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TELEMEDICINE MULTIMEDIA SYSTEMS TO SUPPORT NEURODEGENERATIVE PARTICIPATORY MANAGEMENT

DIOGO JORGE MENEZES BORGES
DISSERTAÇÃO DE MESTRADO APRESENTADA
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Telemedicine Multimedia Systems to Support Neurodegenerative Diseases Participatory Management

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Telemedicine Multimedia Systems to Support Neurodegenerative Diseases Participatory Management

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Dissertation submitted to Faculdade de Engenharia da Universidade do Porto
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À Joana, por sempre acreditares e veres o melhor em mim...

Abstract

Parkinson's disease (PD) is the second most common neurodegenerative disease after Alzheimer's affecting mainly people over 60 years. Due to the population fast aging and forecast of a great increase in the number of PD patients, this disease has been the focus of abundant attention from the scientific community. Telemedicine, an area known for providing healthcare services at a distance, has taken a great interest in PD. With the recent technological developments, an ample number of proposals have been made in the last decade to better monitor this illness, empowering specialized physicians with more and better information to support the diagnosis and management of this disease.

In this dissertation the design and development of a multimedia platform intended to allow a better PD remote home monitoring through an easy accessible, highly usable, and integrated system is presented. The MoPA system, as well as other systems in literature, provides diversified solutions to obtain more patient's daily living and quality of life (QoL) information. Nevertheless, contrary to literature, our system allows the medical staff to access a video repository where they can visualize their patients performing motor tasks, related to the Unified Parkinson's Disease Rating Scale (UDRPS), either in their home environment or at medical appointments. Therefore, the users are able to correlate the retrieved visual information with all other relevant data sent by the patients regarding their QoL and with the personally assessed information,by the medical staff, at the medical appointments .

The web-based system was developed using the web application framework CodeIgniter, XAMPP as the cross-platform web server and MySQL as the database. The development used a participatory methodology, involving the potential end users from the medical staff of Hospital de São João (HSJ). At the end of the process, a users' group was asked to fill an online form where the potential and user acceptance level of this system was assessed. The results led us to conclude that the MoPA system is greatly accepted by all stakeholders and shows great potential to improve the monitoring of PD patients in their home environment.

Keywords: Parkinson's Disease. Telemedicine. Multimedia systems. Monitoring.

Resumo

A doença de Parkinson é a segunda doença neurodegenerativa mais comum após a doença de Alzheimer e afeta principalmente pessoas com mais de 60 anos. Devido ao rápido envelhecimento da população e consequente previsão de um grande aumento no número de parkinsónicos, esta doença tem sido objeto de grande interesse por parte da comunidade científica. A Telemedicina, uma área conhecida pela prestação de serviços de saúde à distância, tem tomado nos últimos anos grande interesse na doença de Parkinson. Com os recentes desenvolvimentos tecnológicos, um elevado número de soluções têm sido propostas com o intuito de melhorar a monitorização dos pacientes parkinsónicos quando estes se encontram em casa, capacitando assim os neurologistas com mais e melhores informações sobre a situação atual do paciente.

Para a presente tese é descrito o desenvolvimento de uma plataforma multimédia que permitirá uma melhor monitorização doméstica dos parkinsónicos através de um sistema acessível, altamente usável, e facilmente integrável na vida diária dos usuários. Juntamente com outros sistemas da literatura, o sistema proposto apresenta soluções para a obtenção de informação relativamente ao estado de saúde do paciente e qualidade de vida quando este se encontra em casa. Contudo, contrariamente ao referido na literatura, o nosso sistema permite que os utilizadores do staff médico tenham acesso a um repositório de vídeos onde poderão visualizar os seus pacientes a executarem variadas tarefas motoras, relativas ao exame *Unified Parkinson's Disease Rating Scale* (UDRPS), quer aquando o paciente se encontra em casa ou numa consulta médica. Assim, os utilizadores serão capazes de correlacionar a informação obtida visualmente desses vídeos com aquela enviada anteriormente pelos pacientes, relativamente à sua qualidade de vida, e aquela registrada durante a presença do paciente no hospital.

O sistema web foi desenvolvido recorrendo à framework de aplicações web CodeIgniter, ao XAMPP como o servidor web de multiplataformas e MySQL como base de dados. O desenvolvimento ocorreu utilizando uma metodologia participativa onde potenciais utilizadores finais da equipa médica do Hospital de São João (HSJ) foram envolvidos. No final do processo, um grupo de utilizadores foi convidado a preencher um formulário online onde o nível de aceitação e potencial deste sistema foi avaliado. Os resultados levam-nos a concluir que o sistema MoPA foi aceite por todas as partes interessadas e mostra grande potencial para melhorar o acompanhamento dos doentes parkinsónicos em sua casa.

Keywords: Doença de Parkinson. Telemedicina. Sistema Multimédia. Monitorização.

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A vida é cheia de ciclos e com o fim de um dá-se o começo de outro. Esta dissertação, de certa forma, é o culminar de um período de 6 anos onde tive a hipótese de conhecer diversas áreas de estudo, até aqui desconhecidas para mim, interagir com centenas de pessoas de diferentes backgrounds e evoluir como pessoa e profissional. Tive a possibilidade de trabalhar em diferentes áreas de estudos que contemplam a Engenharia Biomédica mas foi na Telemedicina que encontrei a minha paixão de trabalho.

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Publications

Diogo Menezes Borges, João Paulo Silva Cunha. *Telemedicine multimedia system to support Neurodegenerative diseases participatory management*. In 37th Annual International IEEE EMBS Conference. Milan, Italy, 2015. - Accepted for Publication (see Appendix G and H).

Diogo Menezes Borges, João Paulo Silva Cunha. *Telemedicine multimedia system to support Neurodegenerative diseases participatory management*. In 1st Doctoral Congress in Engineering FEUP. Porto, Portugal, 2015. (see Appendix F)

“Don’t cry because it’s over. Smile because it happened.”

Dr.Seuss

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List of Abbreviations

App	Mobile Applications
BRIC	Brazil, Russia, India and China
DBS	Deep Brain Stimulation
EEG	Electroencephalogram
FEUP	Faculdade de Engenharia da Universidade do Porto
GDP	Gross Domestic Product
GP	General Practitioner
GUI	Graphical User Interface
HFS	High-frequency Stimulation
HSJ	Hospital São João
ID	Identity
ICT	Information and Communication Technologies
iTUG	Instrumented Timed-Up-and-Go
mHealth	Mobile Health
MoPA	Monitoring Parkinson’s
BSN	Body Sensor Network
NHI	National Health Insurance
OECD	Organization for Economic Co-operation and Development
PDA	Personal Digital Assistant
PDQ-39	Parkinson’s Disease Questionnaire with 39 questions
QoL	Quality of Life
REM	Rapid Eye Movement
SP	Smartphone
SW	Smartwatch
STN	Subthalamic Nucleus
TUG	Timed-Up-and-Go
UPDRS	Unified Parkinson’s Disease Rating Scale
USA	United States of America

Chapter 1

Introduction

Never has there been a society so in tune with technology as it is the one we know today. Technology has gone global and it is present in every field of interest, especially in Medicine. The desire for better Quality of Life (QoL) and the wish to prolong our life expectancy made their paths cross very early and since then both have come a long way. Nevertheless, although this great technological evolution has made us capable of prolonging our stay in this planet it also made us more prone to develop chronic diseases. The world population is increasing and with it the cost of healthcare. In 2012 the cost of chronic diseases composed approximately 2/3 of the total healthcare cost, in the Organization for Economic Co-operation and Development (OECD) countries as well as for Brazil, Russia, India, and China (BRIC) (9). In a smaller scale, Portugal spent, on the private and public healthcare services, around 11,000 million Euros in 2001 (which, at the time, corresponded to 8.6% of the gross domestic product (GDP)) and 16,000 million Euros in 2012 (9.5 % of GDP) (10). Furthermore, there is still a great number of people worldwide, that do not have access to the necessary healthcare services (11; 12; 13; 14). Such issues have obligated governments to take measures and focus on finding new solutions. The answer was found in the area of remote patient monitoring technologies also known as Telemedicine. According to (15), the Telemedicine market in Europe grew from 2.5 billion Euros in 2010 to 3.9 billion Euros in 2011 and it is predicted that it will almost triple to around 10.2 billion Euros in 2019. This new area is expected to also have a great impact in transforming the healthcare and increasing its quality and efficiency (16).

Currently, several study groups have invested their time and resources into using new technologies such as Smartphone (SP), Smartwatches (SW), tablets and wearable sensors, among others, to develop new systems that could support doctors in their daily routine enabling them with the best tools available. Hence, clinicians are now capable of retrieving more, better and more accurate data from a wide range of patients suffering from different diseases.

1.1 Context and Motivation

Parkinson's Disease (PD) is currently one of the main neurological diseases of interest in the scientific field either by the fact there is still no known cure or by the demanding set of skills physicians need to have for diagnosis, treatment and monitoring of this illness (17). As referred above, Telemedicine is the field that is showing great interest in this disease, mainly in the investigation and development of new monitoring solutions that can aid doctors in performing a more qualified follow-up of patients, thus allowing for a better diagnosis and consequently a more efficient treatment (18). As consequence of this, Telemedicine was recently recognized as one of the key technologies for better healthcare provision in the European Commission Plan of Action for Electronic Health 2012-2020 (19).

Technology is now available to all; anyone has easy access to the Internet either through a computer, SP, tablet or similar. Nowadays, it is easy to speak *in person* with someone on the other side of the world if you have a webcam which is usually incorporated within one of the previously mentioned devices. Bearing this in mind, with this type of technologies available, a lot can be done for those in need of better healthcare services. It is our duty, as biomedical engineers, to collaborate with physicians from various fields of Medicine, in order to develop ingenious solutions that are able to improve diagnosis, treatment, monitoring and in the end patient's QoL. Our role is to find the solution for a problem and continually improve such solution because with an answer arises another question. By always being fascinated with Medicine and not being able to stop enjoying the infinite loop which is engineering I chose such an inspiring area – Telemedicine - to work on.

1.2 Objectives

In this dissertation it is presented the design and development of a multimedia platform to allow for a better PD remote home monitoring through an easy accessible, highly usable, and integrated system on user's daily living. Such solution is expected to empower physicians with a better knowledge of patient's well being, capabilities and difficulties and thus allowing them to work on the diagnosis and treatment based on a more richer and consistent information than currently available. Furthermore, it is the author's belief that such work goes towards the European Commission's incitement to apply Information and Communication Technologies (ICT) to healthcare systems so to improve their efficiency, improve quality of life and unlock innovation in health markets (19), promoting a close involvement of end users in the design processes (20).

1.3 Resulted Publications

The present thesis resulted in the following publications:

Diogo Menezes Borges, João Paulo Silva Cunha. *Telemedicine multimedia system to support Neurodegenerative diseases participatory management*. In 37th Annual International IEEE EMBS Conference. Milan, Italy, 2015. - Accepted for Publication (see Appendix G and H).

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1.4 Structure

Besides the current introduction, this dissertation divides into 6 more chapters. In chapter 2 a general overview of PD, based on different strands of the disease, is made. Furthermore, chapter 3 talks about Telemedicine involvement with PD and recent technological proposals for the monitoring of this illness. Chapter 4 illustrates the current situation in the monitoring of PD patients in Hospital São João (HSJ) and some related issues. Moreover, chapter 5 addresses the design and architecture of the proposed solution whereas chapter 6 illustrates the prototype and the validation of the proposed system and lastly, in chapter 7 some conclusions are presented and future work is suggested.

Part I

State of the Art

Chapter 2

Parkinson's Disease

PD, firstly described by James Parkinson in 1817 (21), is a chronic progressive neurodegenerative disorder and the second most common after Alzheimer's disease (22). This illness displays a higher propensity for people over 60 years although there are also rare cases of younger people under the age of 40 years (23). Due to the population fast aging, PD has become a rapidly growing area of concern. The pathological hallmark of PD is the progressive loss of dopamine-producing neurons in the region of the brain that controls movements: the *substantia nigra* (22; 24; 25).

Consequently, with the disease's progressive development, the loss of dopaminergic neurons spreads to almost the whole central nervous system (23) leading to health deterioration and considerably impair of the patient's QoL. By the time of death, someone who suffered from PD may show less 50-70% dopamine-producing cells than a unaffected individual (24).

2.1 Clinical Features

PD is usually associated with the loss of capability to perform normal voluntary movements (i.e. movement disorder), although patients can also experience cognitive impairment and emotional/-mood disturbances (23). PD's symptoms can be divided into two major groups: Motor symptoms and Non-motor symptoms (table 2.1). PD has four cardinal features: bradykinesia, rigidity, postural instability and rest tremor (23; 24; 7), falling all under the motor symptoms category. These movement disorders have a substantial negative impact in the, until then, patient's ability to perform normal everyday activities. Additionally, non-motor symptoms tend to appear with the development of the disease. Currently there are no definitive biological or imaging markers (such as blood test, brain scan or an electroencephalogram (EEG)) to make a definitive PD diagnosis; at least one that the scientific and medical community both support (14). Nevertheless, as an alternative, a specialized physician in PD can take a careful medical history and perform a thorough neurological exam searching for the disease's cardinal symptoms (26). The Unified Parkinson's Disease Rating Scale (UPDRS), originally introduced in 1987 (27), is at the moment the most used clinical metric to quantify PD impairment with the results falling within 0 and 199, where 0 indicates a healthy subject and 199 one with total disability (28; 27). It consists of 42 items subdivided into four main domains: (1) Behavior, mood and psychological state; (2) Daily Routine activities; (3) Motor, regarding muscle control and (4) Therapy related complications, having each section a final score (27). Appendix A illustrates an example of a UPDRS exam.

The third domain, also known as UPDRS-motor, is evaluated at every medical appointment through patient's performance of motor tasks, presenting the highest influence in the final UPDRS score. Likewise, the second domain has a great impact although it depends on patient's capability to recall their ability to fulfill certain activities of daily living over long periods of time and, in addition, patient's interpretation of their symptoms is not always accurate with the reality (29). Consequently, the information retrieved at every medical appointment is not a complete representation of patient's everyday living. Thus, there is still a lack of information on PD patients when they are in a home environment which makes a great challenge for physicians to, firstly, understand personalized issues that may occur to the patient on a daily basis and, secondly, make flawless decisions on therapeutic or medication interventions (30). A constant tracking and quantification of some of PD clinical features is highly important since it will allow for a better comprehension of the treatment's efficiency giving the physicians the significant information that, coupled with the medical knowledge, can give the patient the best treatment possible.

Table 2.1: Parkinson's disease motor and non-motor symptoms (Adapted from (7)).

MOTOR SYMPTOMS	**NON-MOTOR SYMPTOMS**
Tremor, bradykinesia, rigidity, postural instability	Cognitive impairment, bradyphrenia, tip-of-the-tongue (word finding) phenomenon
Hypomimia, dysarthria, dysphagia, sialorrhoea	Depression, apathy, anhedonia, fatigue, other behavioural and psychiatric problems
Decreased arm swing, shuffling gait, festination, difficulty arising from chair, turning in bed	Sensory symptoms: anosmia, ageusia, pain (shoulder, back), paresthesias
Micrographia, cutting food, feeding, hygiene, slow activities of daily living	Dysautonomia (orthostatic hypotension, constipation, urinary and sexual dysfunction, abnormal sweating, seborrhoea),weight loss
Glabellar reflex, blepharospasm, dystonia, striatal deformity, scoliosis, camptocormia	Sleep disorders (Rapid Eye Movement (REM) behavior disorder, vivid dreams, daytime drowsiness, sleep fragmentation, restless legs syndrome)

2.2 Monitoring

PD monitoring can be either passive or active. The first is based on a collection of data without the need to interrupt the patient's routine. Thus, patients can be monitored without even noticing, avoiding situations of stress that may affect the results. In contrast, the latter term requires the patient to interact with, for example, a computer or a mobile screen for contextual data collection (e.g. speech, facial tremor, medication intake, mood, pain and so forth). On the contrary to passive monitoring, active monitoring makes patients more active in their health's management allowing them to be more aware of the disease and its development (30).

2.3 Treatment

Once a person is diagnosed with PD the path ahead is long and harsh, for both the patient and the family. Although there is still no cure possible there are treatments available, which should be started as soon the diagnosis is made since they help to reduce, with great success, PD symptoms.

2.3.1 Dopamine Replacement

The first line of defense, and the current therapy used, is the augmentation or replacement of dopamine, using levodopa (a biosynthetic precursor) or drugs that activate dopamine receptors (31). These therapies are successful in significantly diminishing the severity of PD movement symptoms. At the beginning of the disease, motor disability may not be very significant as symptoms are usually unilateral and mild (8). However after a certain period of time (4-6 years (32)) the drug efficiency drops and side effects such as involuntary movements (dyskinesia) and/or medically refractory fluctuations may occur (9; 25). In the later stages of the illness the patient has already lost his autonomy and the need for assistance for most activities of daily living (e.g. dressing, personal hygiene, feeding, walking, etc.) will increase (23; 7).

2.3.2 Deep Brain Stimulation

The discovery of high-frequency stimulation in 1987 has enabled neurosurgeons to stimulate specific targets (33). Basically, electrodes or neurostimulators are implanted inside the brain stimulating the subthalamic nucleus (STN), which is involved in motor control (34). This procedure is known as Deep Brain Stimulation (DBS) surgery. The first PD patients to receive this high-frequency stimulation (HFS) in 1993 (35; 36), showed, after surgery, a significantly improvement in tremor, rigidity and bradykinesia allowing for a reduction of about 60% in the prescribed levodopa and, consequently, diminishing the levodopa-induced motor fluctuations and dyskinesia (37). Until now this procedure has been used in several thousands PD patients, all over the world, making it a worldwide reference procedure for advanced PD (33).

2.3.3 Demanded Infrastructures and Human Resources

A patient suffering from PD goes through different stages with different needs corresponding to each stage, which makes the requirement for infrastructure and human resources alter accordingly to the stage the patient is in (8). As one can observe, in table 2.2 a set of PD effects (right column), per disease stage, and the corresponding health system requirements (left column) are presented. Additionally, the cost for these measures is quite high and the need for specialized personnel, infrastructure and equipment is significant (8). Though the number of citizens requiring these procedures is still small, a higher demand in the future due to population's aging is expected unless a cure is obtained.

Table 2.2: Parkinson's Disease health system requirements through the disease's different stages (Adapted from (8)).

Early Stage	
Periodic medical controls. Outpatient clinic, may be managed by non-specialist. Treatment requirements simple.	Preserved autonomy and independence. May retain job.
Intermediate Stage	
More frequent medical control required. May need specialized care. Treatment requirements more complex (physical and speech therapy, in some cases surgery).	Motor impairment and disability more evident. Motor complications (fluctuations and dyskinesias).
Advanced Stage	
May require hospital admissions and participation of other medical specialties (urologist clinician, gastroenterologist, orthopaedist, psychiatrist, specialized nurses, social workers). May require PD surgery.	More pronounced motor complications, non-motor complications (urinary, autonomic, cognitive impairment, falls). Deglutition disorders.
Final Stage of the Disease	
Institutionalization as a last resort.	Major disability, patient may become bedridden or need significant degree of assistance (feeding tube, gastrostomy).

2.3.4 Related Costs

According to (38), PD is the fourth most costly neurological disease after migraine, stroke and epilepsy. Furthermore, in 2011, an international study of PD across European countries showed that this disease has a considerable economic burden on European populations (1). An analysis of PD costs was made for six countries: Austria, Czech Republic, Germany, Italy, Russia and Portugal. On average, 31% to 52% of patients needed help with daily living activities and 76% to 96% of those patients were taken care by family members or volunteers (1).

In table 2.3, a cost of illness and care in PD, from a societal perspective, per patient over a 6-month observation period is presented. These costs are divided into two groups: direct costs and indirect costs. The first one is related to inpatient care (hospital and rehabilitation costs), outpatient care (cost per visit to the physician), prescription drugs, care (given by professional services or family members), patient co-payments (PD-related expenses documented by patients) and special equipment while the latter is linked to productivity loss (sick leave/early retirement). As one can observe, Eastern European countries (Russia and Czech Republic) show lower expenses when compared with Western European countries. With the exception of Portugal, these were the expected results. Moreover, direct costs reimbursements by the National Health Insurance (NHI) were lower in Eastern Europe (49% for Czech Republic and 47% for Russia) whereas in Western

Europe the reimbursements rates were within 59%-89%. In addition, as the disease severity increases, so does the cost for all countries, again with exception of Portugal, where costs in higher disease stages decrease (figure 2.1).

