Preliminary evaluation of a self-management health app by people with cognitive impairment

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***Abstract*— Cognitive impairment is associated with increased risk of disability, increased health care costs and potential progression to dementia. An emerging approach to counteract the impact of cognitive impairment is to empower patients with the appropriate tools to effectively manage their own condition. In this work we evaluate the use of KeepWell, a self-management smartphone application developed to assist people with early cognitive impairment to live independently. KeepWell provides services such as reminders, surveys, and educational information that allows users to set physical goals and monitor their physical performance. Participants involved in the evaluation of adoption and usability consisted of individuals diagnosed with early cognitive impairment. A qualitative and quantitative analysis was conducted with 5 and 2 such individuals respectively. Data was codified using grounded theory and affinity diagramming. The findings from the work have resulted in the development of a set of recommendations for the design of self-management mobile applications.**

Keywords—KeepWell, evaluation, self-management, cognitive impairment.

I. INTRODUCTION

Increased life expectancy exposes ageing adults to the risk of developing chronic illnesses [1]. The ageing of the population demands important changes in the delivery of health services, among them the need for individuals to be more proactive in their own care. This has fueled an interest in the use of technology to assist in self-management [2], [3]. In this respect, studies have been conducted to assess the use of technology in the management of chronic conditions such as Chronic Obstructive Pulmonary Disease (COPD), stroke, and early stage dementia [4]–[10]. Nevertheless, the solutions which have been developed are, in most cases, condition specific [11], and not easily adapted for supporting the self-management of multiple chronic conditions.

This paper presents the evaluation of KeepWell, a self-management application developed under the auspices of the Invest Northern Ireland funded Self-Management Project (RD0513844) that aims to create a generic and readily extensible platform to assist individuals suffering from chronic conditions [12]. The evaluation conducted in this study targeted clinically diagnosed patients with an early stage of cognitive impairment. The adoption and usability of KeepWell has been evaluated by a cohort of ageing adults as part of a seven-days intervention.

The remainder of this paper is structured as follows. Section 2 describes related work, state of the art, and limitations of current solutions. KeepWell is presented in Section 3. The methodology of the evaluation of the current work is presented in Section 4. Section 5 provides a description of results. Conclusions are drawn in Section 6.

II. RELATED WORK

Recent years have witnessed an increased amount of interest in self-management technology solutions for chronic health conditions [2], [3]. A self-management solution for people with early stage dementia was reported by F. Martin *et al.,* [4]. The solution targeted different areas of interventions such as maintenance of an active lifestyle, psychological well-being while providing information about dementia provided with tips and strategies to cope with memory changes. Similarly, Heijden *et al.*, presented a framework for self-management of COPD patients supporting functionalities for symptoms monitoring and incorporating treatment advices [5]. Farmer *et al.,* proposed an approach to provide patients with educational materials in the form of text and videos, together with a symptoms diary in which patients could self-report information on occurrence of symptoms and general well-being information [6]. Tabak *et al.*, experimented with the use of a web portal for self-management of COPD supporting teleconsultation between patients and their therapist [7]. Similar web-based approaches have been proposed

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for managing physical disabilities in post-stroke patients [9], [10]. An educational content framework has also been developed to deliver information on exercises and functional skill training by means of a smartphone app [9]. H. Eyles *et al.*, introduced a smartphone app for people affected by cardiovascular diseases [8]. The app allows the user to scan the barcode of packaged food in order to monitor sodium intake.

