

iCarer: AAL for the Informal Carers of the Elderly

P.A. MORENO^a, J.L. GARCIA-PACHECO^{b,1}, J. CHARVILL^c, A. LOFTI^d, C. LANGENSIEPEN^d, A. SAUNDERS^e, K. BERCKMANS^f, J. GASPERSIC^g, L. WALTON^h, M. CARMONA^b, S. PEREZ DE LA CAMARA^b, R. SANCHEZ-DE-MADARIAGA^b, J. POZO^b, A. MUÑOZ^b, M. PASCUAL^b, E.J. GOMEZ^a

^a*Grupo de Bioingeniería y Telemedicina, ETSI de Telecomunicación, Universidad Politécnica de Madrid, Madrid, Spain*

^b*Telemedicine and eHealth Unit, Instituto de Salud Carlos III (ISCIII), Madrid, Spain*

^c*Tunstall Healthcare Group, Whitley, Yorkshire, U.K.*

^d*School of Science and Technology, Nottingham Trent University, Nottingham, U.K.*

^e*S3 Group, Dublin, Ireland*

^f*Pyxima, Tessenderlo, Belgium*

^g*Slovene Federation of Pensioners' Associations, Ljubljana, Slovenia*

^h*Telecare Service, Nottingham City Council, Nottingham, U.K.*

Abstract. In the context of the long-term care for older adults, informal carers play a key role. Daily competing priorities or a care-skills deficit may lead them to stress, anxiety and/or depression. The iCarer project (AAL-2012-5-239) proposes the design and implementation of a cloud-inspired personalised and adaptive platform which will offer support to informal carers of older adults with cognitive impairment. By means of a holistic approach comprising technologies and services addressing the intelligent and interactive monitoring of activities, knowledge management for personalised guidance and orientation, virtual interaction, e-learning, care coordination facilities and social network services, iCarer aims to reduce the informal carer stress and to enhance the quality of care they provide, thus improving their quality of life. The iCarer platform will be evaluated through a multi-centre non-controlled study (4 months; 48 homes located in England and in Slovenia). Currently the iCarer project is completing the development work. The evaluation trial is expected to start in August 2015.

Keywords. Stress Psychological, Quality of Life, Caregivers, Aged, Activities of Daily Living, Pattern Recognition Automated

Introduction

In the context of long-term care [1], older adults in need of care prefer to stay in their homes rather than be institutionalised. They also prefer to receive that care from informal or family carers rather than from formal carers. As a result, family carers provide 80% of the long-term care needed by their elderly dependent. Concurrently, informal carers may be dealing with stress, anxiety and/or depression brought about by skills deficits around supporting the cared for with activities of daily living, etc.

¹ Corresponding Author: jpacheco@coit.es

The iCarer project [2] proposes the design and implementation of a cloud-inspired personalised and adaptive platform which will offer support to informal carers (IC) of older adults (OA) with cognitive impairment to reduce the stress they suffer and to enhance the quality of care they provide, thus improving their quality of life.

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1. Methods

1.1. User needs elicitation

The following methodology has been retained in order to elicit the user needs:

- capture of user needs within the end-user organizations (via brainstorming)
- elaboration of an "informal caregiver interview questionnaire" to gather information about topics such as the care tasks that the IC is performing; the care burden faced by the IC (using questions from the Zarit scale [3]); the IC current care skills and their technology acceptance to improve them; etc.
- subsequent interviews of about 20 ICs in Slovenia and in England
- extraction of end-user needs; combination of the lists of needs issued from the former processes; review considering their impact (reduction of burden, improvement of care), and their feasibility within iCarer; prioritisation

Finally, each end-user need is broken down as a hierarchical view of the support required, thus producing a list of functional requirements.

1.2. Platform services

The iCarer platform will be composed of a suite of modules which provide the different services to support the IC: intelligent monitoring (monitoring environment at home and inference of behavioural patterns of both IC and OA), guidance and orientation (knowledge management system responsible for deciding appropriate recommendations to the IC depending on their needs, or whether a notification is suitable in case of a potential problem when the OA is alone at home), virtual carer (service aiming to automate aspects of the care process reducing the burden, and to provide support to the OA when they are alone at home), e-learning (multimedia contents to improve the quality of the provided care), support to the communication with other caregivers (community forum) and care coordination for ICs and OAs.

The platform will monitor aspects of the IC's condition related to burden and stress and their performance of "activities of daily care" (ADC). Behavioural patterns will be inferred and analysed to detect early signs of a carer's distress. As a result, they will be offered personalised guidance via the e-learning service tailored to improve the performance of those difficult activities. Additionally, when the IC is away from or geographically remote from the OA, the iCarer platform will monitor the OA's activities of daily living (ADL), identifying difficulties and providing them with appropriate guidance, whilst also notifying the IC. Finally, iCarer will feature an IC learning network, as well as coordination support between formal and informal carers.

1.3. Evaluation trial

The iCarer platform evaluation will be carried out through a multi-centre non-controlled study (4 months; a total of 48 homes in England and in Slovenia). The evaluation will involve the study of several variables through standardised questionnaires at the beginning and at the end of the trial. The main variable is the *informal caregiver burden* (measured using the Zarit scale).

2. Results

A set of 13 prioritised user needs has been extracted, leading to the specification of more than 60 functional requirements. The subjects of the multimedia contents have not been considered in their definition as no influence in the functionalities has been detected. A methodology for the final experimental study is available and the process for obtaining the ethical approvals in Slovenia and England has been started.

Currently the project is carrying out the development of the services. The contents catalogue creation is expected to start next. The trials are expected to start in Aug. 2015.

3. Discussion

Some ICT solutions [4, 5] allow the ICs to share experiences through social networks to reduce their distress and loneliness, but they do not provide the ICs with personalised support to cope efficiently with the care burden. In contrast, iCarer, together with a connected care experience letting the ICs share information about the care activities, address the support of the IC's ADC performance and the OA's ADL through a holistic approach combining monitoring services with information management resources, e-learning and coordination tools providing caregivers with the necessary knowledge about OA care and aiming to reduce their burden and stress levels.

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