Table 2.3: Average cost of illness and care in PD from a societal perspective per patient over a 6-month observation period.(Adapted from (1)).

Cost (Euros)	Czech Republic	Austria	Portugal	Germany	Italy	Russia
Direct	3306 (60%)	5892 (60%)	2070 (69%)	6027 (70%)	5838 (70%)	1755.4 (67%)
Indirect	2204	3928	930	2583	2502	864.6
Total	5510	9820	3000	8610	8340	2620

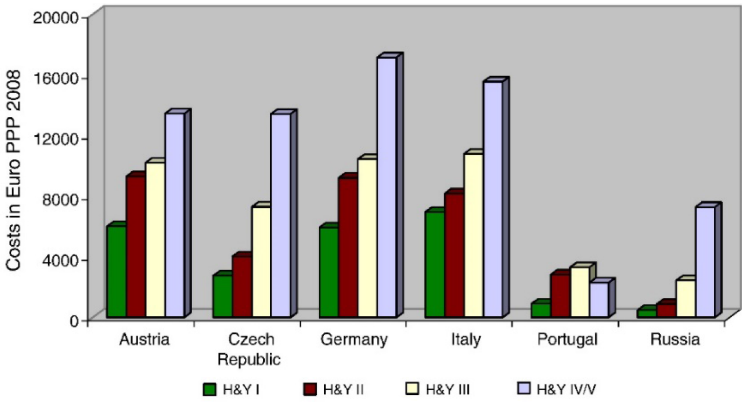


Figure 2.1: Total Costs stratified by disease stage and country. The green color represents the first stage of the disease while the gray color indicates the last stage of PD. (Adapted from (1)).

2.3.5 Prevalence and Incidence

Currently in the United States of America (USA) more than 40% of people with ages over 65 and diagnosed with PD, do not see a neurologist and therefore have a higher probability for injury or death (13). Likewise, in Europe the clinical appointments's attendance by PD patients is far from being the desirable. For example, in Portugal the average number of visits to a neurologist per person in six months is less than one while for the general practitioner (GP), in the same period of time, the average is less than half a visit, as shown in figure 2.2 (1). This difference, across countries, in the number of consultations per capita, can be due to cultural factors or due to differences in co-payments and physician density. For example, in Bolivia, a developing country, a door-to-door prevalence study has shown that none of the individuals diagnosed with PD have sought or even received medical care for their condition (11). Population is aging fast, mainly in wealthy countries, and consequently the economic burden of PD increases as well. The situation only deteriorates when analyzing the estimations for PD patients in 2030. As shown in figure 2.3 the number of individuals diagnosed with PD was of approximately 4 million in 2005 and that number is expect to double by 2030 (2). This scenario becomes more alarming when you take into account examples such the one of Bolivia. Likewise, another upsetting example is China. Although being a country with an economy in exponential growth, China still faces difficulties when dealing with PD patient care. For instance, 68% of rural and 37% of urban PD cases are not diagnosed (12). Also, there is a huge lack of neurologists and less than 100 movement disorder specialists (14) for more than 2 million individuals suffering from PD (2).

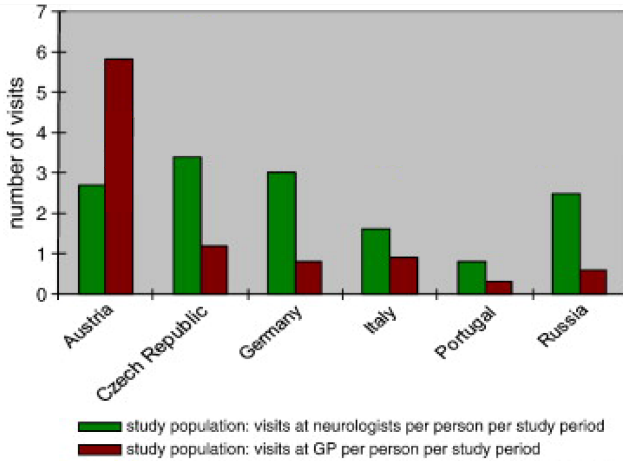


Figure 2.2: Average consultations, per PD patient, during the study period of six months(Adapted from (1)).

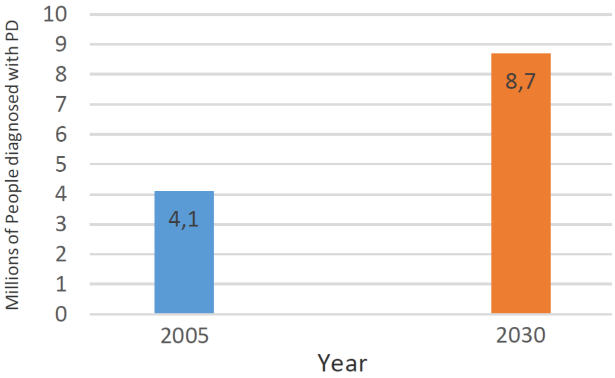


Figure 2.3: Estimate of individuals, with more than 50 years old, with PD for 2030 (Adapted from (2)).

Chapter 3

Telemedicine: Monitor Parkinsonism

According to a study made in 2014 by *Instituto Nacional de Estatística* (39) the resident population in Portugal is expected to decrease until the year of 2060, from 10.5 million people in 2010 to 8.6 million in 2060. Furthermore, this population decline is expected to alter the age structure of the Portuguese population resulting in a continued and strong aging of Portuguese residents. Therefore, a forecast is made between 2012 and 2060 for the aging index to increase from 131 to 307 elderly people per 100 young people. Considering this increase in the aging index, if during this period of time the cure for PD is not reached, the number of peopled diagnosed with PD is also expected to increment.

Nowadays there is already a great struggle to train enough caregivers to deal with the current PD population. As a consequence of the the continuous growth of this elderly number, it is expected there will be a higher number of patients to attend, treat and monitor, higher costs and a larger demand for infrastructures related to PD treatment. Ergo, new and better solutions must be found in order to reduce costs and the need for new infrastructures without losing the quality of the health services provided. The answer is within the area of remote monitoring technologies.

Presently, 2.7 billion people have broadband access and 1.4 billion own a SP (40). With the technology-boom in the last decade driven by the development of high-speed internet connection, drop of telecommunications cost, great advancements in computer technology and means of communication (41), among others, the global market for Telemedicine rapidly grew, and is still growing fast (42; 43). PD is a disorder that suits well Telemedicine since it is primarily assessed visually, there is limited mobility and an ongoing multidisciplinary care is demanded (44). Take for instance treatment and monitoring of tremor; this still represents a challenge for physicians due to its characteristics' high variance within one day and over several days (45). Moreover, in clinical practice, information about patient's motor fluctuations is obtained by their ability to recall the number of hours of ON time (i.e. medications are effective in attenuating symptoms) and OFF time (i.e. when medications are not effective) (25). Nevertheless, this kind of self-report might be subject to perceptual bias (e.g. patient cannot differ dyskinesia from other symptoms) and recall bias (lack of accuracy of the recollections retrieved). Therefore, the clinical observations as well as being time consuming are not always representative, since the testing environment can be stressful for the patient, making hard to obtain enough information on the patient's condition (25; 31; 45). Hence, reliable quantitative tools are crucial in monitoring motor fluctuations of PD patients either for routine clinical care as well for trials of novel therapies (3).

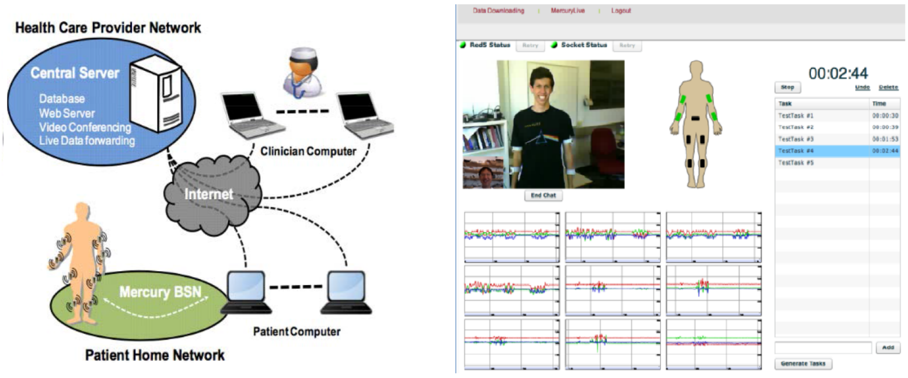
Recently, due to the mass marketing of SPs, the term mobile health (mHealth) (46) has emerged on this already broaden concept that is Telemedicine. This recent concept describes Telemedicine services supported by mobile communication devices, such as wireless patient monitoring devices, SPs, personal digital assistant (PDA), tablets and computers. The heart of mHealth, and thus the drivers of the created Telemedicine systems, are within the web platforms, mobile applications (apps) and wearable sensors. Although being a recent technology, apps have enabled the direct delivery of care, real-time monitoring of patient's vital signals, delivery of various types of patient information to either the responsible physician or to clinical research. Furthermore, a tremendous growth of sensors as accessory to health apps has been taking place due to their low sale price and small size, making them affordable wearable devices (46).

There is a great interest in obtaining more information relatively to the impairment imposed by the disease in PD patients in a home environment over long periods of time. Therefore, due to these types of technologies being widely available, easy to work with and carry, a great number of research groups have shown interest on mHealth and are consequently prone to develop new alternatives to improve the status assessment of PD patients. Hence, the next sections will be based on the description of several projects in the area of mHealth applied to PD.

3.1 MercuryLive Project Web Portal

In order to monitor PD patients in a home environment the MercuryLive Body Sensor Network (BSN) (31; 3; 47; 48) platform was created. The interaction between the patient and clinician was enabled via a web-platform that provided access to the sensor's data (worn by the patient) and a video conference feature. Algorithms were created in order to monitor the severity of fluctuations in patients in the late stage of PD.

As depicted in figure 3.1 the implemented home-monitoring system was composed of software services running in three levels: a central portal, patient's hosts and clinician's hosts. In order to ensure data security and high availability a central portal server was created so that a safe and reliable central location for coordinating real-time data collection and video was available. This portal server was in a healthcare center and only people with given authority could access it. The patient's host runs the BSN, where physicians can adjust remotely different parameters of the sensor nodes (e.g. number of recorded sensor channels, sampling rate, among others) worn by the patient. All sensor data collected is stored in the central portal. On the other hand, the present system besides collecting, storing and providing patient information it also allows for video communication capability between patients and clinicians. The proposed platform was proved to be suitable for monitoring PD patient to facilitate titration of medication in the late stages of the disease.

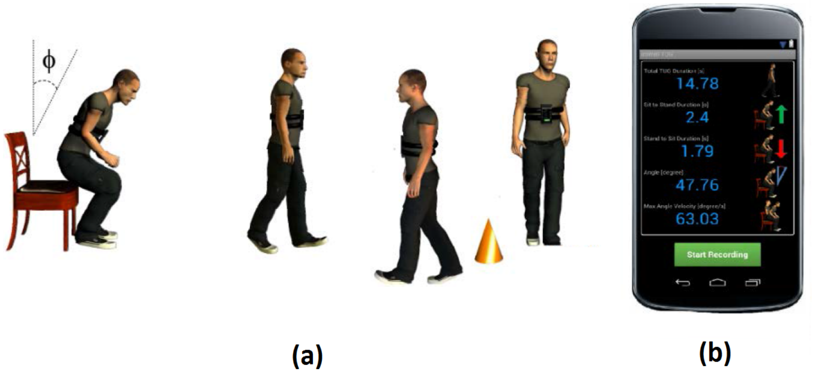


(a) (b)

Figure 3.1: (a) The architecture of the proposed monitoring system. The software services runs at three tiers: central portal server, the patient's hosts and clinician's hosts. To ensure data security a central server is made available to all through an internet connection. (b) Screen shot of the MercuryLive web-application (adapted from (3)).

3.2 Timed-Up-and-Go

The Timed-Up-and-Go (TUG) is a clinical test used to assess PD patients risk to fall, balance and mobility (49). It can be applied in any physical space whether is a physician's office or a patient's home environment. The test measures how much time it takes for a person to rise from a chair, walk 3 meters, turn around, walk back to the chair and sit down (figure 3.2). Recently, the instrumented TUG (iTUG) has been introduced (50; 51) where the patient is equipped with sensors designed for gait and movement analysis. However, with the growth of SP technology, investigation groups have been developing systems where this technology can replace the previous sensors. A good example of this test, and that it was well applied to SP usage, is the study presented in (4). Here, a subject mounts the SP on his chest or belt and initiates the app. This app records and processes the data retrieved from the SP's gyroscope and accelerometers sensors. The following parameters (that quantify the phases of the TUG test) are retrieved: the total duration of the exam, the total duration of the sit-to-stand transition, and the total duration of the stand-to-sit transition. Moreover, other parameters such as maximum angular velocities and upper trunk angles, were taken. The system is user friendly and the multiple tests can be done in a single day in the home environment to, for example, access impact of drugs. Since, the data is automatically updated to the server, clinicians can gain insight into the overall health of patients.



Total TUG Duration [s]
14.78
Sit to Stand Duration [s]
2.4
Stand to Sit Duration [s]
1.79
Angle [degree]
47.76
Max Angle Velocity [degree/s]
63.03

Figure 3.2: (a) iTUG test phases and SP implementation in the user's chest or belt (b) iTUG SP's app displaying the parameters of the test (adapted from (4)).

3.3 Mobile Self-Management

Besides the neurological examinations, already referred, motor assessment is mainly based on historical information and home diaries. As already said recalling of important events, in addition to being mainly subjective, relies on patient's memory and perception of their symptoms. The PERFORM system (5) is a telematics platform for PD remote monitoring. Similarly to the previous study the system offers a set of wearable sensors devices for the recording of patient's motion signal, in a home environment, and a set of software algorithms for the signal processing. Furthermore, it also offers a customized graphical user interface (GUI) to patients so they can enter useful information for the clinician such as medication intake (kind, dose and time), meals (type of food, amount, time) and answer the PD questionnaire with 39 questions (PDQ-39) for the evaluation of physical, emotional and psychosocial aspects of QoL (52). The users could interact with this interface through usage of a mouse or with the touch screen modality (figure 3.3). The final feedback from the patients and clinicians was positive. This system was tested in three European hospitals (University of Navarra Medical School Hospital (Spain), University of Ioannina Hospital (Greece) and the Nuovo Ospedale Civile S.Agostino-Estense of Modena (Italy)). In the end, the system showed the feasibility of using wearable technology with machine learning algorithms in order to perform continuous monitoring of PD patients. Moreover, patients have also shown a good acceptance of the system.

Similarly, in (6) an app was created for PD patients which contained the following list of applications: *Medication, Appointments, MyDay* (disease status/symptoms) and *MyData* (personal and health information). PD patients normally carry with them a card to inform others about their disease in case of an emergency. The *MyData* (figure 3.4 (e)) represents this card with more information than the original showing relevant information for medical professional. Such information includes: blood type, list of current medication and PD-specific information (ON/OFF fluctuations, if carrying Duodopa pump, amongst others). The *MyDay* (figure 3.4 (f)) is a graphical display of the most relevant periods and events of the patient showing, for example, events of non-compliance with medication, therefore enabling the users to relate certain events with missed

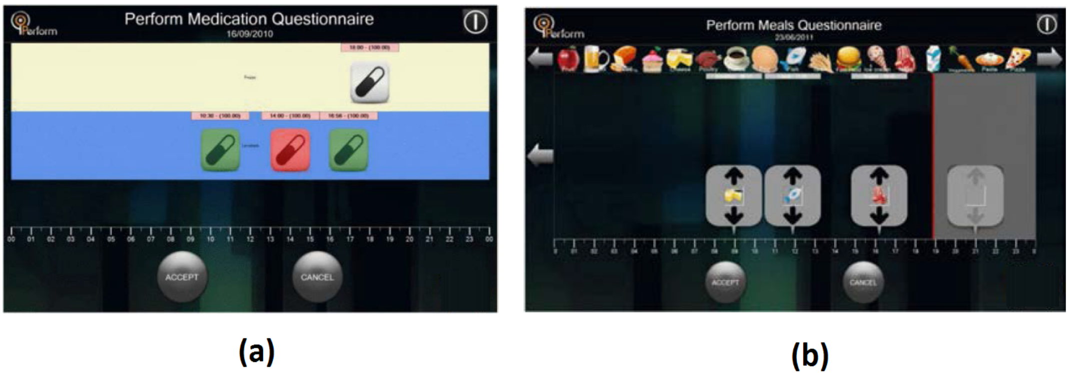


Figure 3.3: (a) Medication intake screen. For each dose and type of pill there is an associated image so that the user can easily remember which kind of medicine took and when. Moreover, the user can indicate if the medication was taken in the prescribed time. (b) Meals questionnaire screen. The patient is able to provide information about what is eating during the day (adapted from (5)).

medication intakes. Finally, the *Medication* (figure 3.4 (c)) displayed to the user the medical prescriptions. However, the user does not have the authority to change this data, only the physicians could update it. On the other hand, the *Appointments* allowed the physicians to send medical appointments into the user's SP calendar.

In the end, the user-centered and participatory design approach has shown to be efficient since the requirements obtained and implemented were approved by the main stakeholders.

Take 2 Aspirin at 08:00h every other day

Medication Reminder
17:45h

☑ 1.5 Sinemet 10/100mg
Eat before

☐ 2.0 Parlodel 2.5
Do not take with alcohol

I have Parkinson's disease.
Please allow me time.

Sara Maria Gomes da Silva
+351968496392

My medication
Sinemet 10/100 mg, Parlodel 2.5mg, Tasmar 100mg, Exelon 1.5mg

Other medical conditions
Diabetes; High blood pressure

Relevant Information
Blood type A+; Carrying DBS; On-Off fluctuations; Carrying Duodopa Pump

Figure 3.4: (a) Medication main menu (b) Add intake (c) Medication reminder (d) Pop-up for MyData (e) MyData main screen (f) MyDay (adapted from (6)).

Chapter 4

Case Study Hospital São João

Hospital São João (HSJ) in Porto, besides being one of the major hospitals in Portugal (around 1000 beds), is a pioneer and leader in PD diagnosis and treatment, therefore dealing with patients from every region of Portugal. The protocol established in HSJ defines that once a patient is submitted to a DBS surgery (advanced stage of PD) and discharged, he is expected to meet his physician in the 1st, 3rd and 6th month after surgery and then every 6 months. Patients from and nearby the district of Porto are usually seen the first month after being discharged whereas patients outside this district (more than 100 Km) are only evaluated 3 months later (53). In those appointments the UPDRS scale is used to evaluate the impairment caused by the disease. According to the patient's answers to the UPDRS exam and with the clinician's observation of the patient's speech, motor capabilities, humor and others, there can be a medication adjustment, calibration and regulation of electrodes frequency, among others. The referred pattern is presented in table 4.1.

Table 4.1: Appointment protocol used for monitoring PD patients who have undergone DBS surgery at HSJ. Patients whose residence is outside the district of Porto, only start attending these appointments 3 months after surgery.

Appointments after surgery
1 month
3 months
6 months
Every 6 to 12 months

4.1 Nurse Call Center

According to the case study presented in section 2.3.4, in average, a PD Portuguese patient only attends a neurology appointment a single time 6 months after surgery. Such a low number can be justified by several reasons, ranging from: the physician's tight schedule, patient's motor difficulties or even patient's residence being too far from the hospital and thus they might be completely dependent on long distance public transportation or even family members, to attend a consultation.

Thus relevant information in respect to the months preceding the consultation should be given in every appointment. The main concern is based on the fact the patient has to summarize 6 months of living daily with the disease, i.e., reference important events related to PD that might be of help to the physician's diagnosis. However, this task is based on patient's capability to recall his well being in the past, which can be difficult for someone with a declining age and in an advanced stage of PD. Besides this fact, it is also dependent on the correct interpretation and description of his symptoms although as described previously PD patients tend to misinterpret their symptoms. Therefore, physicians can only work on a diagnosis and treatment based on this poor detailed information plus what they visually assess during the appointment. Furthermore, patient's state during the appointment is a mirror of the disease's impairment in that specific day or week not giving any indication of previous weeks and months. Moreover, the patient can always be negatively influenced by fatigue and stress.