Although, these systems have been developed for different purposes, and were targeting different morbidities, they share some core functionalities common to any self-management system. Among these: the ability to monitor symptoms through self-reporting, the delivery of educational material to provide useful information to patients, goal setting functionalities related to physical and psychological wellbeing. Nevertheless, proposed approaches to self-management have typically been condition specific [11]. Ageing adults, however, often face polymorbidity, that is, they suffer from multiple chronic conditions [1], [2], yet there has been limited work undertaken in the development of solutions which can address a range of chronic conditions. One example is Patterson *et al.*, who proposed a generic and extensible self-management platform incorporating common basic functionalities for self-management of a number of long term chronic conditions [11]. A generic self-management solution (compared to a bespoke solution for each condition) can help to reduce the cost associated with the design and development phase facilitating future extensibility and providing also the possibility of targeting polymorbidity [11]. A first generic self-management solution has been presented by T. Patterson *et al.,* [12], covering six core areas of functionalities: self-reporting, goal setting, education, measurement of health metrics and the delivery of reminders. This generic platform has been extended to cover multiple conditions, including COPD, dementia and stroke. Hence, this work presents a preliminary evaluation of the platform through the application KeepWell aiming to evaluate its feasibility for self-adoption use in patients affected by early cognitive impairment.

III. KEEPWELL

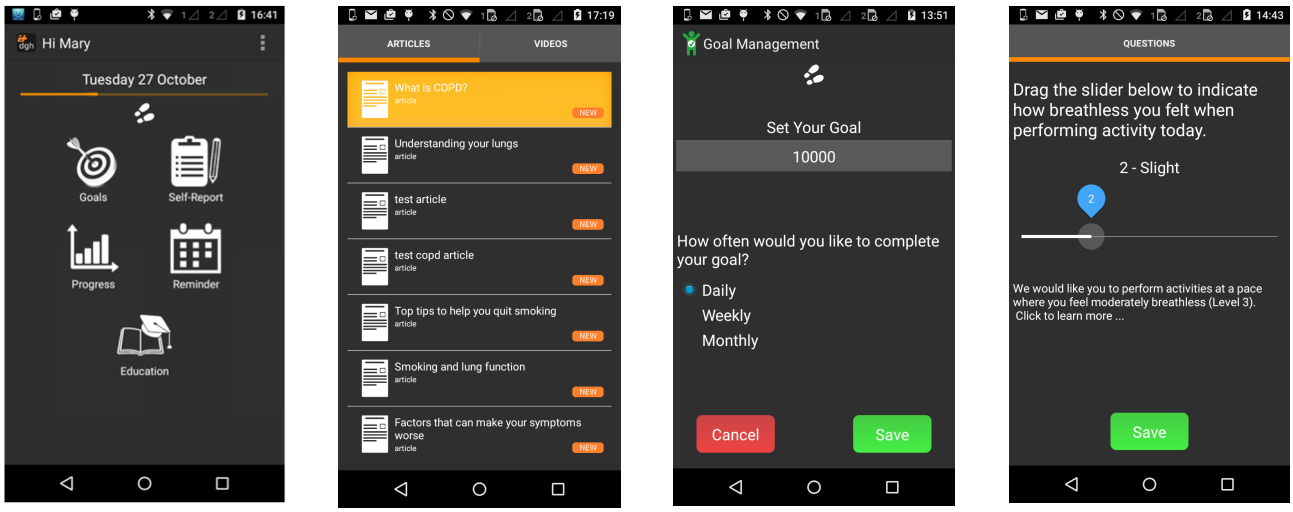
Delivering self-management support digitally, including support for understanding and managing the various chronic conditions, has been shown to improve health outcomes of care for chronic conditions. KeepWeel is a self-management platform developed and validated at Ulster University through exemplars requiring accommodative, restorative and preventative intervention models. This is evidenced through a self-management platform which can be tailored to suit the needs of individuals suffering from dementia, stroke and COPD.

The KeepWell platform is a generic and readily extensible solution to support the self-management of chronic conditions. The platform has four main components. An Android application to deliver educational material, set goals and display health metrics. External health-tracking devices enable the capture and quantification of health parameters. An Educational Authoring Portal to create and manage the educational content is available to the user. A Secure Server provides storage and perform computation as depict in Figure 1.

Figure 1. Architecture of KeepWell [12].

KeepWell consists of six core areas of functionality: education, goal setting, self-reporting, measurement of health metrics, feedback, and reminders all available in the home screen of the application (Figure 2.a).

