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## Solution to support informal caregivers of patients with dementia

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### Abstract

The dementia is a degenerative incurable disease. Giving its high prevalence worldwide, it is considered a major global public health concern. Patients with dementia need long-term care and support at home. Current evidence demonstrates that their informal caregivers are prone to psychiatric and cardiovascular diseases and lack formal support that can help them in their exhausting daily routine. We intend to report the creation of an ICT solution to support informal caregivers of patients with dementia, addressing identified needs. The academic engineering project launched was divided in two phases: 1) requirements analysis and software design and 2) software development and deployment. The user-friendly and smooth functioning application developed, called OneCare, has a set of functionalities that allows the free access to information about the disease, useful resources, medication, outpatient consultation management and communication with peers. We consider that this application may improve effectiveness in care provided by informal caregivers of patients with dementia, while having a positive impact in their health outcomes and quality of life. We advocate that future policies in this area should consider the use of this kind of technology as a way to reduce disease burden, institutionalization needs and increase the chances of living well at home.

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## 1. Introduction

According to the World Health Organization, the number of people living with dementia worldwide is currently estimated to be around 50 million, number expected to triple by 2050.[1] In Portugal, twenty in every thousand inhabitants will suffer from this disease, which is above of the OECD average of 15 cases per thousand inhabitants. [2] Dementia is a comprehensive term for several diseases that are degenerative, progressive and incurable, that affects not only memory, but also cognitive, behavioral, functional and relational capacities of the sick person, beyond what may be expected for normal aging. [1,3,4] Of all forms of dementia, Alzheimer's disease is one of the most common, accounting for 60 to 80% of cases. [5,6] Despite investments made on research, there is still no cure for dementia and mortality remains high, counting 9% of all deaths in 2017 across OECD countries. [3]

People with dementia can live for long periods or even until the end of their life at home if they receive adequate long-term care, which is frequently delivered through formal services, but also through family members or friends. [7] As patient dependence turns high and progressive, caregivers are frequently compelled to stay at home and leave their jobs, consequently suffering from economical frailty, isolation, and burnout. The costs of unpaid labor, absenteeism from work in order to provide care, and direct out-of-pocket costs spending on care represent between 40-75% of the total costs of caring for dementia, which is estimated to be \$US 818 billion. [1,2]

Portugal is among the OECD countries with highest ageing index due to high life expectancy and low fertility rates. The prevalence of dementia increases rapidly with age, with values growing up to 40% among those aged over 90 years. [6] People over 65 years old receiving long-term care in 2015 were estimated in 2,1%, representing more than half of patients in that situation, a part of it under informal care. Current estimates indicate that there are near 300,000 people depending on this type of care in our country. [8] Additionally, in 2037 Portugal is expected to have 40% of the population over 65 years, which turned this issue a very important for internal public health and political agenda.

In 2017, in recognition of the importance of taking action on dementia, WHO endorsed the Global action plan for the public health response to it. [1] A renewed international focus has been put on supporting countries to improve the lives of people living with dementia, their families and carers. [6] Better policies, initiatives and tools that can improve life of these patients, their carers/families must be encouraged. [1]

This article aims to identify requirements/model and build an ICT solution that supports informal caregivers of patients with dementia. Addressing their particular needs, we pretend to develop an online solution that provides knowledge and tools that empower them on overall management of care, also giving them the possibility of information sharing among informal caregivers. Services supported in good software, that easy access to services and health systems, facilitate integration between different settings, levels and professional action, are needed in order to maximize effectiveness of therapies, minimize unnecessary care consumption and improve quality of life of patients and caregivers.

## 2. Informal Caregivers: role and needs

An informal caregiver, often a family member or close relative, provides care typically unpaid to someone with whom they have a personal relationship in order to facilitate their well-being to help in different tasks and activities. [9,11] Their role is particularly important in caring for people with dementia [1] and it is considered difficult, requires time, energy and physical effort. In order to accomplish their tasks, many have to leave their jobs which represents a major drop in family income leading them and their families to an economic and social fragile situation. [12-14] Till recently, in Portugal, informal caregivers were not formally recognized by the government and didn't have access to any support that could help them to face daily difficulties, whether financial, social or related to health. Considering

their important role and difficulties, the Portuguese government approved the creation of a statute that grants them rights, namely financial and healthcare support as well as labor protection. [15]

There is scientific evidence that informal caregivers of patients with dementia have more depressive symptoms and physical problems than informal caregivers of patients with other diseases. [3,13] All are recognized to be at risk of developing cardiovascular diseases as hypertension and also psychiatric disorders as depression or anxiety. [3,16] The maintenance of this situation over time has been associated to burnout. [16]