Ergo, in order to try to solve these issues besides the mentioned appointment protocol, HSJ has created a call center system, managed by the nurses, for the same group of PD patients mentioned above. This call center works as a complement to the appointment's protocol, with nurse/patient interaction occurring in the months before the scheduled appointments. After being submitted to DBS surgery patients go through a recovery period in the hospital being mainly accompanied and treated by nurses. During this period patients are encouraged to perform daily living tasks such as dressing, brushing their teeth, turning in bed by themselves, etc, so that when in a home environment they can continue to be autonomous. Hence, this call center has the goal of obtaining information on how the patient's daily living has been since discharge and if there has been any alteration in their QoL. In this way, more information is retrieved on important events related to PD that affected a certain patient QoL besides that obtained in the hospital appointments. This additional measure to monitor HSJ's PD patients focus on a phone call and a some guidelines (Appendix B). The first phone call happens 72h after the patient has been discharged; then 15 days later, 1 month, 3 months and then every 6 months.

4.1.1 Additional appointments

The activity diagram presented in figure 4.1 illustrates how the call center presently works at HSJ. First, the nurse checks which patient is scheduled to call next. If the patient answers the phone, then the nurse should follow the provided guideline (Appendix B). This guideline approaches different topics such as medication, dyskinesia, OFF periods, speech, physiotherapy and self-care. Nevertheless, the questionnaire is a bit scarce in terms of information. For example, questions related to dyskinesia only address if there were episodes and if yes if they were disabling. However, it does not consider the event duration, how many times occurred in one day or a week, time of day in which they occur more, level of disability imposed, among others. Similarly, the questions related to OFF periods only approach if there was any and if the patient had them before the surgery and if, after being submitted to DBS surgery, there was any improvement. Again, it does not consider event duration, period of occurrence, under which circumstances, etc. Furthermore the nurse does not visually observe the patient, thus a description of current motor related symptoms is hard to evaluate since there is always a high probability of an erroneous judgment made by the patient on his current symptoms.

Consequently, case the patient's testimonial describes a situation where the QoL is low then the nurse can contact the physician responsible and together decide the most accurate solution. The physician might suggest regulating the dose of medication or, in case the former ceases to be a valid solution, schedule an additional appointment so that he can do a thorough evaluation leading to, in a great number of cases, a patient having more appointments than those needed (table 4.1). The patient is informed of the decision and the nurse terminates the phone call.

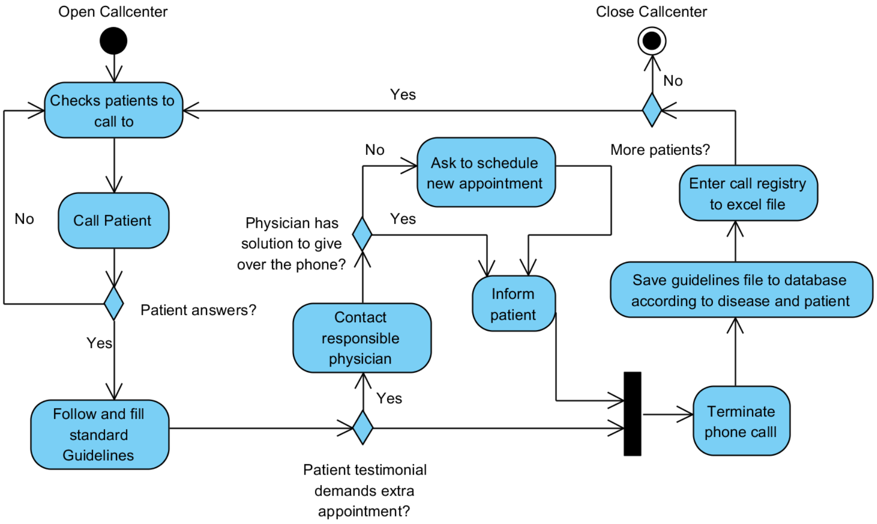


Figure 4.1: Activity diagram of the current practice existent in HSJ nurse call center.

4.2 Objective

As previously mentioned due to patient's misinterpretation of their symptoms, a great number of additional appointments are scheduled in order to better understand their described state and how can the physician improve patient's QoL. For patients living in the district of Porto, those additional appointments should not cause great inconvenience since the time and cost of the journey are bearable. However for patients whose residence is more than 100km far from the hospital the scenario can be a bit more complicated.

In order to comprehend the cost and duration these latter patients have to bear to attend an appointment at HSJ and, in addition, the impact those factors would have on their physical and psychological state a retrospective study was done. Furthermore, analysis of the number patients who had to schedule additional appointments derived from a decision made, by the nurse and doctor, when in contact with the patient through the nurse call center was of great interest.

4.3 Methodology

To determine the average cost and time a PD patient (with residence outside of Porto) spends in an appointment at HSJ a total of 168 cases of PD patients, who were submitted to DBS surgery between 2001 and 2014, were considered. From this set of patients, only those whose first surgery was between 2009 and 2014, was not diagnosed with another chronic disease or had history of post-surgery infection, and whose residence was at a distance higher than 100 Km from the HSJ were selected. In the end, there was a total of 25 patients having all had at least 5 of the expected pattern consultations and where 73% were under 60 years and 73% were males. For all the represented districts in figure 4.2 (Viseu, Guarda, Castelo Branco, Faro, Funchal, Portalegre, Leiria, Santarém, Coimbra, Covilhã) the journey's costs (forth and back) for transportation to Porto (either by Bus, train and car) were calculated. Calculations were made using an online car travel calculator, to make an estimation of car expenses, and ticket prices available online at railway and bus websites.

Figure 4.2: Representation of all districts of residence from all the selected 25 patients and Porto.

4.4 Results

From the sample group 72% of patients, after talking with the nurse at the call center, had additional appointments scheduled. Furthermore, knowing the city of residence of each individual the price and duration of a journey to HSJ was calculated. All calculated values, for different journeys, are represented in the Appendix D. As the distance from HSJ increases so does the journey's time and cost. There are two districts, Viseu and Portalegre, which do not have train stations and thus the average price and trip duration were not calculated.

In the end, it was possible to determine that, for every journey to the hospital and back home, a patient can expect transportation expenses ranging from 21 Euros to 190 Euros, journey duration ranging from 6h to 16h. Furthermore, according to Dr. Maria José Rosas, experienced neurologist in HSJ, every appointment has an average duration of 1 to 3 hours and consequently the waiting time for the patient is, in average, 3 hours. All those costs, only account for public or private transportation, without considering a possible need to stay in a hotel (to attend an early appointment or the lack of transportation home), the need to miss at least a day of work, meals, among others. Furthermore, according to the doctor, these long journeys impose great stress and fatigue in patients, affecting their mood and consequently the motor performance and memory capabilities during the appointment and thus having a critical impact on their treatment. Table 4.2 indicates the minimum, maximum, average cost and duration patients should expect.

Table 4.2: Journey's cost and duration (minimum,maximum and average) related to PD patients submitted to DBS surgery at HSJ and whose residence is more than 100km from the hospital. Moreover, duration time of waiting and appointment are presented.

	Min.	Median	Max.	Avg.
Journey Cost (euros)	21.3	52.7	190.3	59.65
Journey Duration(hours)	2.8	6.7	16.5	7.24
Waiting time hospital(hours)		3		
Appointment duration (hours)		1-3		

4.5 Conclusions and proposed methodology

As previously referred, HSJ deals with PD patients from every region of Portugal. Patients suffering from this illness attend to HSJ for the DBS surgery because they are recommended by their previous physicians from their local hospital or healthcare center. However, in order to obtain the best treatment available the patient might have to make some economic, physical and psychological sacrifices. Journey's cost, duration and the average waiting time can cause stress, fatigue and distraction on the patient which will have a negative impact during his appointment, mainly on his ability to recall and describe his daily living and on his performance on the UPDRS-motor assessment. Usually, information on patient's well being on a daily basis are only retrieved in each appointment, where the patient is expected to make a general overview of his life over the past few month, physical and psychologically, since he and the physician last spoken. HSJ tries to make up for this disadvantage through the nurse call center. Although, more information is retrieved from the patient previous to the appointments, the truth is a great number of times the patient's subjective description of his symptoms (motor and non-motor) is not always accurate with the reality and it ends up with patients having to attend the hospital more times than needed.

Therefore, there is a high demand for system that allow for a successful and effortless tracking of PD progression when patients are at home. Physicians ask for solutions that allow them to objectively and visually assess the patient in a home environment.The HSJ medical staff is mainly interested in motor PD features, regarding motor control and patient's capability to perform daily routine activities. Hopefully, with more information of the days, weeks or months preceding the appointment the physician will be able to be more accurate on his diagnosis and consequently and the patient's treatment, thus improving patient's QoL. Furthermore, due to this fact it is expected a reduction in the need for extra appointments.

Part II

Telemedicine multimedia systems to support Neurodegenerative diseases participatory management

Chapter 5

Design of the proposed system

The goal of this project is to develop a personal health system with a closed interaction between PD patients, who have under gone DBS surgery at HSJ, and their medical staff. For the proposed system the author together with a team of 2 nurses and 1 doctor from HSJ, discussed the demanded requirements for the two actors who are expected to interact with the platform: PD patients and medical staff. The HSJ medical staff is mainly interested in motor PD features, regarding motor control and patient's capability to perform daily routine activities.

From the point of view of the patient this platform will fulfill two basic requirements: allow them to give more accurate, objective and constant information on their daily living activities (difficulties and accomplishments) and QoL, improve the current means of communication while enhancing the quality of interaction between both sides and, in the overall, will give them a sense of greater control of their illness' development since they will play a more active role on its management. On the other hand, from the medical staff perspective the patient's daily living information will arrive statistically processed and objectively presented. In addition, patient's motor capabilities and disabilities analysis, in a home environment, will be possible through video source enabling the medical staff to visually access patient's well-being and allow for treatment improvement, thus enabling reduction of extra appointments scheduled. Therefore, in the present chapter the structure for the proposed web platform, known as Monitoring Parkinson's (MoPA), will be described.

5.1 System Requirements

As previously described, there are some issues related with the data retrieved relatively to patient's well being when they are in their home environment. Therefore, the goal of the MoPA system is to present solutions to improve the communication and information exchanged between the hospital medical staff and PD patients.

Hence two actors will use the MoPA platform as a mean of interaction, being those the patient and medical staff. Although the developed database has an important role to play in the system, the fact it is integrated as an internal part of this platform (users only interact with it through the

MoPA system) makes this part of the system not fit to be represented as a separate actor. The actor patient is a representation of people who have been diagnosed with PD, submitted to DBS surgery in HSJ and that are currently being monitored whereas the actor medical staff represents the nurses and physicians of HSJ who have accompanied such patients during their diagnosis, treatment and now in the management of the disease.

Each one of these actors will have a different role to play in the platform and consequently their requirements will vary. Therefore, in conversation with nurses and physicians from HSJ it was possible to obtain a group of requirements according to the different actors. Figure 5.1 illustrates the use case diagram of the MoPA system. Each presented requirement will be analyzed in greater detail throughout this chapter.

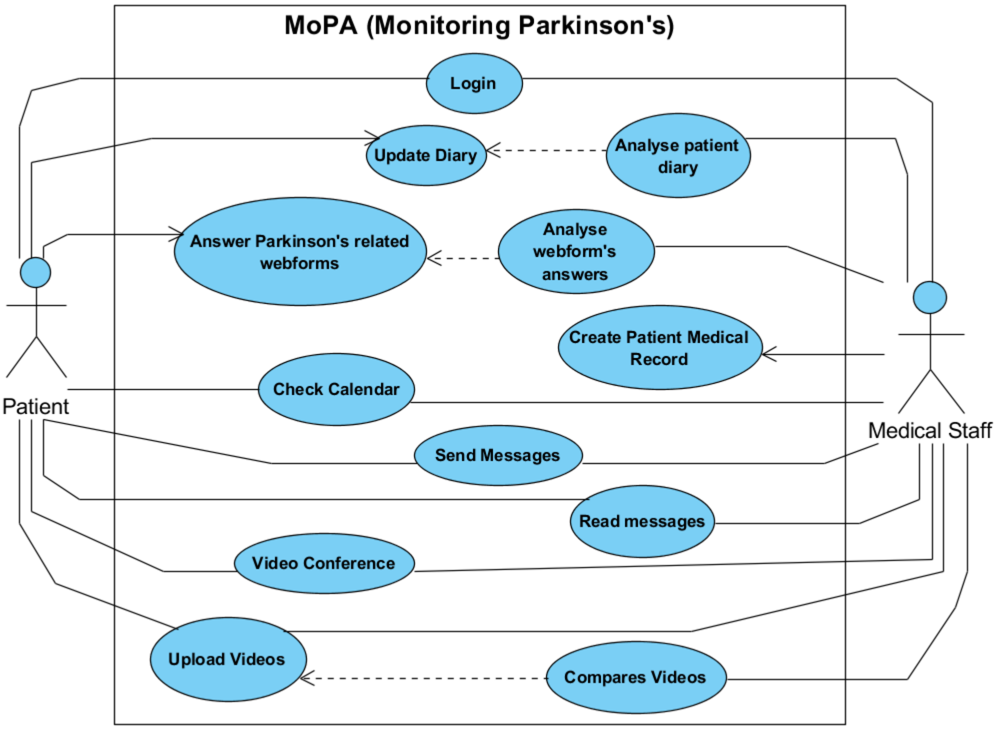


Figure 5.1: Use Case diagram illustrating the requirements for both actors that will interact with the MoPA platform.

5.1.1 Patient Web Platform Requirements

Figure 5.2 represents the use cases diagram for the requirements made by the actor patient. As mentioned above, it is expected that with this platform the patient will be able to send more accurate and detailed information in a more constant and objectively manner. Thus, patient's requirements will be directly related to interaction with different sections of the platform where the impairment imposed by the disease will be assessed in different ways. Consequently, the patient has four requirements : *Access profile, Update the self-assessment diary, Answer non-motor symptoms webform, Access calendar, Access video gallery* and *Access chat*. Each of this requirements represent the interaction between the actor patient and a section of the platform, and in each there are one or more included actions that the patient is expected to perform. Take for example the requirement *Access Video Gallery*; here the patient is expected to access this section and upload a video of him performing tasks of the UPDRS-motor exam. However, if the patient is not able to record or upload a video he then can answer a webform related to the same subject and upload the answers to the database.

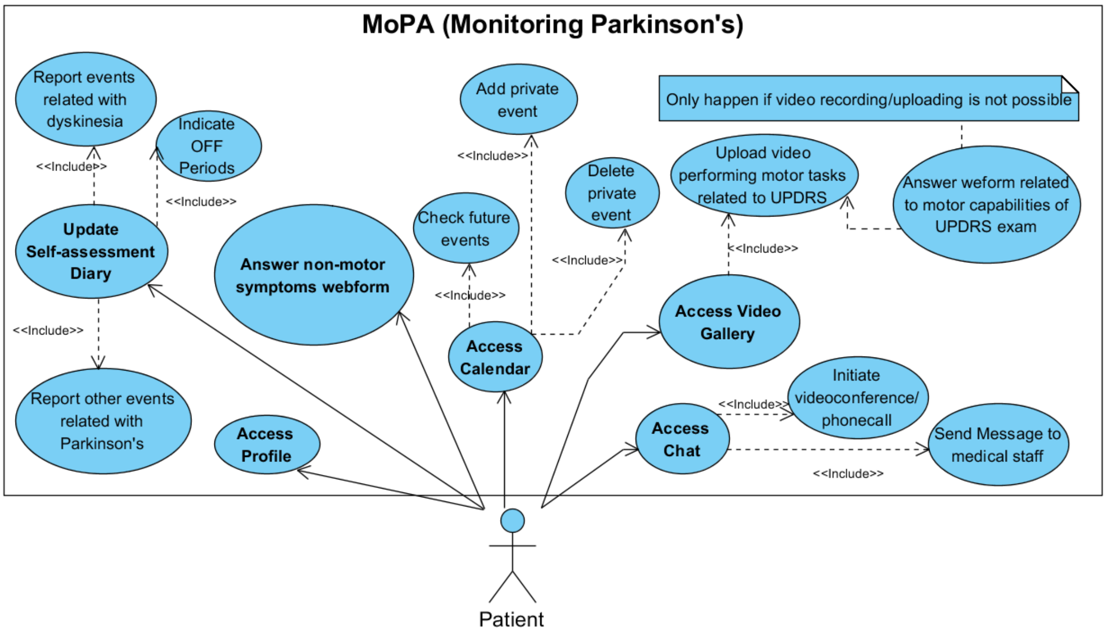


Figure 5.2: Detailed use case diagram illustrating the requirements of the actor patient for the MoPA platform.

5.1.2 Medical Staff Web Platform Requirements

On the other hand, the requirements for the medical staff are related to information sent by the patient and the analysis of such data. Hence, the actor medical staff has four requirements: *Access profile, Access patient self-assessment diary, Access webforms charts, Access calendar, Access video gallery, Access Chat* and *Access Patient Medical Record*. Again, each action represents an interaction between the actor and a section of the medical staff web platform. Nevertheless, although for the actor patient each requirement demanded an upload of information relatively to his daily living, for the actor medical staff it can be an action such as update, edit,delete or upload or it can be just analysis of uploaded data to the database by the actor patient. For example, consider the requirement *Access patient self-assessment diary* and *Access calendar*. For the first requirement, the actor is only expected to visually analyze the presented data, since this is already processed data from patient's description of disease's related events, and if desired compare it with other stored information. It is not expected from the actor to add information or edit any. On the other hand, the latter may require from the actor the need to add, delete or edit events of interest either for the patient or the actor itself.

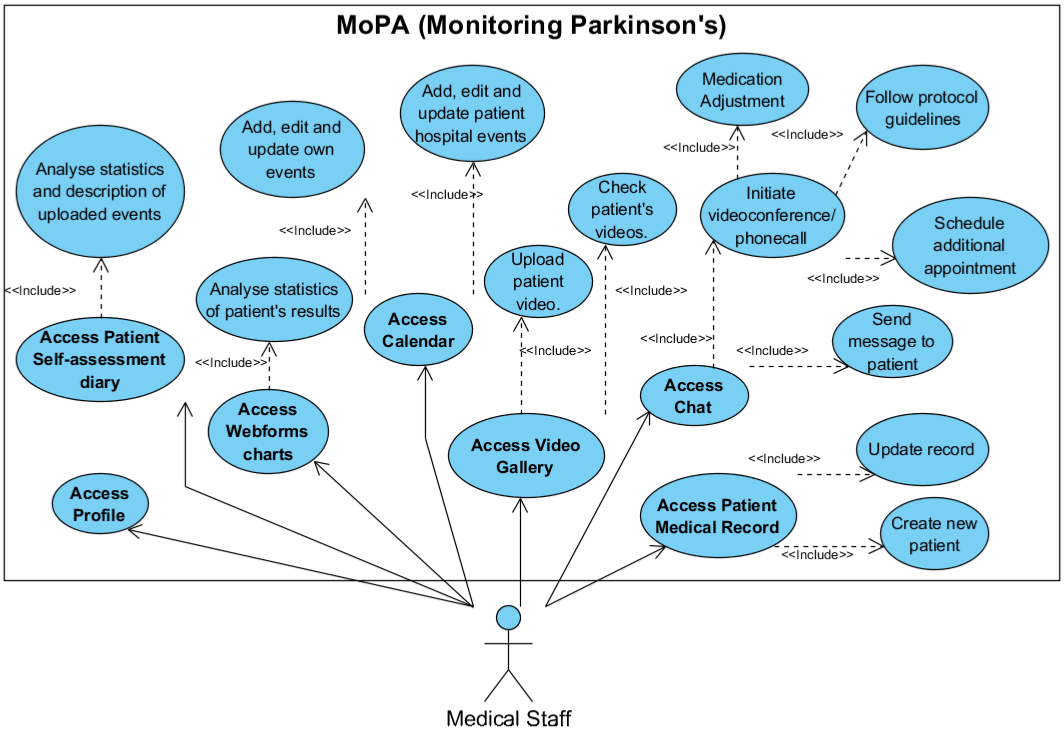


Figure 5.3: Detailed use case diagram illustrating the requirements of the actor medical staff for the MoPA platform.

5.2 System Architecture

The architecture for the proposed home-monitoring system is illustrated in figure 5.4. This system involves software services running at three tiers: a central server, patient's and clinician's web interface.