The inclusion of educational material was identified as a key functional requirement in a self-management paradigm by consulting contemporary academic literature and the engagement with clinicians and previous experience [13]. For COPD condition, the relevant educational material was collected under permission from the Living Well with COPD project; for dementia condition, we utilized material from the Alzheimer's Society; for stroke condition, we incorporated material from the Northern Ireland Chest Heart and Stroke Association. In all instances permission was obtained from the organizations to incorporate the material 'as is' from the electronic resource (PDF or web page) to the app with the inclusion of an acknowledgement of source. A primary advantage of incorporating educational material in the app as opposed to a series of 'standalone' resources is that functionality such as searching for a keyword and favoriting of resources can be implemented. Similarly, as it was previously published [12], the educational content was provided in video and articles displayed in the app along with an icon indicating if the content has been previously viewed as depicted in Figure 2.b. Functionality to create, edit and delete a goal is provided within the app. A wizard-based approach is adopted to guide the patient through creating a goal as presented in Figure 2.c. Self-reporting of workouts or symptoms is available within the application using scrolling bars and checkbox buttons as depict in Figure 2.d. KeepWell has already been evaluated in a study in which clinicians provided assistance with setting up the services provided [13]. Throughout the two-week home-based trial participants set/reported 80 Reminders, 57 workouts, 80 symptoms and 18 goals. Participants additionally completed IBM's System Usability Score (SUS) and general usability questionnaires. Participants provided a mean SUS score of 72.85



a) Home screen b) Educational content c) Goal setting d) Feedback question

Figure 2. Screen capture from KeepWell.

(SD:18.24). This converts to a SUS percentile rank of 69; a rank above 68 is considered 'above average' [14].

Whilst initial results from the previous usability evaluation are promising of KeepWell, there is still much work to be done in terms of additional usability and acceptability evaluation of this solution.

The study described in this paper, however, focuses on evaluating the app's usability and the ease with which it can be adopted by ageing adults with cognitive impairment without professional assistance.

IV. Understanding the Daily Living of People with Cognitive Impairment: Methodology

The study was conducted at the Residential Centre 'Ángeles Cobo López' in collaboration of AgeingLab Foundation (consortium member of the European Union funded project: REMIND[1]), located in the city of Alcaudete in Jaén, Spain. In order to better understand the population constraints when addressing their daily life activities, a one-hour psychomotor therapy session was initially observed following the non-participatory shadowing technique [15]. During the session, 20 patients were guided by a physiotherapist step by step through a pre-established set of activities. Some activities consisted of exercising when sitting on a chair, whereas others required patients to grab different objects, such as wooden sticks and plastic balloons. The activities had an occupation-based approach, which focused on empowering the performance of activities of daily living, such as getting dressed, showering, and eating. Observations were complemented with a semi-structured interview (30 questions) conducted with two caregivers with eight- and two-years' working experience who were responsible for providing rehabilitation therapies. The interview questions covered topics including reasoning of the techniques used to guide patients towards the therapies, engagement strategies, reflexion of therapies on daily life activities and improvement expectations.

The evaluation of KeepWell consisted of measuring a patient's interaction satisfaction and comparing a traditional paper-based self-report mechanism with a digital mechanism. The Questionnaire for User Interface Satisfaction (QUIS) version 7.0 was used [16]. It was mentioned that the study would last for seven days and equipment will be borrowed and then taken back so that the collected data could be retrieved and analyzed. The study lasted for seven days. The interview material and the app were topicalized to include regional vocabulary in advance to facilitate communication more easily with participants.

A. Participants

A candidate pre-selection list of patients was created by the caregivers' supervisor, who was aware of all the patients' conditions. Inclusion criteria were patients taking medication on a regular basis and having motor independency.