Today, it is recognized that informal caregivers are essential for planning and providing care in all contexts, according to desires and needs of the person with dementia. [17] Relevant ones include medications provision, access to non-pharmacological treatments (e.g.; art, music, dance, exercise, cognitive stimulation therapies), contact with dementia support organizations, access to support groups and community-based resources. [18] The daily demands for the caregiver are very high and challenging, and beyond health issues, they usually report a significant deterioration in their quality of life. [12,14,19,20]

Informal caregivers must have access to support and services adapted to their needs, in order to respond and effectively manage physical, mental and social demands inherent to their role. This is recognized and reinforced by the World Health Organization. [1] The creation and implementation of tools, services and multisectoral support can contribute to the prevention and decline of physical and mental health and social well-being of informal caregivers. [2]

The use of technology to support them has been seen as an opportunity of great value, which is reflected in the increased research that has been carried out in this area. The use of digital technology and *apps* for mobile devices that contain tools and resources necessary to provide care for dementia has been studied, with positive results in reducing burnout and improving health outcomes. [21] Peer support seems also to be beneficial for caregivers, providing a source of positive emotional encouragement and a way to voice negative emotions and get help to address issues in everyday life of caring for dementia patients. [22]

In Portugal, so far, to our knowledge, there is only one technological solution available for informal caregivers that is called Help2Care®. It is a digital platform composed of two main software applications: a mobile app where caregivers can access information on their patient's needs and perform care procedures, and a web application where health professionals manage caregivers and their patients. [10] We intend to create a software tool specifically focused on caregivers of patients with dementia needs. As they are, among all caregivers, the ones that have the worst health outcomes related to their role [3,13], we consider that they can largely benefit of its use and get a positive impact in their quality of life and health outcomes. For this purpose, we plan to cover the largest number of needs identified as necessary for their daily activities, turning them accessible and easy to use on a mobile phone, a tablet or a computer, anywhere at any time.

### 3. Designing an application to support informal caregivers in the area of dementia

In order to create a tool that provides the desired services and multisectoral support, an academic software engineering project was launched. The project followed the best-known software engineering practices, being divided into two parts: 1) requirements analysis and software design and 2) software development and deployment.

The requirements specification aims to describe the functionalities to be implemented in the software in order to ensure that informal caregivers of patients with dementia needs are met. After several working meetings of detailed analysis, the macro functional requirements of the application were defined as follows:

- Management of user's profiles
- Management of patients
- Management of appointments, treatments or medications
- Allow interaction (chat) between all informal caregivers
- Make useful information for informal caregivers available

Additionally, the application must be user friendly for users with a low degree of literacy, and should allow the introduction of new contents and information updates. After the requirements definition, that represent the actions needed to be implemented by the software, it was designed the software architecture to be built. For this purpose, it

was chosen a modelling formal language: UML - Unified Modelling Language. UML is a generic language, i.e. allows modelling any system (static and dynamic components) at different levels of analysis from generic models to implementation models.

In order to make a structured and optimized design of the software and guarantee alignment with the requirements defined, several UML artefacts were built. In figure 1, as an example, one of the constructed diagrams (Use Case) is shown.