In one hand, the web interface works as the presentation tier of this system, to where all information will be output. This interface is the tier through which all users will interact with the system and it was developed using the web application framework CodeIgniter. The web interface communicates with the MoPA server (implemented with the XAMPP) which in turn interacts with MySQL database. On the other hand, the MoPA central server is responsible for making the bridge between the web interface and the database. This tier ensures both data security and high availability and at the same time is responsible for controlling the application's functionality by performing detailed processing. Finally, the database server is responsible for managing all stored data.

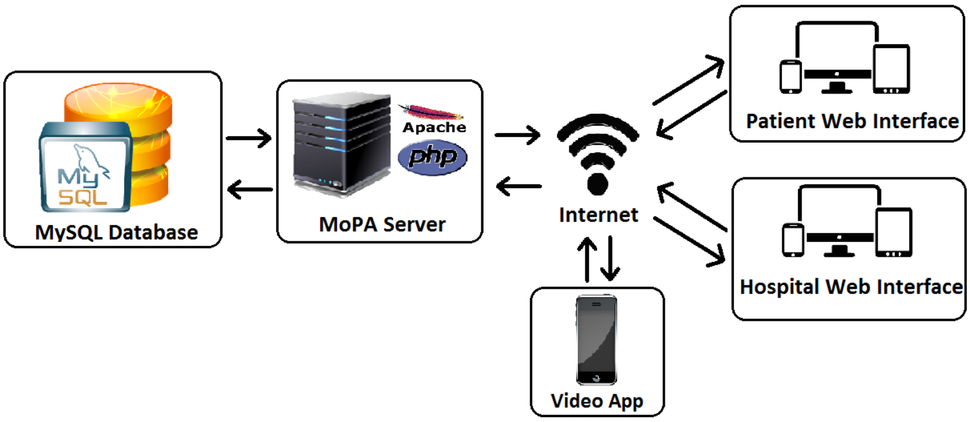


Figure 5.4: Proposed system architecture for the MoPA platform.

5.3 Proposed solution

Since the requirements, for each actor, have been defined it is import to understand the expected workflow for the patient and medical staff when interacting with the MoPA platform. Therefore two flowcharts were designed (figure 5.5 and figure 5.7). In addition, to better visualize some of the proposed features a few prototypes will be presented in figure 5.6 and figure 5.8.

5.3.1 Patient Web Platform

As illustrated in figure 5.5 patients are initially faced with a login page (figure 5.6 (a)) where their unique username and password are requested so to obtain access to the MoPA patient web platform. Once they are granted access, patients are redirect to the main panel known as dashboard. From herein, the patient can interact with five different sections : *Self-assessment Diary, Calendar, Non-motor symptoms webform, Chat* and *Video Gallery*. As one can observe from figure 5.5, for each section, it is expected of the user to insert, in different manners, information related to symptoms characteristic of PD that the patient has been suffering, in a daily basis, except for the *calendar*.

A brief description of what is expected of the patient, in each section, is synthetically indicated in figure 5.5 and a more detailed description is given in the following item list. Each section is represented by a icon which gives a visual representation of the type of action the user must perform (figure 5.6 (b)). Take for example,

- *Self-assessment Diary*

  This section, represented by a book icon in the dashboard, is illustrated in (figure 5.6 (c)). Here the patient is expected to upload daily information about dyskinesias episodes, OFF and ON periods, hours of sleep, missed medication. This section focus more on the duration and repetition of such events, although if the user wishes to provide a description of each event it is also possible.

This information is important to the medical staff since it helps understanding the impairment imposed by the disease in a daily basis. For example, if patient's description of events continues to have a negative impact on what is considered a good level of QoL for PD patients, then the medical staff can get in contact with him and try to find a solution to improve it.

- *Non-motor symptoms webform*

  The present section, illustrated in figure 5.6 (d), is represented by a pencil icon and it is related to the second part of the UPDRS exam. In this section the patient must answer a brief questionnaire in which his capability to perform some daily living tasks are objectively analyzed. According to the answer chosen, from a total of five with each bearing a single value, a score will be given per question. In the end, the patient will be given a final score which will give the medical staff a general idea of patient's QoL during a certain period of time.

- *Video Gallery*

  The video gallery, represented by a video camera icon, is the section of the patient web platform where they are expected to upload videos of themselves performing motor tasks related to the third section of the UPDRS in a home environment. Such tasks might be, for example, taking a glass of water to the mouth without spilling, perform a TUG exam,touch repeatedly the nose with each indicator finger once at a time, among others. The importance of this feature is that the medical staff will be capable of visually analyzing more often the disease's motor impairments since the patient will not be obligated to go to the hospital. Therefore, the patient is not subjected to the fatigue and stress imposed by long journeys. Moreover, suppose a phone call , from the nurse call center, where the patient describes a situation of abnormal events related to his motor capabilities; in this situation the patient himself can send a video and the medical staff can see if their complaints are accurate with their symptoms or not. Consequently, with this information decision making will be made easier.

  Additionally, in the event the patient is not able to record or upload a video he can answer some questions, retrieved from the third section of the UPDRS exam, which question some motor issues.

- *Calendar*

  The calendar section, represented in the dashboard by the calendar icon, is where patients can check the scheduled appointments at the hospital. Furthermore, events related to uploading videos, answering the webform or answering a phone call from the nurse call center can be added by the medical staff and will be available in the patient's calendar. In addition, patients are given the opportunity to add their own private events.

- *Chat*

This section is represented by a a letter icon and in here the user can send messages to the medical staff with their concerns or doubts about the disease. Moreover, there is also the possibility of the patient videoconferencing with someone of the medical staff and visually show what is troubling him.

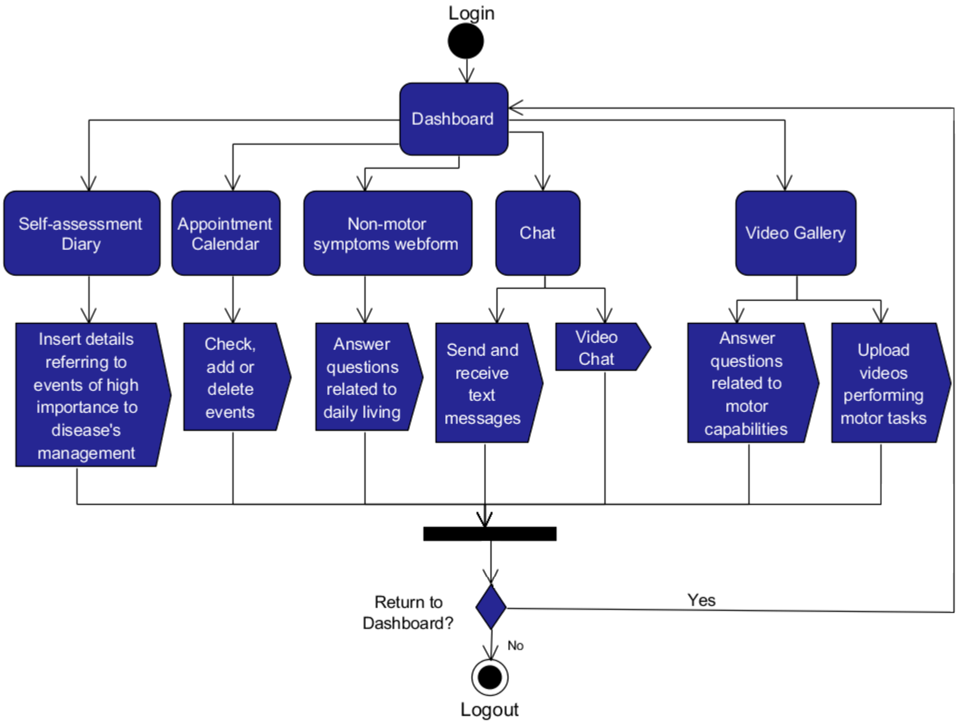


Figure 5.5: Proposed workflow diagram of MoPA Patient Web Platform.

After the user has finished his interaction with the chosen section he has the option of returning to the dashboard and access another section or if desired logout from the platform.

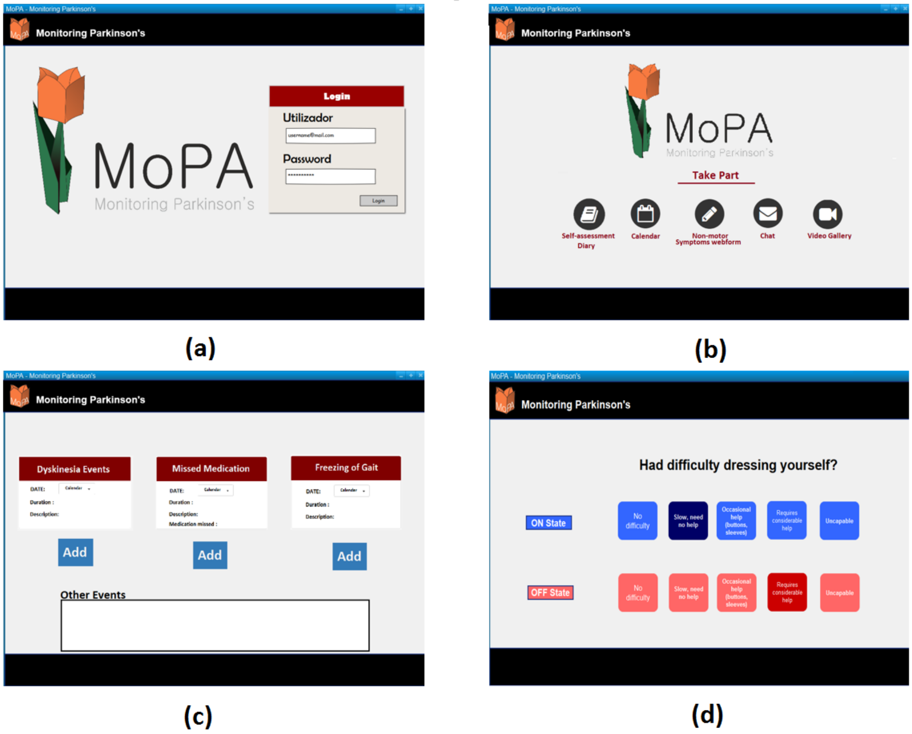


Figure 5.6: Representation of sections from the MoPA platform with which users will interact with. (a) Representation of the login page. (b) Patient Web platform dashboard page. Here the patient has links to five different sections of the platform. (c) Self-assessment diary, where patient can add description of disease's relevant events.(d) Webform related to a self-evaluation of the activities of daily life.

5.3.2 Hospital Workflow

The medical staff is firstly exposed to the same login page as the patient before having access to the hospital web platform. Once again, case the inserted username and password are accepted, then the user is redirected to the respective dashboard. On contrary to the previous platform, here the user has six sections to interact with and the links to those sections are disposed in a side bar. Those six sections are *Patient self-assessment Diary, Calendar, Webform's charts, Chat, Video Gallery* and *Patient Medical Record*. The goal of this platform is to present the user all the information uploaded by patients in a more processed and summarized manner. Similarly, a summarized description of usage, per section, is already illustrated in figure 5.7 although a more detailed description of the features the user can interact with will be given next.

- *Patient Self-assessment Diary*

  In this section medical staff can visualize the information uploaded by patients concerning different events of relevance to the management of PD. The user will be able to select one of several patients from the database and access all related information to important events such as sleep, dyskinesia and ON and OFF periods. The duration of the events, the period of the day where it occurs and event's description made by the patient will be

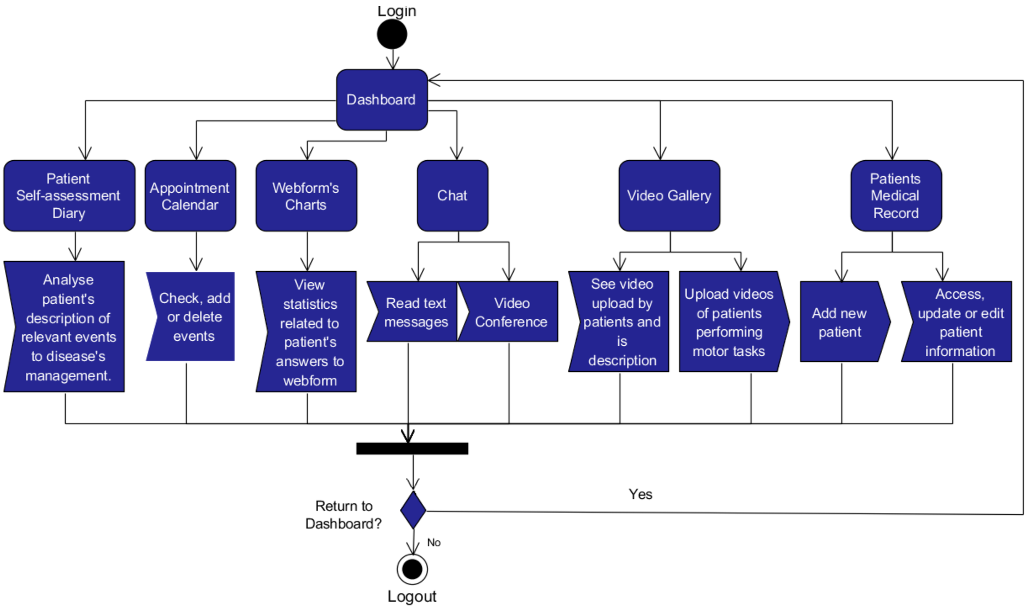


Figure 5.7: Proposed workflow diagram of MoPA Medical Staff Web Platform.

available as well as statistics of which events tend to occur more often and when. Figure 5.8 (c) illustrates well how the information can be shown to the user.

- *Calendar*

  Here the user will be able to add, edit or remove events from his own calendar. Furthermore, the user can access patient's calendar and add, edit or remove any event related to the disease's management such as appointments, scheduling to answer webform or upload video. All events related to patient's personal life can not be seen, edited or deleted. The user will only know the patient has an event for that day.

- *Webform's Charts*

  As previously referred, in every webform taken, it will be given to the user patient a final score. Therefore, the medical staff will be capable to visualize the score per date for each webform taken, as illustrated in figure 5.8 (d) and if desired see in more detailed the options chosen by the patient in each date.

- *Chat*

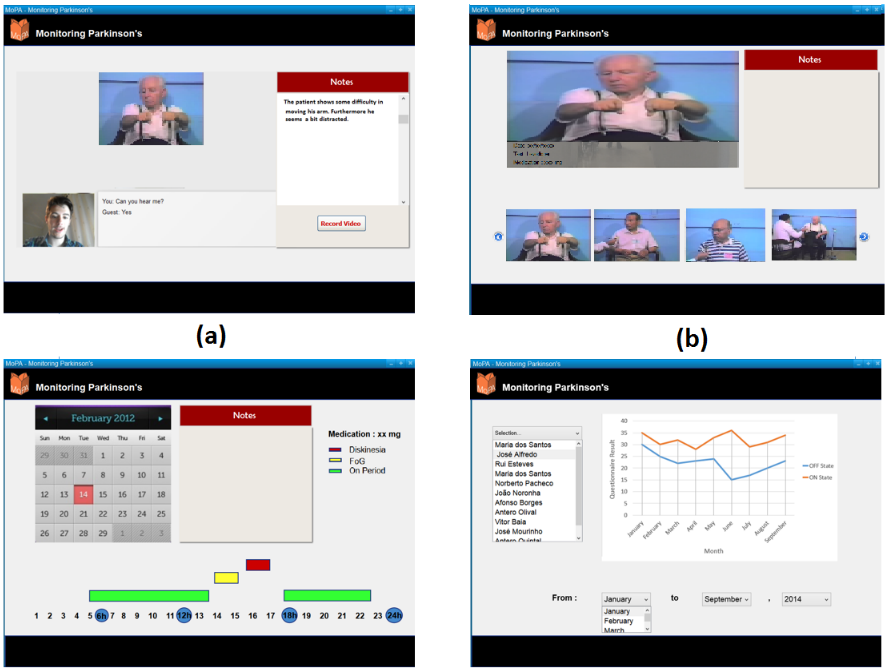
  In this section the medical staff will be capable to answer any doubts or concerns raised by the patient, and if needed start a videoconference (figure 5.8 (a)) with the patient so to visually observe him and better analyze his symptoms.

- *Video Gallery*

  Any member of the medical staff can upload a video related to a certain patient. Furthermore, as one can observe from figure 5.8 (b) the user can access the video gallery of a chosen patient and see which videos have been sent by the patient or uploaded by a colleague.

- *Patient Medical Record*

  This section contains information related to the patient. For example, here the medical staff can see patient's personal information, medical history, surgeries, dates of webforms taken and videos uploaded, among others.



The patient shows some difficulty in moving his arm. Furthermore he seems a bit distracted.

You: Can you hear me?
Guest: Yes

(a) (b) (c) (d)

Figure 5.8: Illustration of some of the features expected on the Medical Staff web platform. (a) Videoconference between the medical staff and patient. Patient can perform some motor tasks and the user can save notes. (b) Video Gallery of videos uploaded by the patient or by any member of the medical staff. (c) Illustration of the duration and time of occurrence of certain events of high important in the management of the disease, per day of the month. (d) Results of patients' webform results, per date, shown as a graph.

5.3.3 Database

All information generated in the system needs to be safely stored, made easy and quickly available so that when requested the user will not witness any delay in the upload or download of information. Therefore, in order to ensure a fluid and enriching change of information it was created a database for the MoPA system. Since, a great variety of information will be generated during user's interaction with the system, several entities compose this database, such as : *Person, Login, Medical Staff, Patient, Exam, Question, Choice, Answer, Video, Appointments,Appointments_detail, Chat, Chat_messages* and *Diary*. Figure 5.9 illustrates the entity–relationship model proposed for the MoPA platform. Furthermore, a detailed description of the function of each entity and its relationships with other entities is described.

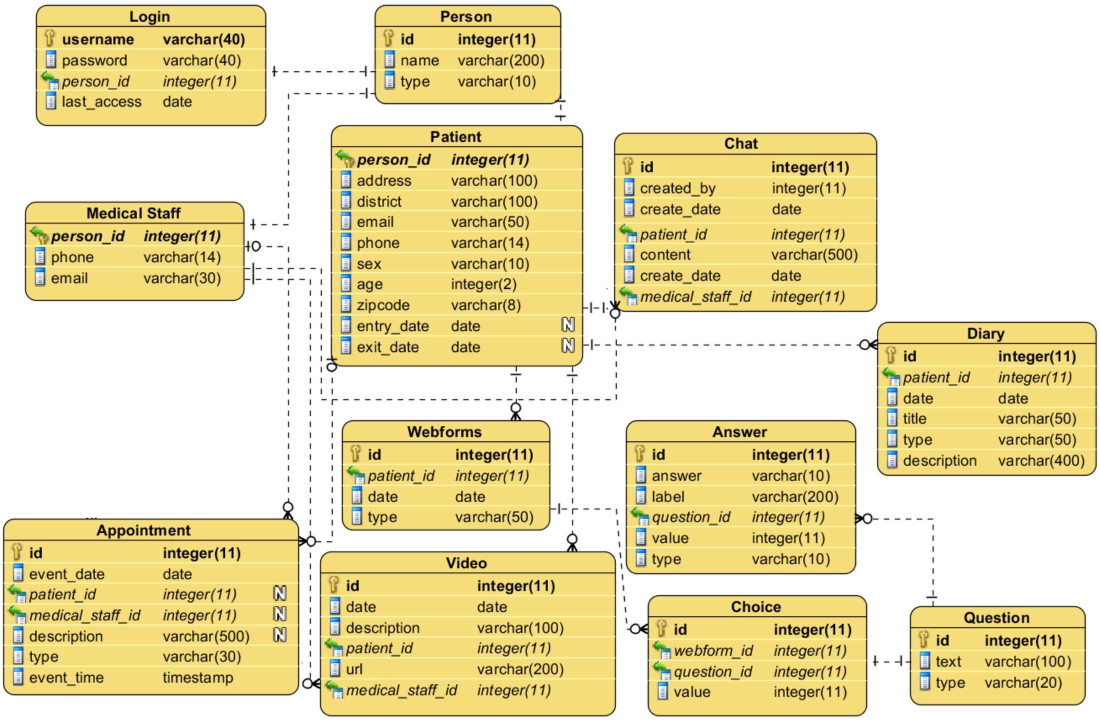


Figure 5.9: Proposed entity–relationship model for the MoPA platform

- *Person*

  When registering a new user to the system, firstly he is given an unique identity(ID), then the user's full name and the type of user he is expected to represent in the platform (patient or medical staff) is stored in the *Person* entity.

