An Informal Carer Hub to support carers looking after COPD patients in UK and Netherlands

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Abstract. In the UK, about 3 million people live with Chronic Obstructive Pulmonary Disease (COPD). Informal carers such as family and friends play a vital role in promoting well-being among older adults suffering from COPD. However, difficulties experienced by caregivers are increasing and affecting their quality of life. New technologies and innovations such as m-health have the potential in reducing the burden of these carers. In this paper, we propose an Informal Carer Hub (ICH), which is part of the WELCOME EU project to help informal carers better manage COPD patients in 2 European countries: The United Kingdom and The Netherlands. The acceptability of the system has been tested by making use of a modified version of the Technology Acceptance Model (TAM 3). The aim of this study was to ensure that the proposed informal carer application is easy to learn, effective to use and acceptable from the informal carers' perspectives.

Keywords: COPD, Informal Carer, M-Health, WELCOME, TAM

1 Introduction

Informal carers such as family and friends play a vital role in the care pathway of patients who suffer from Chronic Obstructive Pulmonary Disease (COPD). By 2020, COPD will be the third cause of mortality worldwide (Cavailles *et al.*, 2013). Informal caregiving can be defined as 'the act of providing assistance to an individual with whom the caregiver has a personal relationship'(Kasuya RT, Polgar-Bailey P, 2014). They provide necessary and cost-effective care for COPD patients. Informal carers are the largest source of social care and support in the UK; there are about 6.4 million informal carers supporting people of all ages (Nesta, 2014). The roles of informal carers in the care pathway of COPD patients vary from monitoring breathlessness, lifestyle of patients and helping with personal hygiene. COPD in the elderly may be complicated by the presence of several comorbidities such as coronary heart disease, heart failure and lung cancer which lead to an increase in the responsibilities of these carers and make the management of COPD difficult.

Different studies carried out in the United States and European countries showed that patients add objective and subjective burden to carers' everyday tasks (Kasuya RT, Polgar-Bailey P, 2014). It was found out that carers had a lack of practical, accessible, timely information to support COPD patients (Washington *et al.*, 2011). One in five carers has to leave their jobs because they are unable to cope with both working and caring (Nesta, 2014). Exacerbations of COPD are responsible for a high number of the annual hospital admissions (Utens *et al.*, 2014). The cost of hospitalisation due to exacerbations is significant and would have been much more without the support of informal carers who provide their help in terms of physical and psychosocial support. (Simpson *et al.*, 2010).

Many well-rated COPD management mobile applications can currently be found on the mobile market to support patients, for example, "MyCOPDTeam" and the "NHS Resp Assist" applications are both helpful to patients and have been highly rated. However, to date, very few mobile applications have been specifically designed to support informal carers coping with COPD patients. Proposed systems such as the CaMeli (AAL, 2016) and the Saliig++ (Boman, Persson and Bartfai, 2016) projects both provide a communication channel for informal carers to help elderly patients and patients who suffer from cognitive impairment in their day to day activities. They both make use of distributed network of interconnected tablet devices, with integrated video cameras and other Ambient Assisted Living (AAL) Technologies. However, they do not specifically focus on the needs of informal carers dealing with elderly COPD patients with comorbidities.

The WELCOME EU project (Wearable Sensing and Smart Cloud Computing for Integrated Care to COPD Patients with Comorbidities) (Chouvarda *et al.*, 2014) aims at providing an integrated care system in 5 EU countries to support patients, healthcare professionals and informal carers. In this paper, we focus on the Informal Carer Hub (ICH) prototype which has been designed to provide informal carers with the necessary information and other needs to better manage their loved ones remotely. The proposed system allows health care providers to customise the ICH according to different care, oraganisational needs, patients and informal carers' preferences. The evaluation of the ICH prototype has been carried out in the UK and Netherlands so far.

2   Methods

In order to understand what are the needs of informal carers who cater for COPD patients, a user requirements analysis was performed in our previous study (Nabhani-gebara *et al.*, 2014). The literature and the interviews carried out in 5 EU countries gave an insight to design the ICH prototype which would address the needs of carers in different countries.

2.1 Ethical Approval

Ethical approval has been obtained from CIRO (Netherlands), Croydon University Hospital (UK) and Kingston University (UK) in the month of September and December 2015 respectively. 12 informal carers in total have been recruited for the usability and acceptance of the prototype. Informal carers who participated were mainly husbands, wives, daughters or any other family member of a patient suffering from COPD with or without comorbidities.

2.2 System's Architecture and Design

According to the user requirements and the literature, there is a mixed view on the different functionalities that the ICH should provide due to privacy issues. Thus, for the design of the system, some of the functional requirements identified have been made optional and the informal carer hub was individualised according to patients' and informal carers' preferences upon registration to the system. The application is fully web based, making it accessible on iOS and Android tablets.