The controlled group consisted of patients who were interested in joining the study but lack of experience using mobile phones. The exclusion criterion for the controlled group consisted on not being confident in handwriting (due the intervention design; Section IV.B for details). Six patients were interviewed, and one was excluded due to a handwriting impairment.

The intervened group consisted of seven pre-selected patients. During the interview, details about the study were presented. Aspects such as borrowing a smartphone and a wearable device overwhelmed two patients, who were therefore excluded. One patient opted to withdraw from the study due to the short-term benefit (*i.e.*, 7 day-study), especially as they

[1] https://cordis.europa.eu/project/rcn/207045_en.html

would not be able to keep the devices. The exclusion criterion consisted of having a basic experience level with mobile devices such as being unable to charge the mobile and wearable device. Two patients were excluded as they did not satisfy this criterion. Therefore, two patients qualified for the study. Qualified patients stated that they did not currently own a mobile device, however, had owned one for approximately 3–5 years before they moved into the residential center. They reported that they had never owned or used a wearable smartwatch/activity tracker.

In total, seven patients participated in the study, five volunteers in the control group and two in the intervention group. All patients were clinically diagnosed with early mental disorders such as bipolarity, depression, or dementia.

Ethical approval was provided by AgeingLab Foundation under the auspices of Personal and Public Involvement, which include the involvement of expert caregivers as specialist advisers in the evaluation of the KeepWell. Observations of patients were conducted under the Residential Centre 'Angeles Cobo López' ethical and privacy countenance.

B. *Intervention*

The control group were asked to write a diary of activities by answering five questions. Material (paper-based diary and pen) and a training session that lasted 10–15 minutes was provided. The intervention group were asked to answer the same questions by using the mobile phone and wearing a step counter on their wrists, and to complete a training session that lasted 20–25 minutes. Furthermore, patients were invited to ask any questions they had. Maintenance training consisting of verbally guiding them to utilize the paper-based diary or navigate along the app was given. The maintenance session lasted no more than 10 minutes and was provided on two consecutive days.

V. RESULTS

A. *Quantitative study results*

The results from the QUIS demonstrated that patients perceived KeepWell as being easy to use, enjoyable to use, expressed satisfaction when operating it, and had no problems regarding battery consumption, with an overall rating up to 87 percent. Similarly, screen design decisions such as organization of information and navigation were rated up to 88.89 percent. It is not surprising that terminology was rated high (100 percent) due to the *a priori* topicalization conducted, as mentioned above. Conversely, patients stated that they initially struggled operating the app (75 percent). They reported difficulty reading the text (80 percent) due to visual tiredness, and that they struggled to play/launch the informative video files (80 percent) due to technical complications. The pre-defined color and sound was rated up to 95 percent (Table 1).

	Average agreement	**Standard deviation**	**User's satisfaction**
Overall reaction to the software	8.83	1.18	88.33%
Readability (Screen)	8.00	2.83	80.00%
Organization (Screen)	10.00	0.00	100.00%
Interaction (Screen)	9.00	1.41	90.00%
Terminology and system information	10.00	0.00	100.00%
Learning	7.50	3.54	75.00%
System capabilities	8.00	2.83	80.00%
System reliability	8.00	1.41	80.00%
Usability and UI	9.50	0.71	95.00%

Table 1. Results from QUIS evaluation based on 10 rating scale (1 = Strongly disgree; 10 = Strongly agree). User's satisfaction column represents the ratio out of the max score a participant could have given. Overall reaction to the software includes 6 different sub-criteria (*i.e.,* perception, learning courve, user experience, battery consumption, engagement, customization).

Secondly, a set of activities was performed by patients and the time was measured. The tasks included those previously completed during the clinical evaluation of KeepWell [13]. In Figure 3, we compare the geometric mean of time taken from the two intervention patients compared with the mean time taken by one expert. The overall difference (after excluding the highest and lowest value) between patients and the expert is 6.97 seconds, which is considered not critical considering the experience and the limited time participants spent interacting with the app. The poorest performance was in creating a reminder; it was observed that participants struggled to find the letter in the keyboard to type the content of the reminder.

