measurements that furthermore can be obtained in almost all contexts. Especially the use of assistance devices in the care of people with dementia may combine the assessment and the assistance dimensions and offers intriguing possibilities to address some of the care needs.

Target Audience

The results of the present thesis are relevant to various stakeholders who are involved in dealing with dementia and related disorders as well as its consequences.
First, the outcome of the different studies are of high interest for clinicians working in memory clinics since we tried to demonstrate the additional value of ICT use in clinical practice for routine assessments

and this without increasing necessarily workload. The automatically detected events may serve as clinical decision support for diagnosis and could even further guide the appropriate selection of intervention. Patient's behavioral, cognitive and functional status can be assessed objectively without the presence of the typical observer's biases. The results of this thesis will aid clinicians improving the accuracy of diagnosis and thus, prognosis by increasing knowledge about early indicators of developing progressing towards dementia pathology. As a result, they can better inform patients and their families about risks and what specific actions need to be taken.

Products

The main product of this thesis is the proposal of novel solutions for the holistic management of dementia that exploit both medical knowledge and the latest advances in ICT. Specifically, multi-parametric remote monitoring and individual-tailored analysis of physiological, behavioral and lifestyle sensor-based measurements have, throughout the project 'Dem@care', shown to be obtainable, and on a long term will be integrated in a complete remote care system. This will include a loop for people with dementia and their informal caregivers that: a) monitors and assesses their health status by integrating a multiplicity of body, wearable and static sensors, b) enables time evolving context-sensitive profiling to support reactive and proactive care, c) provides personalised supportive feedback. Furthermore, a professional loop that: a) provides objective observations regarding the health progression of the person with dementia and medication effectiveness, b) warns professionals about unfavourable trends, c) supports preventive care decision making and updating of care plans for the person with dementia.

To meet these goals, the project capitalised upon continuous advances in pervasive computing and sensor technologies to power a multi-parametric monitoring framework that will sustain context-aware, personalised and adaptive feedback mechanisms for the remote

management of people with dementia. The studies performed for this thesis validated mainly the interest of using such a system in dementia care, thus underlining the importance of exploiting and even commercializing the project's outcome. To allow for the comprehensive assessment of a person's condition and enable the early identification of alarming and potentially hazardous behaviour patterns, as well as prolong independent living for patient who are still at early stages of the disease. Through the combination of the multisensorial processing technologies and advanced knowledge and reasoning methodologies the results of this thesis provide a uniquely comprehensive and personalised solution for dealing with issues related to dementia also outside a hospital. This is expected to have very positive repercussions on a personal level for the person with dementia, on a societal level for medical professionals and informal caregivers, but also on an economic and technological level. Notably, being confronted with an ageing population, and the ensuing socio-economic costs that it entails, Europe's health system has been forced to undergo radical changes, strongly promoting more preventative care, and directing efforts to provide treatment and care at home rather than in the hospital. In line with this shift, a holistic, integrated solution is proposed, taking into consideration medical, behavioral and cognitive aspects, to allow people with dementia to retain their current standing in society, avoiding unnecessary hospitalization, significantly reducing the cost on the health system, and the burdens on their caregivers and themselves.

Innovation

The different studies performed for this thesis, were highly innovative and among the first ones that tried to demonstrate the use of ICT-based tools for clinical assessment purposes of dementia patients. The aim was to validate the sensor measurements by associations with classical assessment instruments and accordingly promote a holistic solution for the remote management of people with dementia. Advantage was taken of recent progress in multi-sensor technologies, knowledge and reasoning

methodologies, while placing emphasis on proactive and personalised management of wellness and independent living, rather than the mere reactive management of dementia related symptoms. From the early beginning on of the project, patients were involved in the co-design process of the multiple sensor-based system.

Physiological sensors were deployed to provide measurements that are pertinent to chronic health issues related with dementia, and to activity characteristics that can be indicative of its progression, augmenting the data currently used to evaluate a person‘s condition.

Audio sensing for cognitive state detection were investigated, focusing on the investigation of new lines of research with regards to the correlation between vocal characteristics and stages of dementia. Speaker identification and audio segmentation strategies were improved, to deal with the challenging problem of recognizing the voice of the person of interest in the presence of background noise or in the midst of other speakers.

Several advances in challenging problems in visual sensing were made to serve the goals and purposes of the Dem@Care system. Video data collected from wearable and static sensors were calibrated and fused to take advantage of their complementary nature. This lead to improved daily activity recognition performance, thanks to additional localisation information that provides context to the other camera data. Person detection and tracking methods were developed that make use of contextual scene information for accurate person localisation and tracking.
A comprehensive view of the patient’s lifestyle, behavioral patterns and daily activities was studied for accurate diagnosis, and for correlating observed behaviours with the different stages of dementia. This will significantly advance the typical clinical workflow for dealing with dementia, which currently involves very subjective and incomplete means of recording, such as questionnaires and diaries.

Valorization process

Generally, in order to exploit our findings for clinical practice, and integrate ICT measurements into large clinical cohort trials, some research still has to be done. The first step is validation of the use of such technologies in larger cohorts to demonstrate clinical meaningfulness and thus, receive recognition in the clinical scientific and medical world. This could eventually lead to a change of attitude in general practitioners and research investigators towards more willingness for using ICT in routine assessment procedures.
Moreover, the 'de-mystification' of ICT usage by showing that it is actually easy and simple to use, could facilitate its gradual integration in the users work routine and increase acceptability.

On the technological side, work needs to be done on system development and sensor integration. The goal is for these to work in concert with each other to allow a reliable and complete assessment of a patient by merging information coming from different sensors into easily understandable feedback. The immediate and accurate visualization of the recorded data is of great importance in order to facilitate an easy use in clinical practice and allow support for feedback to patients and their caregivers. Another challenge represents the fusion of data coming from different sensors for meaningful automatized interpretation of detected behaviors for a more complete assessment of a patient's cognitive and functional status as well as the storage and transfer of big data.

Reliability of these ICTs is hard to achieve. Several initiatives have been organized to establish recommendations for ICT use in AD, as also being described in the present thesis. Some clinical studies on long duration have shown the difficulties in identifying strong benefits of using ICTs for people with AD. More efforts in performance and evaluation of ICTs are needed to help industry meet user needs and researchers (in particular pharmaceutical) in considering the available

technologies for clinical trials. A solid economic model is a major issue: who will pay for assistive technology? Who will install and maintain ICTs at AD patients' homes? The cost–effectiveness balance for assistive technology remains an important matter of debate.
We do have to ask the question, why many projects like Dem@care seem to develop sensor-based systems for assessment and monitoring of patients but remain 'stand alone models?' This means that these types of systems are rarely being released on the market or commercialized and successfully integrated and applied in clinical practice or clinical trials. What are the major barriers to scaling such systems? It may be the associated costs, the required effort, fear of replacing somebody's work with a machine, the lack of confidence in the technology itself. In the future, these potential explanations should be further investigated in order to meet better the user's needs and overcome these obstacles.

Nevertheless, the present thesis represent a first step in a new direction by showing the potential benefits and promises of ICT use in a clinical context and therefore its utility to help maintain or even improve the current quality of care for people with dementia.