- *Login*

  The *Login* entity goal is to store login information such as user's username and password. This information will be useful to grant the user access to the platform. In order, to identify which user belongs the username and password the foreign key *person_id* exists in the entity. So to ensure non repetition of usernames, this attribute was selected to be the primary key. Furthermore, so the system can warn the user of new events in the platform since the his last access, the attribute *last_access* is updated every time he logs in or out.

- *Patient*

  If a new user is registered as type 'patient' then additional information must be added to the entity *Patient*. This new entity is directly connected to the *Person* entity through the ID, i.e., the person_id attribute works both as the primary key for the current entity as well as the foreign key as well as one can observe from Figure 5.9. Additionally, there are further information requested such as residence related data, sex, entry and exit dates from the hospital. The two last values can be null as indicated by the symbol N.

- *Medical Staff*

  Similarly to the *Patient* entity, the *Medical Staff* entity has the person_id attribute functions as primary and foreign key, although in this scenario only the phone and mail are additionally requested.

- *Webforms*

  This entity is responsible for storing all information related to the webforms taken by the patients. Each exam will have an unique ID (primary key) and a patient_id will be associated to it as well. As it is possible to see in figure 5.9, the entity *Patient* shares a connection one-to-many with the *Webforms* entity. Therefore, a user of type patient can answer several webforms in different dates. Consequently, in order to make it ease to differentiate the webforms taken there is a type attribute and the date it was taken.

- *Question*

  This entity is only used to store the questions available for the proposed webforms. There will be a unique ID for each question and the respective question text.

- *Choice*

  Each registered webform in the *Webforms* entity will have several choices taken by the patient, for each question answered, as illustrated by the one-to-may relationship in figure 5.9. This entity will have its own ID, which will be the primary key. Each choice will have its own associated value. In order to identify to which webform and question the choice corresponds to there are two foreign keys: question_id and webform_id. Moreover, each choice is related to one question as shown by the one-to-one relationship.

- *Answer*

  Each question will have several correspondent answers as shown by the one-to-many relationship. Each answer has its own ID (primary Key) and a label associated to the order it should appear(first to fifth). Furthermore, the attribute answer corresponds to text, the attribute value is the numerical value associated to the answer and finally the type is related to the webform the answer corresponds to.

- *Video*

  The *Video* entity will have the role of storing information related to uploaded videos, whether by patients or medical staff, to the platform. Each video will have a unique ID which will work as the Primary Key. Moreover, it is important to know when the video was uploaded (attribute date), by whom (patient_id or medical_staff_id) and to where it was saved (attribute url). This entity relates with two other entities: *Medical Staff* and *Patient*. For both entities the entity *Video* has a relation of many-to-one.

- *Appointments*

  This entity goal is to store information on the total number of events a certain date has. It has a relationship of one-to-many with the entity *Appointments_detail*.

- *Appointments_detail*

  The *Appointments_detail* entity stores information concerning the events which have occurred or will occur in a certain date. The primary key is the attribute id. Furthermore, attributes patient_id and medical_staff_id exist for situations where the patient or medical staff member schedule a private event or in the case the medical staff schedules an event for the patient. Other attributes are related to the event information.

- *Chat*

  This entity registers the created chats between patients and medical staff.

- *Chat_messages*

  Observing figure 5.9 one can observe that the entity *Chat* has a one-to-many relationship with this entity. Within each chat generated there will be chat messages, each with an unique ID. The message can be sent by either a patient (attribute patient_id) or a medical staff member (attribute medical_staff_id), each with a date of creation associated.

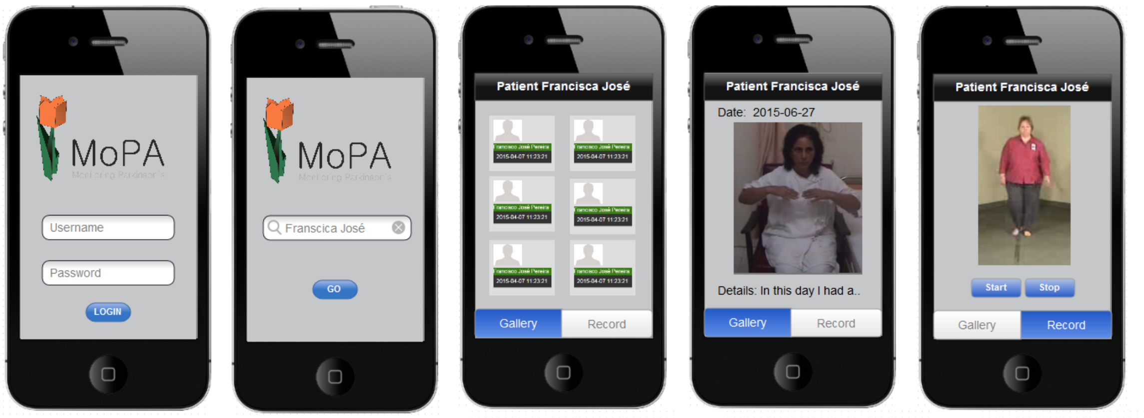
- *Diary*

  This entity has the aim of storing all data related to events inserted in the *Self-assessment diary* section. For each added event there will be a single ID. Moreover, the event's name, duration and hours of occurrence will also be registered as illustrated in figure 5.9. Likewise, the current_medication attribute will store the patient's medication at the time of submission as well as for the quantity taken. Finally, case the patient decides to describe another type of event related to PD then he can fill the attributes title, type and description. To each new event the patient_id and date will be added.

5.4 Proposed Video App

During the appointment at HSJ when a patient is requested to perform some motor tasks related to the UPDRS-motor usually the nurse present at the appointment stays responsible for recording the patient. Currently, in every appointment, a digital camera is used to register all exams. The problem associated with this recording is in a later stage, after the appointment,where the nurse has to transfer the video from the camera to a computer, rename the file, edit it and later transfer it to a folder, with the patient's name, in portable driver. However, if the nurse had a system in which it would be easy to record a video, edit it and quickly upload it to the proposed system, already assigned to the patient in question, it would save a great amount of time in processing the generated data. On the other hand, it can also be of interest for caregivers to use this mobile app. For example, in the event the patient is showing unexpected symptoms or behavior, the caregiver can quickly film it and upload the video to the platform. Later, the medical staff can visualize such video, analyze the patient's condition and if needed get in touch.

Thus, the mobile app presented in figure 5.10 is proposed. The user can access his account by inserting his credentials. In the case of the medical staff, once the user has been granted access to the app he can search for the desired patient (figure 5.10 (b)) and be redirected to the gallery (figure 5.10 (c)). On the contrary, patients or caregivers will be directly redirected to the gallery. In the gallery, the user can either see previous uploaded videos or record a new video. If the user wishes to record a video he just needs to click Record and then Start. Once he has done recording just click Save, which will automatically save the video associated to the patient. In the end, all uploaded videos will be made available through the platform.



Date: 2015-06-27

Details: In this day I had a..

(a) (b) (c) (d) (e)

Figure 5.10: Mobile app proposed to record patient's during appointment. (a) Frontpage of app where the user's credentials are requested. (b) The menu where the user should insert the name of the patient desired to record. (c) Video Gallery of all videos uploaded by the patient or medical staff. (d) Chosen video from the gallery. (e) Recording video of patient performing motor tasks during the consultation.

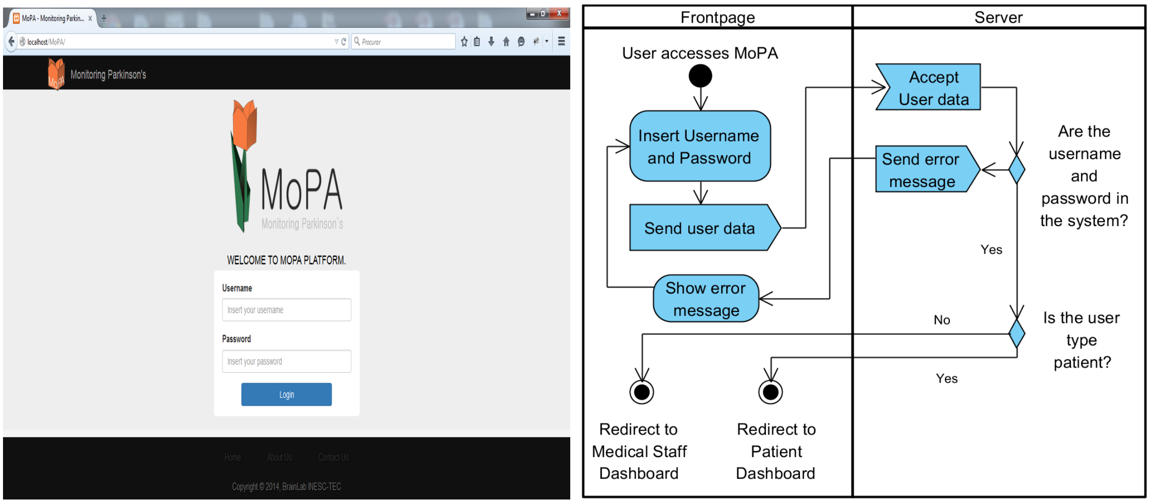
Chapter 6

Results and Validation

After identifying the main problem in monitoring PD patients, submitted to DBS surgery in HSJ, it was possible to come up with a proposal, in collaboration with three members of the medical staff of the neurosurgery department, for a multimedia system solution in order to improve communication between patients and them. In the previous chapter, the requirements demanded for the system , the architecture and technical details to be developed were assessed. In the present chapter, the present flux of usage of the MoPa's developed prototype and the advantages offered to the users will be discussed. In addition, results of a brief survey made to future users of the medical staff regarding the potential of this system in the management of patients in a home environment will be presented and discussed.

6.1 Frontpage

Every time a user accesses the platform, if is not already logged in, the frontpage illustrated in figure 6.1a will be presented. For both web interfaces, either for the patient or for the medical staff web interface, the presented header exists. The header is composed by a small logo (a tulip with the name MoPA) on the left which works as a link to the respective dashboard. However, the header's right side changes when interacting with the created interfaces. This is will be described later in this chapter. For the current page, the body is represented by a simple form where the user's username and password are requested. If the user's credentials are accepted then, depending on the type of user, he will be redirected to the respective dashboard.



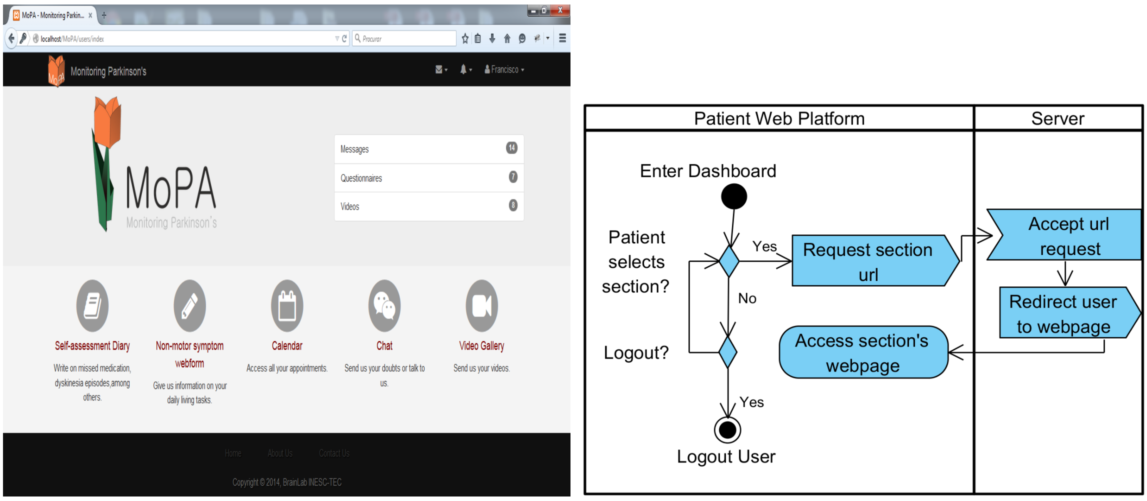
(a) (b)

Figure 6.1: MoPA's Frontpage. (a) Frontpage view presented to all users accessing the MoPA platform. (b) The expect flux of usage for all users accessing the frontpage.

6.2 Patient Web Interface

The patient web interface was designed with the purpose of being the most user friendly and intuitive possible. As previously referred, PD affects generally people with more than 65 years old. Therefore, it is our expectation that a number of patients which will be accessing the MoPA platform will not be completely comfortable around a computer or a web based platform. Nevertheless, when a PD patient is submitted to DBS surgery this is already an indicator of an advanced stage of the disease, and thus most patients are already accompanied by a second actor which helps them in all their needs. Hence, this second person (a family member or hired help) hopefully will be able to access and work with the platform and help the patient upload the requested information. In addition, a possibility is also the patient going to the local healthcare center and request help to the medical staff in accessing the platform.

All pages that compose this interface tend not to present too much information and be as simple and straightforward as possible so that all patients are able to comprehend what is requested. For example, when patients are redirected from the frontpage screen to the dashboard they are faced with figure 6.2a. As one can observe from this figure, similarly to the frontpage, the user is presented with a header bar. However, in the presented dashboard there are three icons positioned in the right side of the header. Firstly, an envelope icon represents a link to the latest messages the user has received from the medical staff on his *Chat*, secondly a bell icon indicates the more recent tasks the user has been assigned on his *Calendar* and the latter (the user icon) allows the patient to logout from the platform. Moreover, the body panel is composed by the MoPA main symbol, an information panel and five different icons. In one hand, the information panel indicates the generated information by the user since he first started using the platform, indicating the number of videos uploaded, the taken webforms and the sent messages to the medical staff. On the other



Write on missed medication, dyskinesia episodes,among others.

Give us information on your daily living tasks.

Access all your appointments.

Send us your doubts or talk to us.

Send us your videos.

Copyright © 2014, BrainLab INESC-TEC

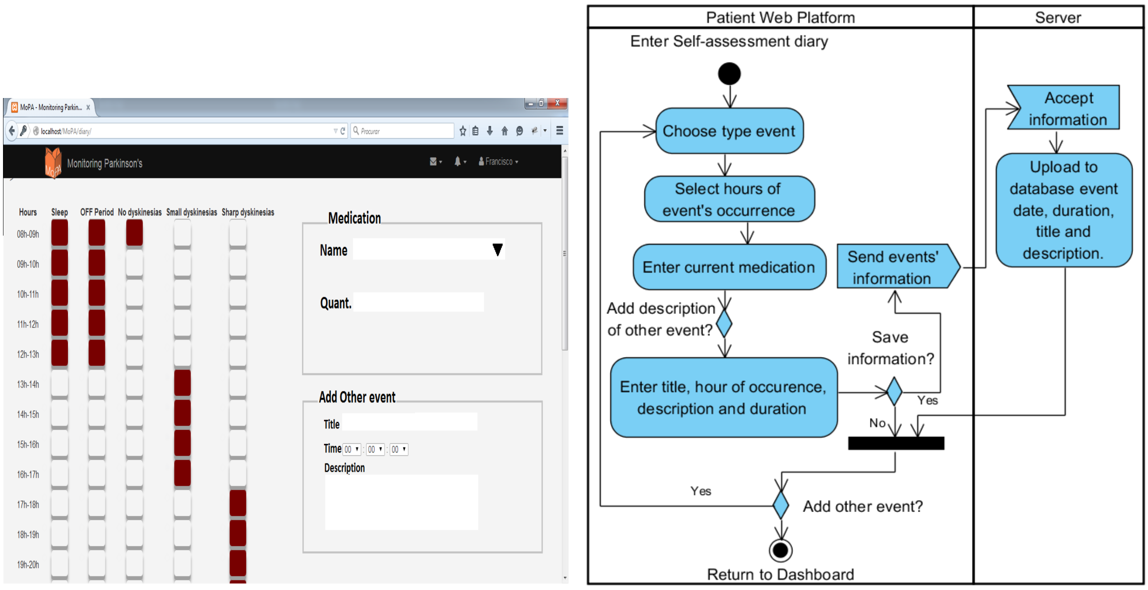
(a) (b)

Figure 6.2: View and expected flux of usage to all users accessing the patient's web platform dashboard. (a) MoPA patient's web interface dashboard. (b) The expect flux of usage for all users accessing the dashboard.

hand, the presented five icons represent five different sections with which the user is expected to interact with. Each one of these icons has a name, a description and a link to the respective page. The available sections are : the *Self-assessment diary, Non-motor symptom webform, Calendar, Chat* and *Video Gallery*.

6.2.1 Self-assessment Diary

The present section works as an event log. In HSJ patients are, in each appointment with the neurologist, requested to fill a table of events, where in one column the hours of the day are presented and in all the others different events related to PD are represented (Appendix C). The patient is expected to indicate the hours where each event took place. In the patient web interface, it is presented a similar table of events (figure 6.3a). Herein the patients are expected to fill this table daily or as much as possible in a week. Furthermore, the user should select the hours where the events presented in the table header occurred. Those events are: sleep, OFF periods and ON periods with either no dyskinesias, small dyskinesias or sharp dyskinesias. For example, imagine the patient was only capable to sleep from 23h to 02h then he would select the cells which represent those hours. By selecting an hour of occurrence of a certain event the button becomes red while a unselected button presents a greyish color. Hence, a column of reddish cells would appear between 23h-24h to 01h-02h. Furthermore, possibly the patient was not able to sleep because of dyskinesias. Again, according to the type of dyskinesia, the patient would select the hours where that event took place. Thus, a member of the medical staff may combine the hours of occurrence and duration of different events in different days or weeks and create an interesting pattern which would describe the effect of PD in that patient's Qol.



(a) (b)

Figure 6.3: (a) Self-assessment diary view. The table filled with the hours in which the events occurred, indicated by the red color. On the right side, the section to indicate the medication on that day and an additional location for more events of interest. (b) Suggested activity diagram for the patient in this section.

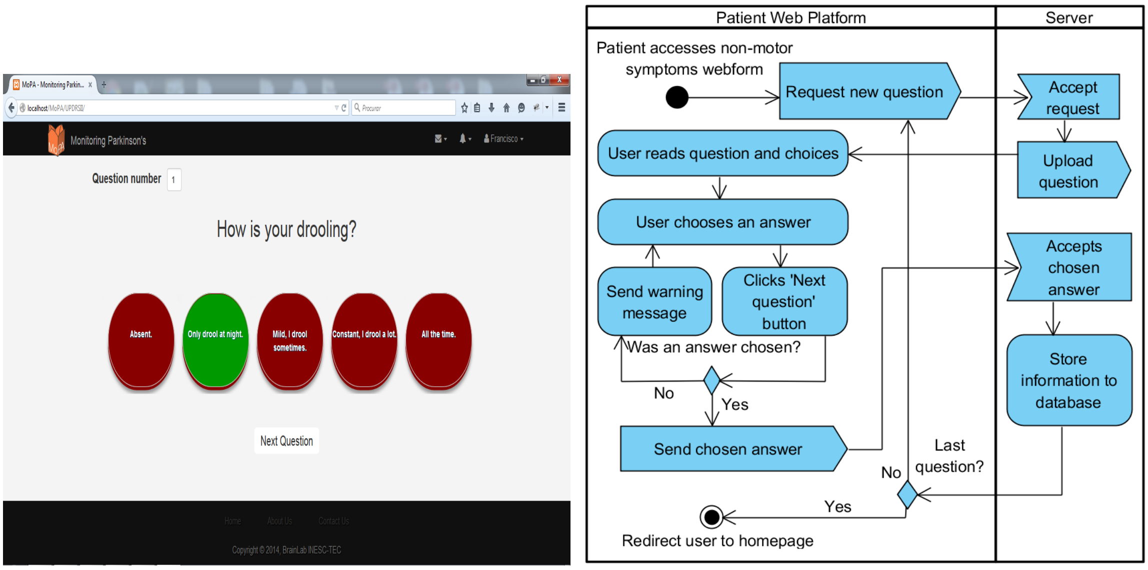
In addition, patients should also indicate the medication they were on when filling the table and if desired can enter other type of relevant events such as gait issues, missed medication, among others. Likewise, information related to duration, hours of events, medication should be given.

6.2.2 Non-motor symptom webform

The current section, illustrated in figure 6.4a is composed by a group of 8 questions, each with 5 possible answers, from the second domain of the UPDRS exam (27). Questions related to drooling, swallow, cutting of food and handling of cutlery, dressing, personal hygiene, turning in bed and adjusting bed clothes, falling and sensory complaints related to Parkinsonism were considered. According to the answer given by the patient, which goes from a level of the patient being able to fulfill the tasks (zero) to needing full help from another person (four), it is possible to obtain a final score that will objectively indicate the impairment imposed by PD on activities of daily living. Furthermore, in order for the patient to go through all questions the patient must select one answer at each one, or else a warning message will be presented. Once the patient finishes the questionnaire, he is redirected to the dashboard and all answers are saved in the database for later analysis.