Overall, the intervention participants did not fail to perform any activity. They reported that they have adopted the use of the app as part of their daily basic activities. One patient stated: *"In the morning, the first thing I do is click on the app to report that I have woken up and check that there are 0 steps on my wrist-worn tracker"*.

Evidence of 10 to 1 self-report annotation with KeepWell compared to the traditional paper-based diary emerged. Some patients from the control group showed reluctance to continue reporting activities after writing the first couple of reports, stating that they would have written the same every day. In contrast, the intervention group reported that the reporting activities appealed to them. Paper-based diaries were utilized to complement and structure the guidelines below.

B. *Qualitative study results and design insights*

To distil information in a structured manner, the semi-structured interviews and observation sessions were codified using grounded theory and affinity diagramming [17]. As part of the post-intervention participants described their day-to-day activities using the app, they were asked to share their thoughts, constraints, and experience self-reporting their daily life activities as part of the intervention (previously described in Section IV.A). Overall, the patients in the intervention group

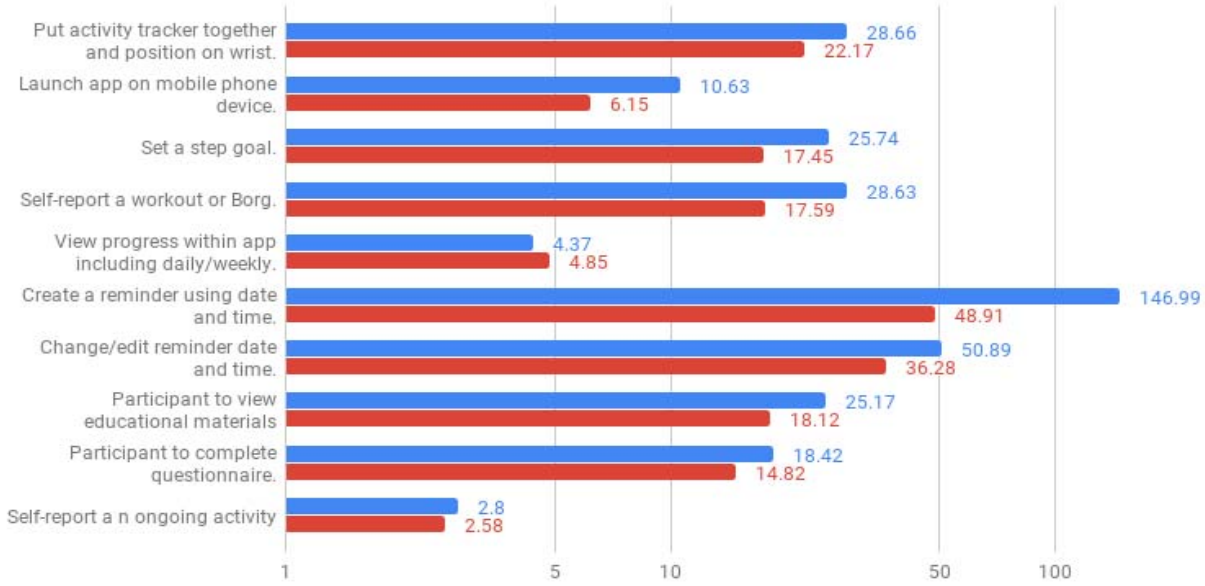


Figure 3. Time task test consisted of main operative activities enabled through KeepWell. This graph compares the time performance between a participant of the study in blue (n = 2) after a 7-day intervention against timing of an expert user in red (n = 1). Units are given in seconds.

reported that they had an engaging experience, whereas others stated that they struggled to report the quantity of activities performed. The qualitative data collected and analyzed during the observation and interviews has confirmed earlier findings about the importance of providing timing communication between the app and the user as well as data privacy concerns [18]–[20] and provided the following additional guidance for the design of cognitive impairment reminder apps:

1) **Cost-benefit.** Users are sensitive to effort investment. As previously mentioned, one of the patient opted to withdaw from the study due to its short-term benefit, argueing that his learning curve was too great compared to the few days's benefit of using the services provided. Hence, the app should have a tangible and meaningful benefit to compensate the user's effort. Although patients were not concerned about ownership of data, they stated that they wanted unrestricted access to historical data so that they can reflect on their activities by comparing their performance longitudinally.