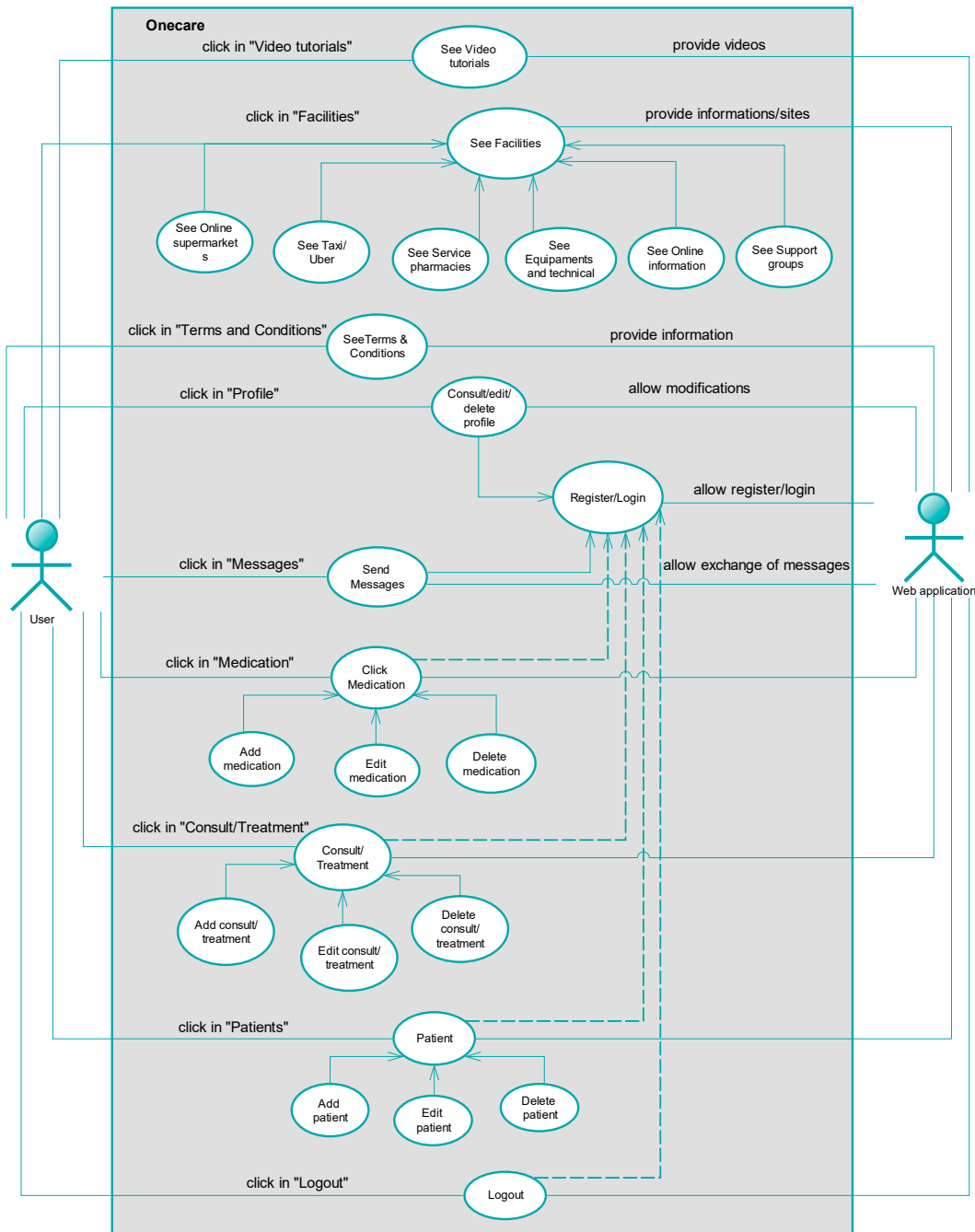


Figure 1 – OneCare’s Use Case diagram

In addition to implementing functional requirements, in order to ensure the smooth functioning of the web application, the following non-functional requirements, relating to the general aspects of the system's operation, were also defined:

- Fast and intuitive interface
- Appealing design
- Database updated in real time
- Password encryption

#### 4. OneCare Software

After good software specification (UML diagrams, data models design), it was taken a special focus to the interface design (menus, reports, menu structure and screens).

Thus, it was intended to build an application easy to use and to understand, with a set of different functionalities, accessible from a home page. However, before the caregiver is able to use the application, it must register himself by accessing a special page, according to figure 2. In this page the caregiver can register by filling the form with the information requested – name, e-mail, gender, birth date, password and confirm password. When registering, it is necessary to choose an avatar. Before completing the registering process, the user is requested to agree with the Terms and Conditions. If the caregiver is already registered, he/she can login in the same page by clicking on “Login” and it will change the form to the login form, where the requested credentials are e-mail and password.

Figure 2 – Register/Login page

After the registration and/or login the user will have full access to a set of different functionalities accessible from the home page. From here (figure 3), the caregiver can access the main functionalities of the application. Only the video tutorials and facilities can be accessed without logging in. If the caregiver is not logged in, and clicks in one of the other options, he/she will be forward to the log in page.

The logo, on the top bar, is present in every page and forwards to the home page. The drop-down menu in the right corner allows access to the caregiver's profile and to log out from the application. If the log in is not done, this drop-down menu cannot be accessed. Instead, the corner will have the options to register or to *log in* in the application.

In the page's body are the six menu options with the respective icon representation, to facilitate the identification of the functionalities from each option. In the bottom left corner, the application's Terms and Conditions can be accessed. This button is present in every page, with exception for the register and *log in* pages.

As a note, if the caregiver scheduled an appointment for the current day, a notification will appear below the drop-down menu, as a reminder.