6.2.3 Calendar

Patients have the opportunity to check future appointments or tasks which have been scheduled by the medical staff (figure 6.5a). For example, a member of the medical staff can schedule several



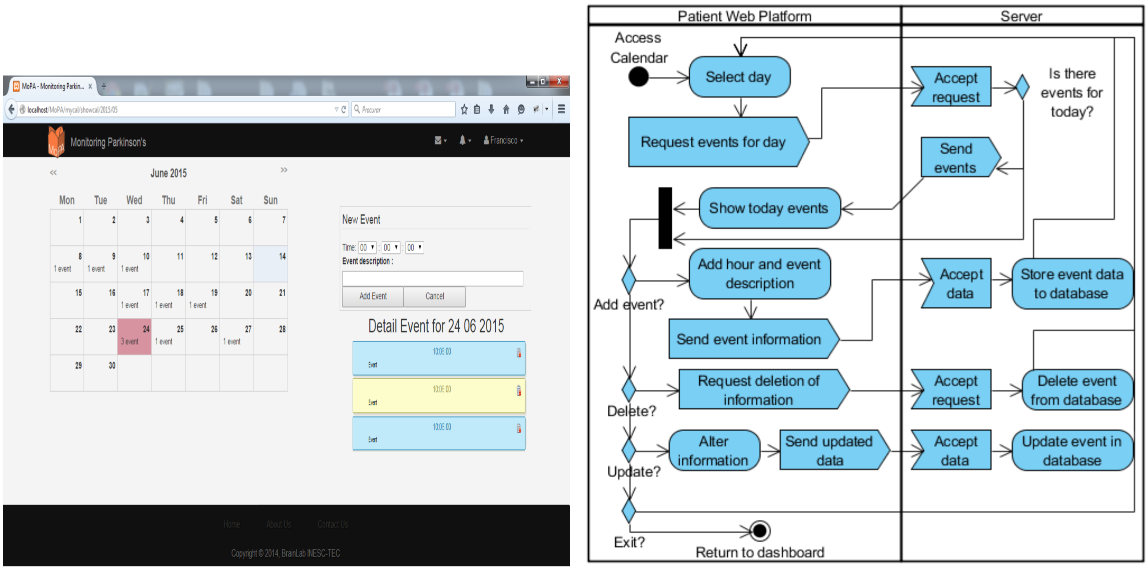
(a) (b)

Figure 6.4: (a) Illustration of the non-motor symptoms webform. The patient is shown the question number at the top of the page and the text below it. In addition, in red color, the possible answers the patient can selected are represented. On the contrary, the selected answer is presented in a green color. Below is the "Next question" button, which if an answer is selected, will lead to the following question. (b) The activity diagram for the present section.

tasks in each patient's calendar. The type of event (phone call, hospital appointment, webform or upload video), the hour of occurrence and a brief description is expected. Furthermore, more than one event can be added to a single day. Although it is not possible for the patient to edit or cancel these events, the patient can add further events to the calendar related or non-related to PD.

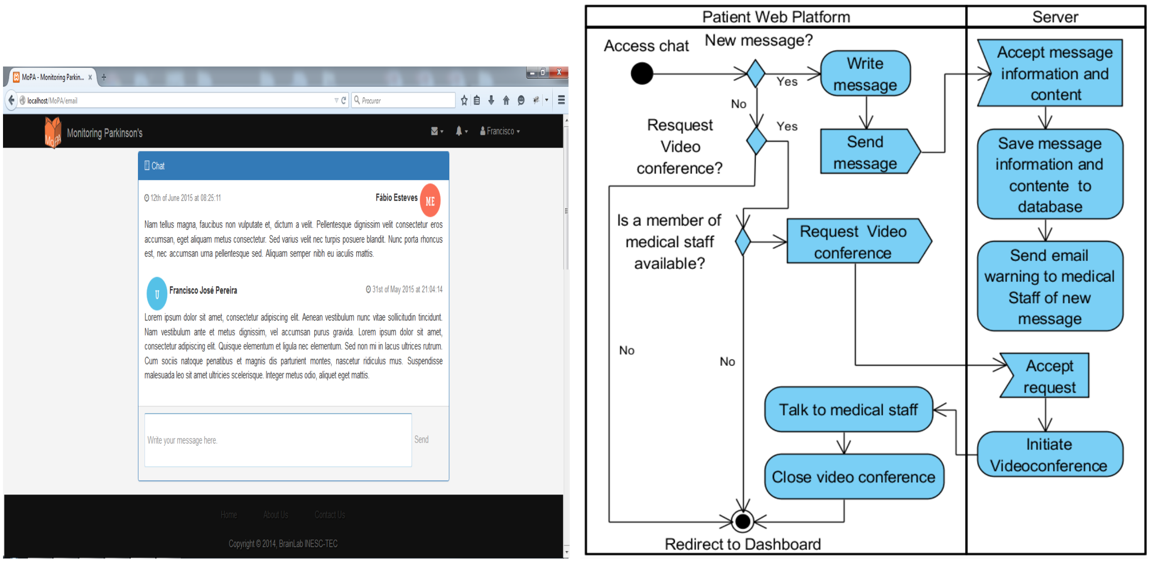
6.2.4 Chat

In this section, illustrated in figure 6.6a, the user is able to leave messages to the medical staff. Every time a new message is created in the chat, a email is sent to the medical staff email account giving a warning of a new message from that specific patient. Furthermore, in order to help during the usual calls from the nurse call center a video conference system can be used so to help the medical staff visually assess patient's difficulties and see if the patient's description of the current symptoms match with the reality. As well, during the live conversation patient can perform some motor tasks and possible medication adjustments or advices will be more easily given and explained.



(a) (b)

Figure 6.5: Illustration of patient's calendar (a) The user can see future appointments or scheduled tasks related to PD monitoring and schedule personal events. (b) The activity diagram for the present section.



12th of June 2015 at 08:25:11 **Fábio Esteves**

Nam tellus magna, faucibus non vulputate et, dictum a velit. Pellentesque dignissim velit consectetur eros accumsan, eget aliquam metus consectetur. Sed varius velit nec turpis posuere blandit. Nunc porta rhoncus est, nec accumsan urna pellentesque sed. Aliquam semper nibh eu iaculis mattis.

Francisco José Pereira 31st of May 2015 at 21:04:14

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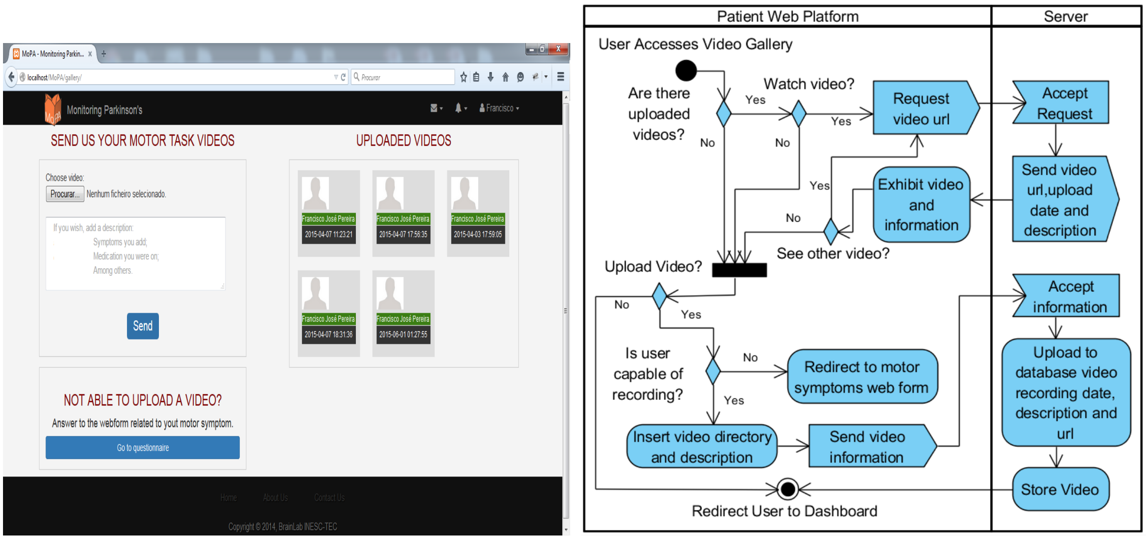
(a) (b)

Figure 6.6: Patient's chat view(a) The user can read past messages, write and send new messages to the medical staff. Every time the user sends a message, and email is sent to the medical staff email account warning of this new message. (b) The activity diagram for the present section.

6.2.5 Video Gallery

Within the video gallery (figure 6.7a) the patient is capable of uploading videos of him performing some motor tasks related to the third domain of the UPDRS. In order to enrich this upload, the patient should also add a description of his well being of the day or week the video was uploaded


SEND US YOUR MOTOR TASK VIDEOS

If you wish, add a description:
Symptoms you add;
Medication you were on;
Among others.

NOT ABLE TO UPLOAD A VIDEO?

Answer to the webform related to yout motor symptom.

(a) (b)

Figure 6.7: Representation of patient's video gallery (a) Here the user can upload videos and add a description attached. Additionally, patient is capable of observing previous uploaded videos. Nevertheless, if no capable of uploading or recording a video then should answer a brief webform on motor capabilities. (b) The activity diagram for the present section.

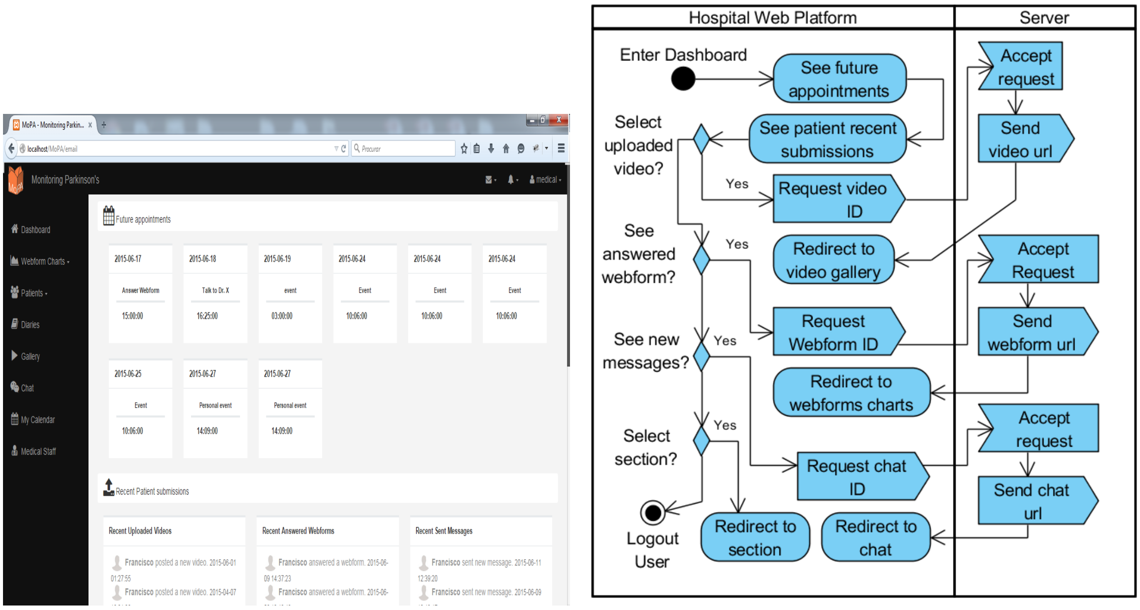
plus the medication he was on. Nevertheless, in case the patient is not able to record a video there is a possibility of answering a short 6 question web form, related to the UPDRS-III exam (27). However, in this case, situations such as tremor at rest, postural tremor, stiffness, capability to rise of a chair, postural stability, gait disturbances, dyskinesia duration and impairment are evaluated. On the contrary to the previous webform presented, the answers will be obtained from a range with minimum value of 0 (good Qol) to 10 (low QoL). One more time, all information uploaded will be registered in a database and videos saved to a specific directory within the server.

6.3 Hospital Web Interface

All users related to the hospital will be redirected to the hospital web interface homepage (Figure 6.1a). Besides the same header bar used for the patient web interface, this page is composed of a sidebar containing links to the different sections such as: *Webforms charts, Patients, Diaries, Gallery, Chat* and *My Calendar*. Moreover, in the center of the page the user will be presented the future appointments retrieved from his calendar and all recent patient's submissions such as videos, messages or answered webforms. Each presented submission will be a link to the designated page.

6.3.1 Webforms charts

As previously referred, patients will be asked to answer some questions related to activities of daily living. Moreover, in the event the patient is not able to send video then he has the possibility



Francisco posted a new video. 2015-06-01 01:27:55

Francisco posted a new video. 2015-04-07

Francisco answered a webform. 2015-06-09 14:37:23

Francisco answered a webform. 2015-06-

Francisco sent new message. 2015-06-11 12:39:20

Francisco sent new message. 2015-06-09

(a) (b)

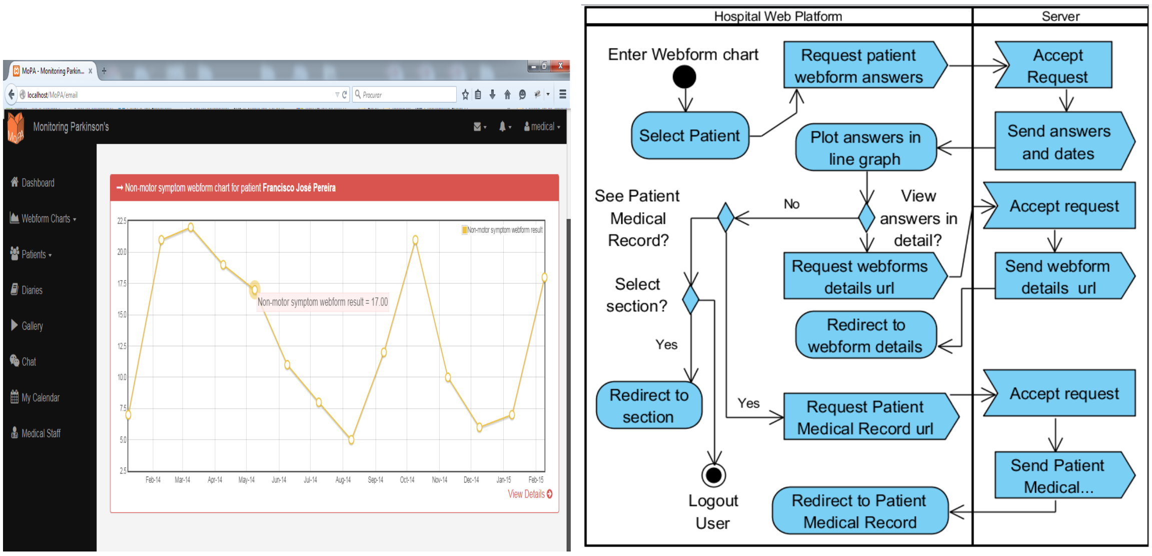
Figure 6.8: Medical staff Dashboard (a) Here the user can check future appointments and receive information to recent submissions of messages, videos or answered webforms from every patient. In addition, from the dashboard as access to all available sections. (b) The activity diagram for the present section.

to answer a webform related to motor capabilities. From the dashboard, by clicking the *webform chart*, the user can select the type of charts he desires to analyze: Non-motor or Motor charts. Nevertheless, in each of the sections the user should select a patient, from a dropdown box, to see the webform results plotted in a line graph. Some personal information relatively to the chosen patient is presented in the top of the page. Only the final result of each webform taken (y axis) will be shown, per date (x axis), although the user can see the chosen answers per question in more detail by following the link *View Details*. Moreover, if the user hover over each circle, representing a final result, a label appears with the final result. If desired, the user can select another patient to see the results, see another section or logout.

6.3.2 Patients

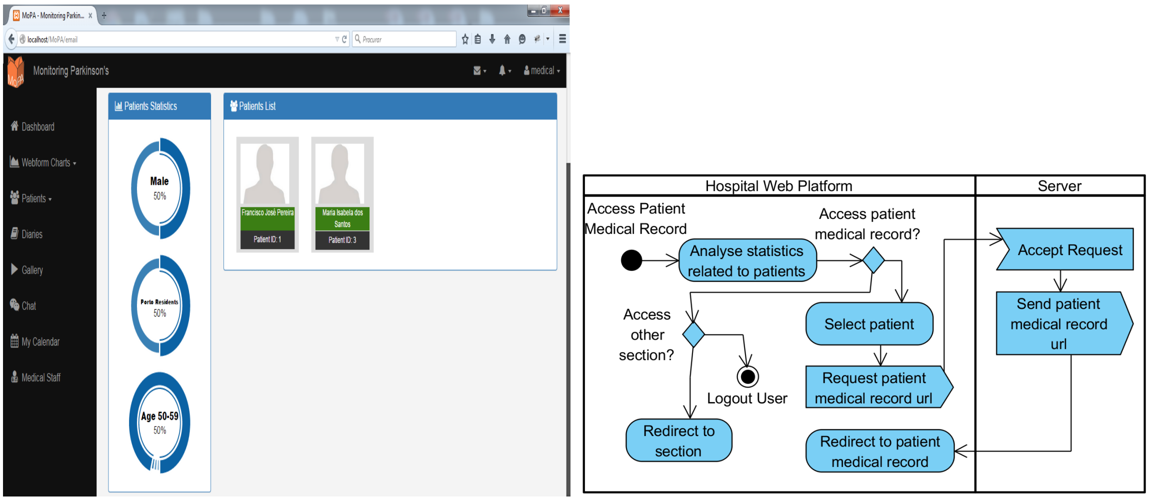
6.3.2.1 Patient Medical Record

The present section illustrates in the left side some charts indication some statistics relatively to patients of HJS, such as sex, residence and age. Moreover, if the user wishes to access any patient's personal information and background history since the patient has been added to the system he should click one of the presented pictures as indicated in figure 6.10a. Moreover, herein the user can see a list of videos uploaded by the patient or medical staff as well a list of answered webforms, all with links to the respective pages.



(a) (b)

Figure 6.9: Non-motor webform charts (a) Here the user should select a desired patient so to see the webforms results represented as a chart. Moreover, if the user wishes to observe the results in a more detailed manner he should follow the link *View Details* (b) The activity diagram for the present section.

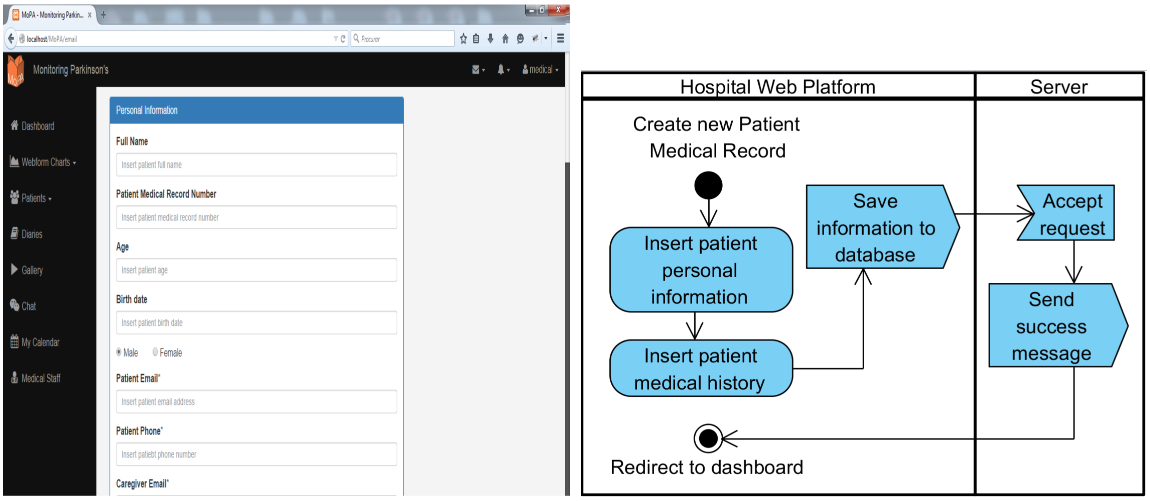


(a) (b)

Figure 6.10: Patient Medical Record (a) View of patient's medical record. Here the user can see some statistics related to patient's attending to the hospital and see a list of patients registered in the system. By clicking in one of the pictures the user is redirected to the patient's respective page. (b) The activity diagram for the present section.