2) **Meaningfulness.** Information should be at the right level of detail and in the right amount. It was observed that adopting new concepts is challenging, so analogies such as *[Caregiver] "Everybody, move your arms as if you are rocking a baby"* are commonly used for patients to engage quickly and follow the new tasks during physical and cognitive therapies. In the context of software development, triggering notifications at the appropiate time [18] and using language that users are familiar with can reduce the effort required for interacting with the app.

3) **Privacy.** Participants reported that they would be likely to share some data with their peers and relatives. Nevertheless, as confirmed in the early findings [20], each user has a different perception of what sensitive information means. Therefore, implementations should allow users to specify the openness of collected data.

4) **Engagement by personalization.** During the physical therapy, it was observed that patients were likely to respond when responding to personalized messages. The patient should have the experience that the mobile app interaction is customised to them. For example, when the caregiver said *[Caregiver] "Well done, Jose, you did more squats than yesterday"*, the patient immediately smiled and showed more endurance when performing subsequent activities. As part of the interviews, patients stated that they prefered to keep the interaction simple. In the context of the mobile app, it is paramount to envision that messages can be built up from the previous activities log to provide users with tailored content, and that allowing users to personalize frequent functions as quick access can increase the perception of autonomy and empowerment.

5) **Inclusion.** Patients would like to extrapolate their previous knowledge to interact with new apps. Therefore, making available a service to interact by using different channels is advisable, for example, enabling voice commands and text function, so that users adopt the mechanism with which they feel more familiar *[Patient] "I already know how to use my old mobile, so it wasn't that difficult to get used to this one [smarphone with touch screen]"*.

6) **Tonality.** A good understanding of the user needs to be considered to address the message content properly. If the content is too direct, they might feel that their free will is being threatened, to which they might respond with resistance and be more likely ignore the message's content [19].

7) **Trustworthiness.** Taken from the QUIS, users relied upon the information they were given via the app. Therefore,

the app should use high quality and updated sources. Similarly, the app should reflect the user's activity/feedback in real time to avoid confusion and the perception of incorrectly operating the app *[Patient] "Sometimes my stepts didn't show up on the screen of the mobile but it does on my wrist counter, thus I trusted everything was fine"*.

8) **Feasibility.** Patients with similar cognitive impairment characteristics might have enough energy to climb stairs more than once a day, whereas others might struggle to walk on a flat floor. In the context of physical milestones, the app should be sensitive to an individual's capacities to build the experience for the user so that they feel that a challenge has been customized for them.

Patients reported that mobile devices were a trustworthy mechanism of communicating with relatives and are used in case of emergency. Therefore, installing an app should optimize the use of battery as well as keep basic communication/functionality services enabled.

VI. Conclusion and Future Work

In this paper, we evaluated KeepWell, a mobile application for encouraging self-management for ageing patients with long-term medical conditions. While the related work Section illustrates that there is already some work available, none of these efforts provide user validation. The KeepWell architecture has been previously presented, and interaction design validated for clinicians.

The primary contribution of this work was to articulate and preliminarily validate the design space of using mobile computing by patients diagnosed with early cognitive impairment. Data was analyzed using grounded theory and affinity coding. The results that emerged consisted of eight guidelines that can help to model mobile application for patients with early cognitive impairment. Our results indicate that KeepWell is feasible and perceived as useful by ageing patients. Nevertheless, as future work, we propose to conduct a robust study to improve the user experience and reduce the learning curve, so patients with no previous experience using mobile technology can more easily adopt it in their daily routine.

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