Figure 1 shows the overall architecture. AngularJS has been chosen to develop the platform as it is being used to implement modern web applications and has got features to improve the development experience. It is supported by Google and follows the Model-View-Controller (MVC) pattern (Ramos *et al.*, 2016). It forces modularisation of code and allows developers to manage dependencies hence increasing testability.
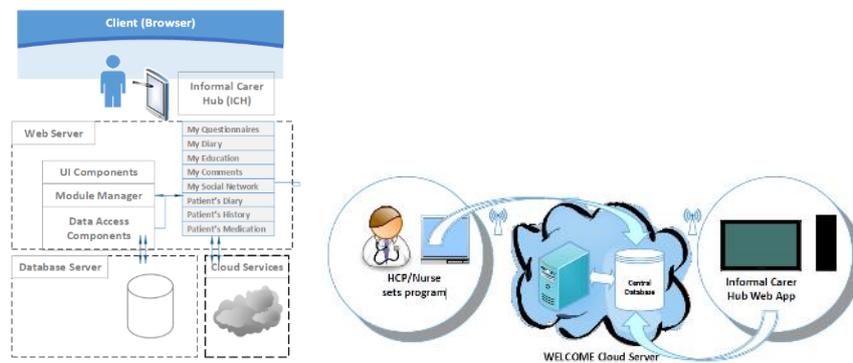

Figure 1: ICH Architecture

The informal carer hub has been designed to allow carers to follow up appointments of their loved ones, remind them to take their medications, view their patient's diary as well as their own diary, contact their registered healthcare professional and get access to educational material based on patients' comorbidities so that they can help them better manage their COPD. They will also receive different questionnaires

(e.g. Hospital Anxiety and Depression Questionnaire) from health care professionals to follow up on their own quality of life to make sure they are getting enough support via the integrated care system.
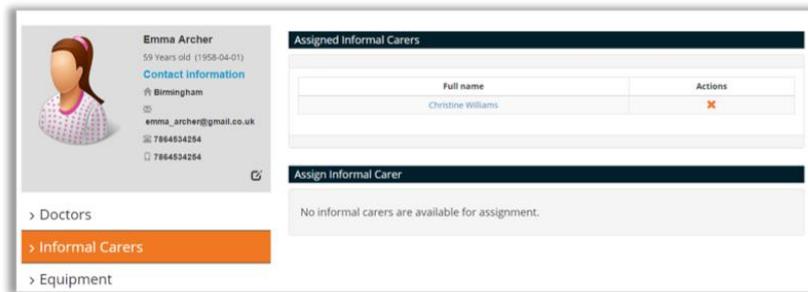
Figure 2: HCP application used to assign an informal carer Christine Williams for patient Emma Archer

The informal carer application is modular and customisable per users' needs and also allow patients to decide which modules to allow informal carers to get access to due to privacy issues.

3 Evaluation and Results

The protocol used in the usability study with the 12 informal carers recruited is similar to the approach used in the usability study carried out with patients in our previous study (Sobnath *et al.*, 2016). Informal carers were first given a short questionnaire regarding their everyday use with mobile technologies such as tablets, mobile phones, WIFI, etc. A brief explanation of the functionalities of the informal carer application and the aims of the system were presented to them.

Table 1: Description of evaluation method for informal carers

Steps	Description
1	Filling up of mobile technology questionnaire for informal carers
2	Providing participants with tablet preloaded with ICH application
3	Providing participants with 4-5 usability tasks on the ICH application
4	During the execution of the tasks, video recording has been used to save user's interactions with the system. The time taken to complete the tasks was also noted down.
5	Observation about any difficulties encountered was written down.

6	Providing the participants with 2-3 questionnaires to fill regarding ease of use, design, user experience and acceptance after completion of tasks.
7	Analysis of results

On top of the usability studies, the acceptance of the proposed integrated care system needed to be evaluated by informal carers by applying the Technology Acceptance Model (Venkatesh, 2008). All the data collected were transcribed and analysed with SPSS. The results are described in the next section of this paper.

3.1 Post-study system usability questionnaire (PSSUQ)

The PSSUQ, an instrument designed by IBM, has been used to assess users' perceived satisfaction with the application measuring 1) System Usefulness, 2) Information Quality and 3) Interface Quality. It uses a 7 scale Likert system where statements were designed so that low number indicates a high usability satisfaction with the system. A modified version of the PSSUQ questionnaire has been used which consists of 16 items. The table below shows the results obtained from 12 informal carers in the UK and the Netherlands.

Despite the small sample size, where the usual parametric statistical tests may not interpret the outcomes accurately, a simple t-test has been performed to obtain an overall impression of the numeric data. The t-tests have been performed to compare the mean scores of the two different groups (UK and Netherlands).