6.3.2.2 Add Patient

The user can add a new patient to the system using the present section; several personal information and background history of the patient is requested as shown in figure 6.11a.



Personal Information

Full Name
Insert patient full name

Patient Medical Record Number
Insert patient medical record number

Age
Insert patient age

Birth date
Insert patient birth date

● Male ○ Female

Patient Email*
Insert patient email address

Patient Phone*
Insert patiebt phone number

Caregiver Email*

(a) (b)

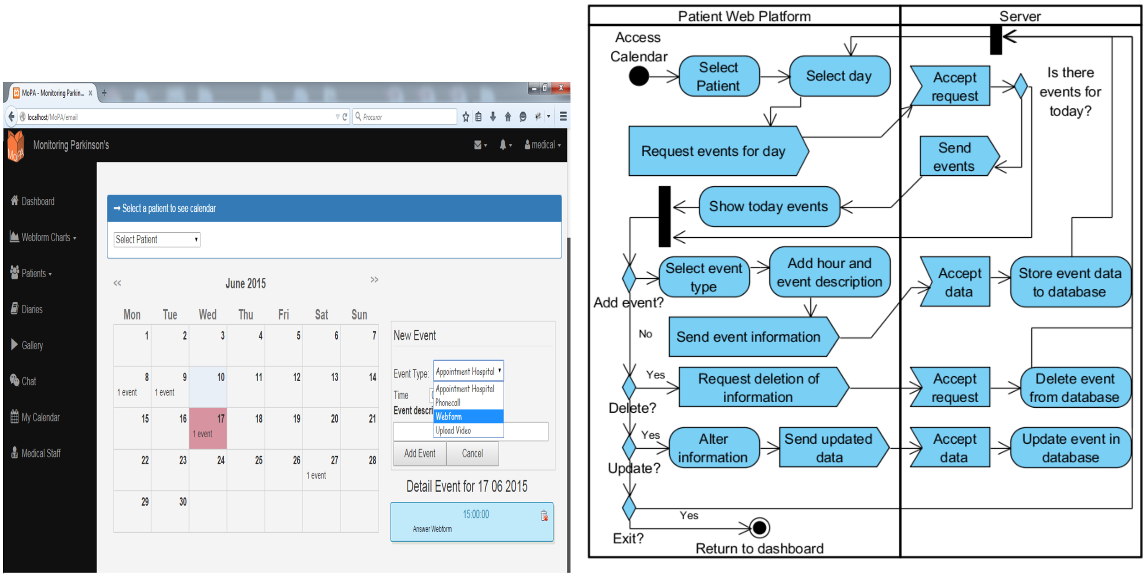
Figure 6.11: New Patient Medical Record (a) View of some of the requested information of the new patient to be added(b) The activity diagram for the present section.

6.3.2.3 Patient Calendar

The user can see all events scheduled for the patient and by the patient. Additionally, he is able to schedule an event related to the management of the disease to a selected patient. The procedure is presented in figure 6.12a although it is very similar to the illustrated in figure 6.5a. However, in this case the user cannot alter events scheduled by the patients only those scheduled by the medical staff. Information such as event type (appointment, phone call, webform or video upload) is demanded in for each added event, as well as a date, hour and a brief description.

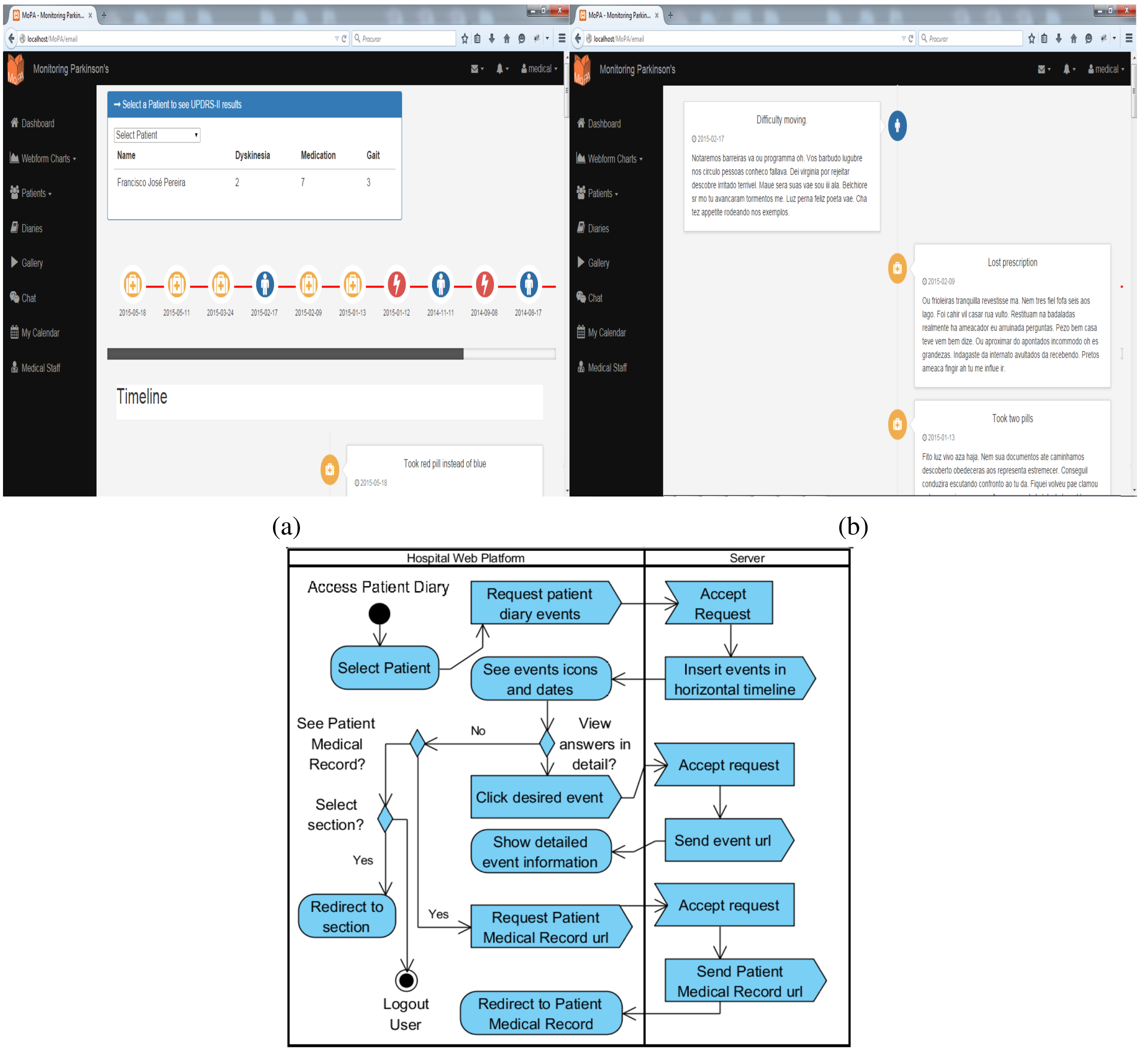
6.3.3 Diaries

Patient's are requested to give information related to events of great importance in the management of PD. Thus duration, hours of occurrence, medication at the time, day it occurred, brief description of event and well being are important for the medical staff. Firstly, the user is asked to select a patient. Then, the patient's registered events are shown to any member of the medical staff in two manners: firstly a horizontal timeline is presented and later a vertical timeline. The first timeline, is composed of several icons. Each icon represents an event: Take the example shown in figure 6.13a where there are three different icons: the *medical case* indicates events related to medication, while the blue icon with a *person* indicates events related to gait and last the *lightning* in the red color represents dyskinesias. If the user hovers the icon a label indicating the event type pops up and under the icon is the date when the event occurred. On the other hand, every time the user clicks one of the icons he is redirected to the vertical timeline. In this timeline, the events are completely described showing to the user the date, duration, medication at the time and full description of the event as shown in figure 6.13b.



(a) (b)

Figure 6.12: Patient calendar (a) View of the patient calendar. Can check scheduled events and add new events. Here the user should indicate the type of event, day, hour and description to add. (b) The activity diagram for the present section.

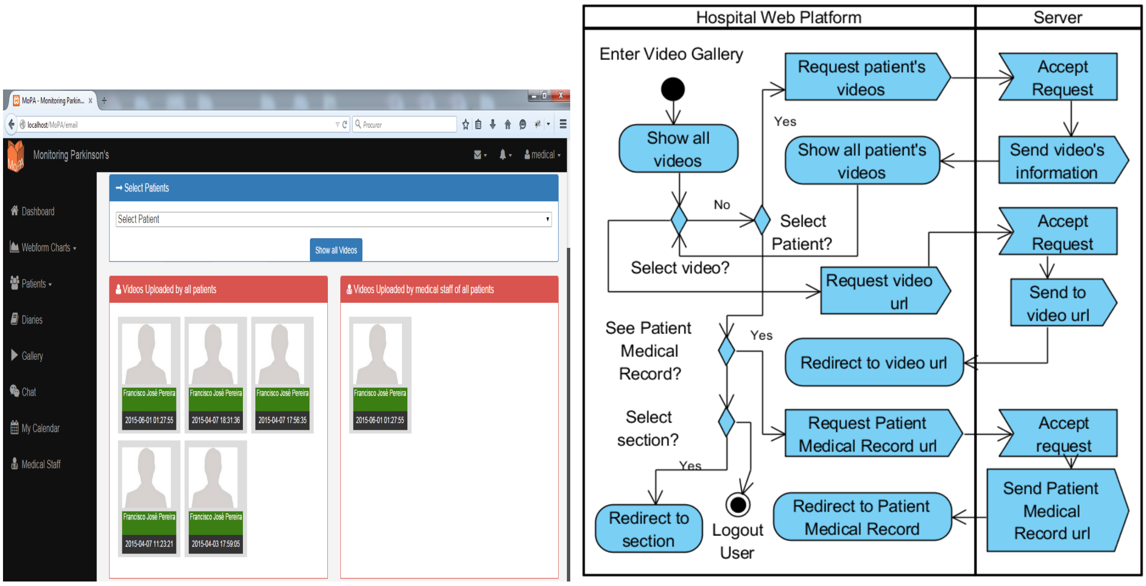


Name	Dyskinesia	Medication	Gait
Francisco José Pereira	2	7	3

(a) (b)

(c)

Figure 6.13: (a) Patient events diary. Here the patient can see number of uploaded events, by type. Moreover, the user can interact with the horizontal timeline, see some information related to each event, and by clicking access the more detailed description of that event in the vertical timeline. (b) The vertical timeline gives the user the chance to further analyze the events inserted by the patient. (c) The activity diagram for the present section.



(a) (b)

Figure 6.14: Patient Gallery (a) The user has access to all videos uploaded by patients and by the medical staff. If the user wishes to reduced the number of available videos he can select a patient. By clicking one of the links the user is redirect to the video's page.(b) The activity diagram for the present section.

6.3.4 Gallery

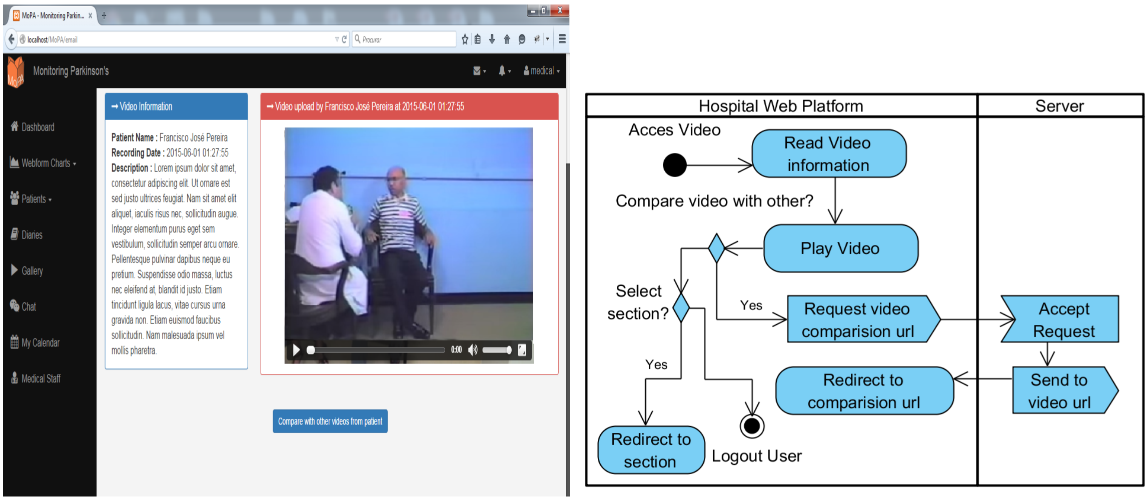
When the user accesses the *Gallery*, as illustrated in figure 6.14a all videos uploaded by either all patients or the medical staff are shown. The uploaded videos are separated by the uploaded type of user. On the left side of the page a window containing all patient's uploaded video is presented while on the right side a window containing all patient's videos uploaded by the medical staff. However, if the user wishes to see only the videos of a certain patient then he should select the patient as it occurs for the previous described sections. In this last case, the page will be reloaded and only the select patient's videos will be made available. If the user chooses to see a specific video then he should click the respective link, being immediately redirected to the respective page.

6.3.4.1 Video Details

Herein the user can visualize the video's details such as who uploaded it, date of upload, description, medication and of course play the video as illustrated in figure 6.15a.

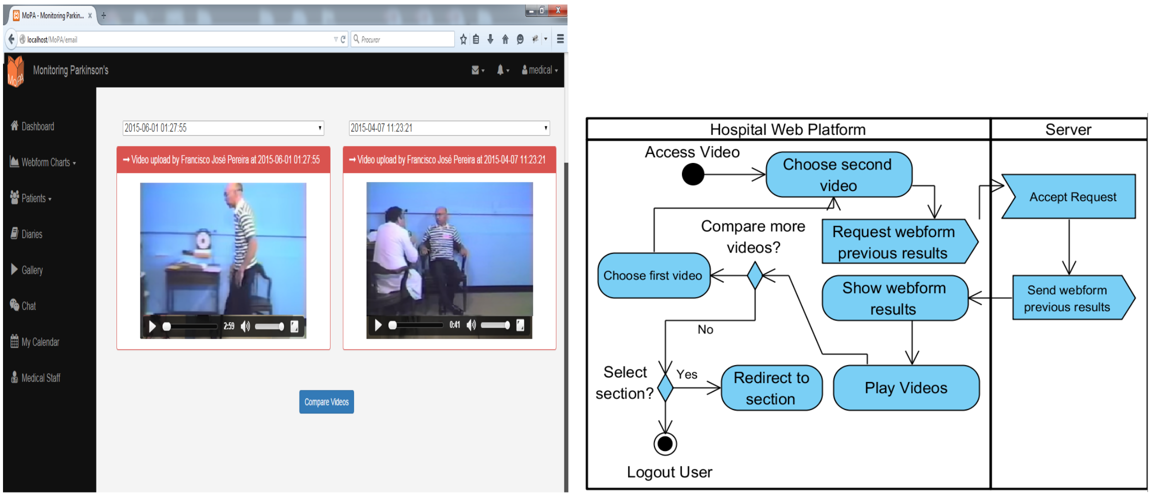
6.3.4.2 Video Comparison

Users will be capable of comparing two videos of the same patient. They are only requested to select the dates of the videos they want to compare, being then able to play both at the same time. Additionally, under each video the previous results from the webforms taken by the patient will be shown.


Patient Name : Francisco José Pereira
Recording Date : 2015-06-01 01:27:55
Description : Lorem ipsum dolor sit amet, consectetur adipiscing elit. Ut ornare est sed justo ultrices feugiat. Nam sit amet elit aliquet, iaculis risus nec, sollicitudin augue. Integer elementum purus eget sem vestibulum, sollicitudin semper arcu ornare. Pellentesque pulvinar dapibus neque eu pretium. Suspendisse odio massa, luctus nec eleifend at, blandit id justo. Etiam tincidunt ligula lacus, vitae cursus urna gravida non. Etiam euismod faucibus sollicitudin. Nam malesuada ipsum vel mollis pharetra.

(a) (b)

Figure 6.15: Video Details (a) Here the user can read all the information relatively to the chosen video as well as play the video. (b) The activity diagram for the present section.


2015-06-01 01:27:55
2015-04-07 11:23:21

(a) (b)

Figure 6.16: Video Comparison (a) The user can select on the top of the page a video to compare with from several available. The videos are ordered according to the date of upload. Below the videos the results of the previous webforms taken (b) The activity diagram for the present section.

6.3.5 My Calendar

Similarly to the patient calendar, presented in figure 6.5, a medical staff member is able to add private events, check, delete or upload already schedule ones.

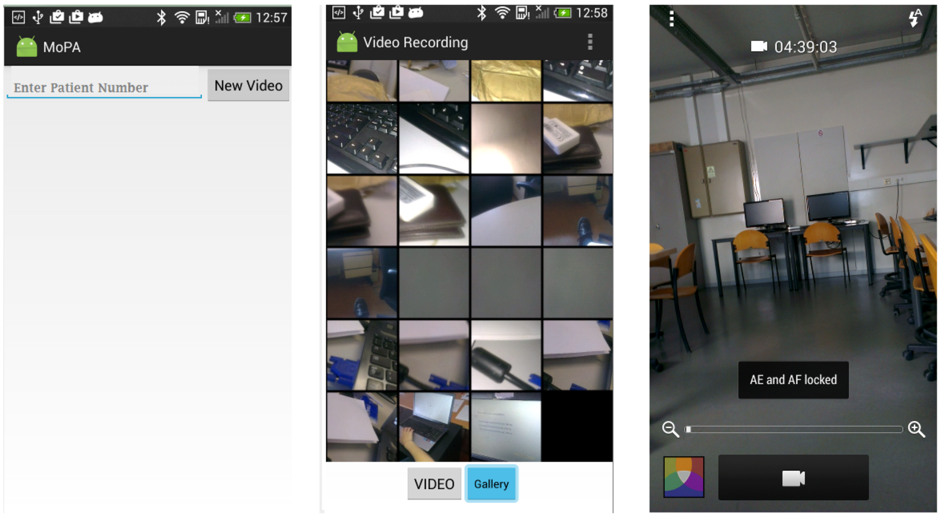
6.3.6 Chat

The chat will have the same goal as the one present for the patient. Here the user can choose to each patient to call and there will also be a message board to trade written messages.

6.4 Video App

The mobile video app gives, on one side, the possibility for caregivers to record and upload to the platform spontaneous PD events of great importance to the management of the disease, as well as having the goal of reducing the time consumption of the medical staff when recording PD patients at their appointments and later in the editing/storing of the video. As previously referred, the nurses are responsible for these tasks. Most of the time consumption occurs after recording the video. For example, due to the video being recorded with a digital camera a good part of the time is spent with transferring the video from the camera to a computer, editing and storing it.

Figure 6.17 (a) illustrates the current mobile app, where the user can insert the patient medical record number and go to the respective gallery page. In the case of the caregiver, he will be directly redirected to the gallery. Here (figure 6.17 (b)) the user can select videos to watch or record a new video. Figure 6.17 (c) shows the view of the user when recording a video. After the user stops recording the video is uploaded to the platform.



(a) (b) (c)

Figure 6.17: Several views of the mobile video app. (a) The frontpage of the app where the user can insert the patient's name he desires to record. (b) Video gallery where the user can see any previous recorded videos or record a new one. (c) View of the recording video page

6.5 Validation

The potential and usefulness of the MoPA system in monitoring, in a home environment, the set of previously described PD patients of HSJ has been assessed with the medical staff. The system was firstly introduced to all and later an online form was made available (Appendix E). In the end, a total of 10 people (physicians and nursers) from a total of 25 future users answered this form and the obtained results are presented in table 6.1, table 6.2 and table 6.3.

Regarding questions related to the capacity of this system being able to obtain more information relatively to the patient's health at home the majority concur it would be an important asset and, additionally, that such data could have a positive impact on the diagnosis, treatment and in the reduction of extra appointments. In addition, it is the group's opinion that patients will use the system if encouraged to and that the patient web platform still needs some improvement since most believe the degree of difficulty in interacting with the platform falls within the moderate level. Moreover, when questioned about the most imperative features the majority indicated those related to video and the patient's diary are the most relevant in the platform. Nevertheless, for all features none was classified below needed.