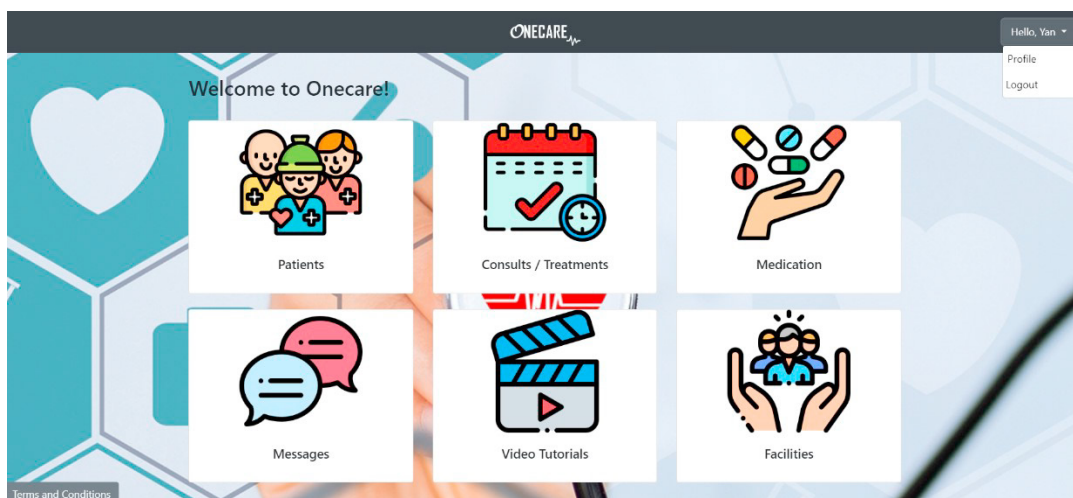


Figure 3 – Home page

Below it is possible to understand the objective of each menu option available in the home page, through the respective description.

### Patients

The caregiver can add patients by clicking on the “Add Patient” button, which will redirect to a page enclosing a form that the caregiver has to fill out with patient data. After adding the patient, the information from the form will appear in the “Patient Management” table, where is possible to read, edit and delete the patient. By clicking on the patient name in the table, it will redirect to a page where is possible to view the form with the patient’s information. For editing and deleting there are two icons, yellow and red, respectively. Before deleting a patient, a pop up to confirm the deletion will appear.

### Consults/Treatments

The caregiver is able to schedule appointments and treatments and also consult the agenda. To schedule, it is necessary to click on the button “Schedule Consults/Treatments” that will redirect the caregiver to a page with a form that he/she has to fill out. After adding the consult or treatment, the event will automatically appear on the agenda. If the patient has an event on the current day, a notification will appear on the main page to remind the caregiver. By clicking on the event, it is possible to edit and delete the consult/treatment. Before deleting, a pop up will appear on the page to confirm the deletion.

### Medication

On this page, the user can add medication to his/her patient (s) by clicking on the “Add Medication” button, that will forward the caregiver to a page with a form, which has to be filled. After adding the medication, the form data will appear in the “Medication management” table, where it is possible to read, edit and remove medication.

By clicking on the name of the medicine in the table, it will forward the user to a page where he can view a form with the information about it. To edit the medication, it is necessary to click on the yellow icon that will return a page with a form where the data about the medication can be changed. It is possible to delete the medicine by clicking on the red icon, that will make a pop up appear to confirm the removal.

### Messages

The feature considered most important in the application was communication between the caregivers registered on the platform, to be possible to talk and exchange doubts or advice between them. The Messages page was created with that objective (figure 4).



Figure 4 – Chat Room

### Video Tutorials

On this page the user has several options of videos from different categories. To view a video, the user must click on the desired video image and the video will appear in front of the page inside a rectangle.

### Facilities

One of the application's objective was to facilitate the search for useful information, gathering it in the same place. In the facilities, it is possible to search for supermarkets that deliver at home, transports, pharmacies and medical equipment. It is also possible to access important information online about dementia, published in different sites.

## 5. Conclusion

Based on literature review, this paper characterizes the burden associated to dementia diagnosis and identifies relevant unsatisfied needs of caregivers, proposing the development of an ICT solution that improves effectiveness and efficiency of their daily tasks, facilitates access to relevant information and services and lowers the number of hours of informal care, as it integrates a variety of services in one entry point for caregivers. The creation of a chat room, that is a distinctive functionality of this software, underscores the recognized importance attributed to reduction of social isolation. By facilitating the connection between users, the exchange of experiences and doubts, we hope to improve peer support, contributing to mitigate anxiety and depression frequently reported by these caregivers. With this tool, it seems possible to educate and empower informal caregivers in an easy and accessible way, also improving interactions with healthcare services without fails or loss of important information, as the list of actual medication, that is essential for any medical encounter. That information can be shown by caregivers to healthcare professionals and be analyzed by them.

Future policies should consider the take-up of solutions like OneCare, maximize their use and impact on community and support setting new functionalities based on clients' feedback and new technological trends. By giving free access to ICT solutions that support people in their needs and promoting the continuum of care we can aim to reduce disease burden, institutionalization and increase the chances of living well at home.

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