Table 2: PSSUQ results for informal carers in UK and The Netherlands

| Question Item (PSSUQ)	Country (Mean Score)		
	UK	Netherlands	p-value
Overall Satisfaction	1.82	2.43	0.52
System Usefulness	1.60	2.36	0.49
Information Quality	2.10	2.78	0.79
Interface Quality	1.71	2.08	0.38

As can be shown in Table 2, the p-value ranges from 0.38-0.79 confirming that the results between the 2 groups (UK and Netherlands) do not have any significant differences. Informal carers in both countries can use the innovative application in their daily life with a good level of overall satisfaction, system usefulness, information and interface quality with a score ranging between 1.6 and 2.78 out of 7 where a lower number indicates high usability.

3.2 Technology Acceptance Model 3 (TAM 3)

According to the validated TAM theory, participants' intention to use the technology determines the actual use of the informal carer application and attitudes towards

technology affect the intention to use it (Venkatesh, 2008). The most common factors that affect the adoption of an IT system are Perceived Ease Of Use (PEOU) and Perceived Usefulness (Alharbi and Drew, 2014). A modified version of the TAM 3 questionnaire was used and the tool was found to have a high overall reliability of 0.858. PU is defined in this context as "The degree to which an informal carer believes that using the proposed informal carer application will enhance his task as a carer". PEOU is defined here as "The degree to which an informal carer believes that using the support tool is free from physical and mental effort". The Behavioural Intention to use the application (BI) was hypothesised as the main predictor of actual usage behaviour. 8 out of 12 participants successfully completed the questionnaire.

The relationships between PEOU, PU, BI and other factors, as seen in Figure **3** regarding the acceptability and use of the informal carer application, is hypothesised based on the TAM 3 model.
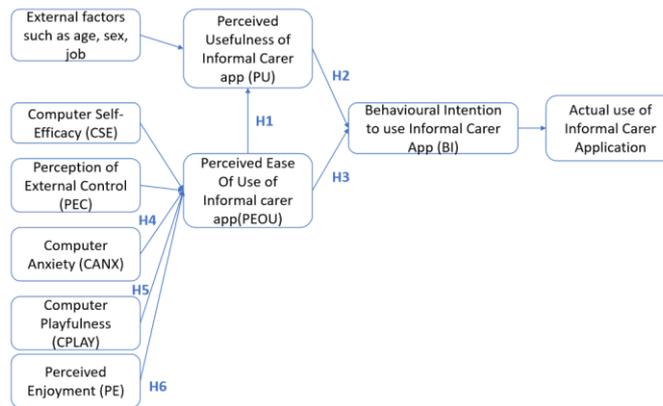
Figure 3: Applying TAM model to see acceptance of Informal Carer Application

The above hypotheses (H1-H6) have been tested by finding the Pearson correlation coefficient (r) and by running the two-tailed test significance (p). The hypotheses have been tested to obtain an overall impression of the numeric data.

H1: Perceived ease of use (PEOU) positively affects perceived usefulness (PU) of the informal carer application. The hypothesis was confirmed since there is a significant correlation (p=0.02) between PU and PEOU with a value of r= 0.775 for the Pearson's correlation. Perceived ease of use (PEOU) positively affects perceived usefulness (PU) of the informal carer application.

H2: Perceived usefulness (PU) positively affects behavioural intention (BI) to use the informal carer application. Hypothesis 2 was not supported by the model since

p=0.134 (p>0.05). Perceived usefulness (PU) did not necessarily affect positively the behavioural intention (BI) to use the informal carer application.

H3: Perceived ease of use (PEOU) positively affects behavioural intention (BI) to use the informal carer application. H3 was well supported by the model. It could be concluded that perceived ease of use (PEOU) positively affects behavioural intention (BI) to use the informal carer application with a p-value less than 0.05 and a high correlation of 0.745.

H4: Perceived ease of use (PEOU) is higher when there is less anxiety (CANX) in using information technologies. This is partially supported by the negative r-value obtained meaning that the less anxious you are, the higher is the perceived ease of use. However, since the p-value is more than 0.05, there is not enough significant evidence to come to a conclusion.

H5 and H6: Perceived ease of use (PEOU) increases with an increase in computer playfulness and perceived enjoyment. Both hypotheses are supported by the model with a p-value of less than 0.05 and high correlation in both cases. Therefore, we can conclude that perceived ease of use increases with an increase in computer playfulness (CPLAY) and perceived enjoyment (PE).

Results show that most hypotheses were supported by the model therefore informal carers could potentially use the proposed platform as a support tool to monitor their loved ones.

4   Conclusion

To date, no mobile applications for supporting informal carers dealing with COPD patients have been found on the mobile markets. Informal carers in both countries can use the innovative application in their daily life with a good level of overall satisfaction, system usefulness, information and interface quality as shown by the PSSUQ results. The study showed that 4 out of the 6 hypotheses were statistically proven which means that most of the results were supported by the model. Since the number of informal carers recruited were only 12, all hypotheses could not be proven due to limited resources. Informal carers who met the eligibility criteria were hard to find especially in the Netherlands since patients often visit the hospital on their own. However, the model shows that if there is an increase in PEOU and PU, then there will be a high probability that informal carers will use the system in the future. The study shows that informal carers have a high behavioural intention of using the proposed application.

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