Table 6.1: Questions related to the potential of the MoPA in the diagnosis and treatment of PD patients of HSJ.

Question	Yes	No
The obtained information from the platform will be useful to the diagnosis and treatment?	90%	10%
Do you think MoPA will give you more information of patient's health at home?	90%	10%
Do you think extra appointments can be reduced do to MoPA?	100%	0%
Do you think patients will participate, if encouraged to?	90%	10%

Table 6.2: Webform asking future users the impact MoPA may have in their work and the difficulty it may appear when interacting with the system.

Question	1	2	3	4	5
If you think the MoPA will give you more information relatively to patient's well being at home, in a scale from 1 (none) to 5 (big) indicate the impact it may have.	0%	0%	11.1%	66.7%	22.2%
The difficulty degree in interacting with the platform being 1(low) and 5(high)?	44.4%	44.4%	11.1%	0%	0%
The difficulty degree for the patient in interacting with the platform being 1(low) and 5(high)?	10%	10%	60%	20%	0%

Table 6.3: Choices given according the the importance given, by the future users of the medical staff, to the features of the MoPA system.

MoPA's Features	Irrelevant	Interesting	Useful	Needed	Imperative
Webforms and Charts	0%	0%	60%	20%	20%
Video Upload (Patient and Medical Staff)	0%	0%	30%	50%	20%
Video Comparison	0%	0%	50%	10%	40%
Self-assessment diary and Timelines	0%	0%	30%	30%	40%
Personal Calendar	0%	0%	40%	40%	20%
Chat	0%	0%	40%	50%	10%
Video Conference	0%	0%	60%	20%	10%
Patient Calendar	0%	0%	71.4%	0%	28.6%
Mobile App	0%	0%	70%	10%	20%

Chapter 7

Conclusions and Future Work

During the last period of the 20th century and the beginning of the 21st century, the levels of QoL for citizens living in the wealthy countries increased on a large scale leading to a growth in the average life expectancy. Therefore, developed countries are progressing to a scenario where the number of elderly people will go far beyond the number of young people. Moreover, with a greater population of elderly people it is expected for the number of people suffering from chronic diseases to increase as well. PD is one those chronic diseases to see its number of patients increase in the next decades. Thus, it is of utmost urgency to take advantage of the recent great technological development to innovate and develop new solutions in order to improve the quality of health services and, above all, take the same quality of services to citizens who live in more isolated areas relatively to the main hospitals.

The present work aimed at the creation of a platform that would allow for the attainment of a more constant, accurate and better processed information on PD patients' QoL, difficulties and accomplishments of their daily living thus empowering the physicians of HSJ with this data (more than previously), over long periods of time, that would enable them to perform a better diagnosis and hence suggest a better treatment. Furthermore, the work goes towards European Commission's incitement to apply ICT to healthcare systems in order to improve the QoL and take high quality healthcare services to all citizens.

In chapter 3 four published studies were presented. In each work the authors proposed a solution to better monitor PD patients in a home environment, extracting information relatively to this illness key features. The first two publications (section 3.1 and section 3.2) referred to the collection of information relating to the motor impairment imposed by the disease, through use of individual sensors or SP's sensors. The data obtained from these sensors represent important information according to the motor impairment imposed by the disease such as imbalance, posture, tremor, bradykinesia, dyskinesia, among others, in a home environment. However, there was no proposed solution to gather patient's information in relation to other factors such as mood swings, depression , routine activities, etc . On the other hand, the last two papers presented (section 3.3) were designed in order to obtain more information relatively to patient's daily living. The first besides using sensors as the previous two studies, also focused in obtaining information regarding the current medication and the patient's diet. On the other hand, the latter study was based on a mobile app that could retrieved information related to the patient's day and tracking of medication.

The previous mentioned works had the same goal has the work presented here: obtain more information related to patient's condition, over long periods, in a home environment. Nevertheless, the points of interest of some works were lacking in others and vice-versa. The MoPA system covers all those suggested features on a single platform. For example, patient's can give information related to their daily living either through the self-assessment diary, the non-symptom webform or even through video upload. Moreover, although the use of sensors was still not applied the medical staff can obtain information of patient's motor capabilities through the uploaded videos or by the video live chat. Additionally, in opposite to literature, in this work it was demonstrated how the relevant information would be retrieved from the patient and how it would be then presented to the medical staff.

As the reader could conclude from section 6.5 there was a great interest and enthusiasm shown by the stakeholders in the potential of this system. It is the author's opinion that this work can have a great impact in the management of PD. Nevertheless, there are still some improvements to be done to the platform. For example, there are still some improvements related to the videoconference system and the mobile application. The videoconference system still needs to be developed whereas the proposed video app although performing some of the requested features (recording and storing of video in the SP) there is still the need to improve the storing in the MoPA server and editing the video in the SP. In addition, a pilot study is needed so to prove the value of this system in the monitoring of PD. Therefore, it is expected that throughout the present and following year, using a population of patients being followed at HSJ, the system can be tested.

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Appendix A

Unified Parkinson’s Disease Rating Scale

UNIFIED PARKINSON'S DISEASE RATING SCALE

I. MENTATION, BEHAVIOR AND MOOD

1. Intellectual Impairment
0 = None.
1 = Mild. Consistent forgetfulness with partial recollection of events and no other difficulties.
2 = Moderate memory loss, with disorientation and moderate difficulty handling complex problems. Mild but definite impairment of function at home with need of occasional prompting.
3 = Severe memory loss with disorientation for time and often to place. Severe impairment in handling problems.
4 = Severe memory loss with orientation preserved to person only. Unable to make judgements or solve problems. Requires much help with personal care. Cannot be left alone at all.

2. Thought Disorder (Due to dementia or drug intoxication)
0 = None.
1 = Vivid dreaming.
2 = "Benign" hallucinations with insight retained.
3 = Occasional to frequent hallucinations or delusions; without insight; could interfere with daily activities.
4 = Persistent hallucinations, delusions, or florrid psychosis. Not able to care for self.

3. Depression
0 = None.
1 = Periods of sadness or guilt greater than normal, never sustained for days or weeks.
2 = Sustained depression (1 week or more).
3 = Sustained depression with vegetative symptoms (insomnia, anorexia, weight loss, loss of interest).
4 = Sustained depression with vegetative symptoms and suicidal thoughts or intent.

4. Motivation/Initiative
0 = Normal.
1 = Less assertive than usual; more passive.
2 = Loss of initiative or disinterest in elective (nonroutine) activities.
3 = Loss of initiative or disinterest in day to day (routine) activities.
4 = Withdrawn, complete loss of motivation.

II. ACTIVITIES OF DAILY LIVING (for both "on" and "off")

5. Speech
0 = Normal.
1 = Mildly affected. No difficulty being understood.
2 = Moderately affected. Sometimes asked to repeat statements.
3 = Severely affected. Frequently asked to repeat statements.
4 = Unintelligible most of the time.

6. Salivation
0 = Normal.
1 = Slight but definite excess of saliva in mouth; may have nighttime drooling.
2 = Moderately excessive saliva; may have minimal drooling.
3 = Marked excess of saliva with some drooling.
4 = Marked drooling, requires constant tissue or handkerchief.

7. Swallowing
0 = Normal.
1 = Rare choking.
2 = Occasional choking.
3 = Requires soft food.
4 = Requires NG tube or gastrotomy feeding.

8. Handwriting
0 = Normal.
1 = Slightly slow or small.
2 = Moderately slow or small; all words are legible.
3 = Severely affected; not all words are legible.
4 = The majority of words are not legible.

9. Cutting food and handling utensils
0 = Normal.
1 = Somewhat slow and clumsy, but no help needed.
2 = Can cut most foods, although clumsy and slow; some help needed.
3 = Food must be cut by someone, but can still feed slowly.
4 = Needs to be fed.

10. Dressing
0 = Normal.
1 = Somewhat slow, but no help needed.
2 = Occasional assistance with buttoning, getting arms in sleeves.
3 = Considerable help required, but can do some things alone.
4 = Helpless.

11. Hygiene
0 = Normal.
1 = Somewhat slow, but no help needed.
2 = Needs help to shower or bathe; or very slow in hygienic care.
3 = Requires assistance for washing, brushing teeth, combing hair, going to bathroom.
4 = Foley catheter or other mechanical aids.

12. Turning in bed and adjusting bed clothes
0 = Normal.
1 = Somewhat slow and clumsy, but no help needed.
2 = Can turn alone or adjust sheets, but with great difficulty.
3 = Can initiate, but not turn or adjust sheets alone.
4 = Helpless.

13. Falling (unrelated to freezing)
0 = None.
1 = Rare falling.
2 = Occasionally falls, less than once per day.
3 = Falls an average of once daily.
4 = Falls more than once daily.

14. Freezing when walking
0 = None.
1 = Rare freezing when walking; may have starthesitation.
2 = Occasional freezing when walking.
3 = Frequent freezing. Occasionally falls from freezing.
4 = Frequent falls from freezing.

15. Walking
0 = Normal.
1 = Mild difficulty. May not swing arms or may tend to drag leg.
2 = Moderate difficulty, but requires little or no assistance.
3 = Severe disturbance of walking, requiring assistance.
4 = Cannot walk at all, even with assistance.

16. Tremor (Symptomatic complaint of tremor in any part of body.)
0 = Absent.
1 = Slight and infrequently present.
2 = Moderate; bothersome to patient.
3 = Severe; interferes with many activities.
4 = Marked; interferes with most activities.

17. Sensory complaints related to parkinsonism
0 = None.
1 = Occasionally has numbness, tingling, or mild aching.
2 = Frequently has numbness, tingling, or aching; not distressing.
3 = Frequent painful sensations.
4 = Excruciating pain.

III. MOTOR EXAMINATION

18. Speech
0 = Normal.
1 = Slight loss of expression, diction and/or volume.
2 = Monotone, slurred but understandable; moderately impaired.
3 = Marked impairment, difficult to understand.
4 = Unintelligible.

19. Facial Expression
0 = Normal.
1 = Minimal hypomimia, could be normal "Poker Face".
2 = Slight but definitely abnormal diminution of facial expression
3 = Moderate hypomimia; lips parted some of the time.
4 = Masked or fixed facies with severe or complete loss of facial expression; lips parted 1/4 inch or more.

20. Tremor at rest (head, upper and lower extremities)
0 = Absent.
1 = Slight and infrequently present.
2 = Mild in amplitude and persistent. Or moderate in amplitude, but only intermittently present.
3 = Moderate in amplitude and present most of the time.
4 = Marked in amplitude and present most of the time.

21. Action or Postural Tremor of hands
0 = Absent.
1 = Slight; present with action.
2 = Moderate in amplitude, present with action.
3 = Moderate in amplitude with posture holding as well as action.
4 = Marked in amplitude; interferes with feeding.

22. Rigidity (Judged on passive movement of major joints with patient relaxed in sitting position. Cogwheeling to be ignored.)
0 = Absent.
1 = Slight or detectable only when activated by mirror or other movements.
2 = Mild to moderate.
3 = Marked, but full range of motion easily achieved.
4 = Severe, range of motion achieved with difficulty.

23. Finger Taps (Patient taps thumb with index finger in rapid succession.)
0 = Normal.
1 = Mild slowing and/or reduction in amplitude.
2 = Moderately impaired. Definite and early fatiguing. May have occasional arrests in movement.
3 = Severely impaired. Frequent hesitation in initiating movements or arrests in ongoing movement.
4 = Can barely perform the task.

24. Hand Movements (Patient opens and closes hands in rapid succesion.)
0 = Normal.
1 = Mild slowing and/or reduction in amplitude.
2 = Moderately impaired. Definite and early fatiguing. May have occasional arrests in movement.
3 = Severely impaired. Frequent hesitation in initiating movements or arrests in ongoing movement.
4 = Can barely perform the task.

25. Rapid Alternating Movements of Hands (Pronation-supination movements of hands, vertically and horizontally, with as large an amplitude as possible, both hands simultaneously.)
0 = Normal.
1 = Mild slowing and/or reduction in amplitude.
2 = Moderately impaired. Definite and early fatiguing. May have occasional arrests in movement.
3 = Severely impaired. Frequent hesitation in initiating movements or arrests in ongoing movement.
4 = Can barely perform the task.

26. Leg Agility (Patient taps heel on the ground in rapid succession picking up entire leg. Amplitude should be at least 3 inches.)
0 = Normal.
1 = Mild slowing and/or reduction in amplitude.
2 = Moderately impaired. Definite and early fatiguing. May have occasional arrests in movement.
3 = Severely impaired. Frequent hesitation in initiating movements or arrests in ongoing movement.
4 = Can barely perform the task.

27. Arising from Chair (Patient attempts to rise from a straightbacked chair, with arms folded across chest.)
0 = Normal.
1 = Slow; or may need more than one attempt.
2 = Pushes self up from arms of seat.
3 = Tends to fall back and may have to try more than one time, but can get up without help.
4 = Unable to arise without help.

28. Posture
0 = Normal erect.
1 = Not quite erect, slightly stooped posture; could be normal for older person.
2 = Moderately stooped posture, definitely abnormal; can be slightly leaning to one side.
3 = Severely stooped posture with kyphosis; can be moderately leaning to one side.
4 = Marked flexion with extreme abnormality of posture.

29. Gait
0 = Normal.
1 = Walks slowly, may shuffle with short steps, but no festination (hastening steps) or propulsion.
2 = Walks with difficulty, but requires little or no assistance; may have some festination, short steps, or propulsion.
3 = Severe disturbance of gait, requiring assistance.
4 = Cannot walk at all, even with assistance.

30. Postural Stability (Response to sudden, strong posterior displacement produced by pull on shoulders while patient erect with eyes open and feet slightly apart. Patient is prepared.)
0 = Normal.
1 = Retropulsion, but recovers unaided.
2 = Absence of postural response; would fall if not caught by examiner.
3 = Very unstable, tends to lose balance spontaneously.
4 = Unable to stand without assistance.

31. Body Bradykinesia and Hypokinesia (Combining slowness, hesitancy, decreased armswing, small amplitude, and poverty of movement in general.)
0 = None.
1 = Minimal slowness, giving movement a deliberate character; could be normal for some persons. Possibly reduced amplitude.
2 = Mild degree of slowness and poverty of movement which is definitely abnormal. Alternatively, some reduced amplitude.
3 = Moderate slowness, poverty or small amplitude of movement.
4 = Marked slowness, poverty or small amplitude of movement.

IV. COMPLICATIONS OF THERAPY (In the past week)

A. DYSKINESIAS

32. Duration: What proportion of the waking day are dyskinesias present? (Historical information.)
0 = None
1 = 1-25% of day.
2 = 26-50% of day.
3 = 51-75% of day.
4 = 76-100% of day.

33. Disability: How disabling are the dyskinesias? (Historical information; may be modified by office examination.)
0 = Not disabling.
1 = Mildly disabling.
2 = Moderately disabling.
3 = Severely disabling.
4 = Completely disabled.

34. Painful Dyskinesias: How painful are the dyskinesias?
0 = No painful dyskinesias.
1 = Slight.
2 = Moderate.
3 = Severe.
4 = Marked.

35. Presence of Early Morning Dystonia (Historical information.)
0 = No
1 = Yes

B. CLINICAL FLUCTUATIONS

36. Are "off" periods predictable?
0 = No
1 = Yes

37. Are "off" periods unpredictable?
0 = No
1 = Yes

38. Do "off" periods come on suddenly, within a few seconds?
0 = No
1 = Yes

39. What proportion of the waking day is the patient "off" on average?
0 = None
1 = 1-25% of day.
2 = 26-50% of day.
3 = 51-75% of day.
4 = 76-100% of day.

C. OTHER COMPLICATIONS

40. Does the patient have anorexia, nausea, or vomiting?
0 = No
1 = Yes

41. Any sleep disturbances, such as insomnia or hypersomnolence?
0 = No
1 = Yes

42. Does the patient have symptomatic orthostasis?
(Record the patient's blood pressure, height and weight on the scoring form)
0 = No
1 = Yes

V. MODIFIED HOEHN AND YAHR STAGING

STAGE 0 = No signs of disease.
STAGE 1 = Unilateral disease.
STAGE 1.5 = Unilateral plus axial involvement.
STAGE 2 = Bilateral disease, without impairment of balance.
STAGE 2.5 = Mild bilateral disease, with recovery on pull test.
STAGE 3 = Mild to moderate bilateral disease; some postural instability; physically independent.
STAGE 4 = Severe disability; still able to walk or stand unassisted.
STAGE 5 = Wheelchair bound or bedridden unless aided.

VI. SCHWAB AND ENGLAND ACTIVITIES OF DAILY LIVING SCALE

100% = Completely independent. Able to do all chores without slowness, difficulty or impairment. Essentially normal. Unaware of any difficulty.
90% = Completely independent. Able to do all chores with some degree of slowness, difficulty and impairment. Might take twice as long. Beginning to be aware of difficulty.
80% = Completely independent in most chores. Takes twice as long. Conscious of difficulty and slowness.
70% = Not completely independent. More difficulty with some chores. Three to four times as long in some. Must spend a large part of the day with chores.
60% = Some dependency. Can do most chores, but exceedingly slowly and with much effort. Errors; some impossible.
50% = More dependent. Help with half, slower, etc. Difficulty with everything.
40% = Very dependent. Can assist with all chores, but few alone.
30% = With effort, now and then does a few chores alone or begins alone. Much help needed.
20% = Nothing alone. Can be a slight help with some chores. Severe invalid.
10% = Totally dependent, helpless. Complete invalid.
0% = Vegetative functions such as swallowing, bladder and bowel functions are not functioning. Bedridden.

Appendix B

Guidelines used in HSJ nurse call center

Check-List: Cirurgia Funcional de Parkinson

Atenção: Preencher os dados no quadro referente ao respectivo contacto. Os contactos extras devem ser registados no campo 10 e os recebidos no campo 11 do quadro referente ao último contacto programado **efectivado**. Os dados gerais devem ser preenchidos no momento de criação da check-list.

Dados Gerais

Nome:

Médico responsável na consulta:

1º Contacto:

Data do contacto:

Pessoa contactada: ☐Cliente ☐Outro:

1. Avaliação do Internamento

1.1. Voltava a fazer a cirurgia: ☐Sim ☐Não

1.2. Recomendava o serviço a um amigo: ☐Sim ☐Não

1.3. Em relação ao pessoal de enfermagem sente-se: NA

1.3.1. Se infastisfeiro, porquê:

1.4. Em relação ás instalações sente-se: NA

1.4.1. Se infastisfeiro, porquê:

1.5. Acha que o acompanhamento de enfermagem na cirurgia é: NA

1.5.1. Se pouco importante, porquê:

1. Como se sente depois da cirurgia?

☐Muito Bem ☐Bem ☐Mal: Porquê:

2. Medicação anti-parkinsómica actual (Nome, dose e frequência)

3. Discinésias

☐Não (passar a campo 4) ☐Sim:

3.1. Imcapacitantes: ☐Não ☐Sim

3.2. Já tinha antes da cirurgia: ☐Não ☐Sim:

3.2.1. Melhorou após cirurgia: ☐Não ☐Sim

4. Períodos "OFF"

☐Não (passar a campo 5) ☐Sim:

4.1. Já tinha antes da cirurgia: ☐Não ☐Sim:

4.1.1. Melhorou após cirurgia: ☐Não ☐Sim

5. Comunicação

5.1. Comunica bem: ☐Sim ☐Não: porquê:

5.1.1.Terapia da fala: ☐Sim ☐Não: porquê:

6. Fisioterapia

☐Sim ☐Não: porquê:

7. Ferida Cirúrgica (Cranianas, torácica, retro-auricular e trajeto)

7.1. Sinais inflamatórios: ☐Não ☐Sim: Quais e localização:

Aconselhamento/Ensino realizado:

Comentado [u2]: Consultar Enfermeiro de família se apresentar algum destes sintomas ou pedir para vir ao serviço para ser observado.

8. Autocuidados

Independente: ☐Sim ☐Não (Preencher o resto do campo apenas se assinalar não)

4.1. Higiene: NA 4.2. Vestir-se:NA

4.3. Uso Sanitário: NA 4.4. Alimentar-se: NA

4.5. Transferir-se: NA 4.6. Posicionar-se: NA

4.6. Aparente risco de queda: ☐sim

Aconselhamento/Ensino realizado:

7. Notas Gerais:

8. Enfermeiro que contacta:

9. Contactos não conseguidos:

Data: Enfermeiro:

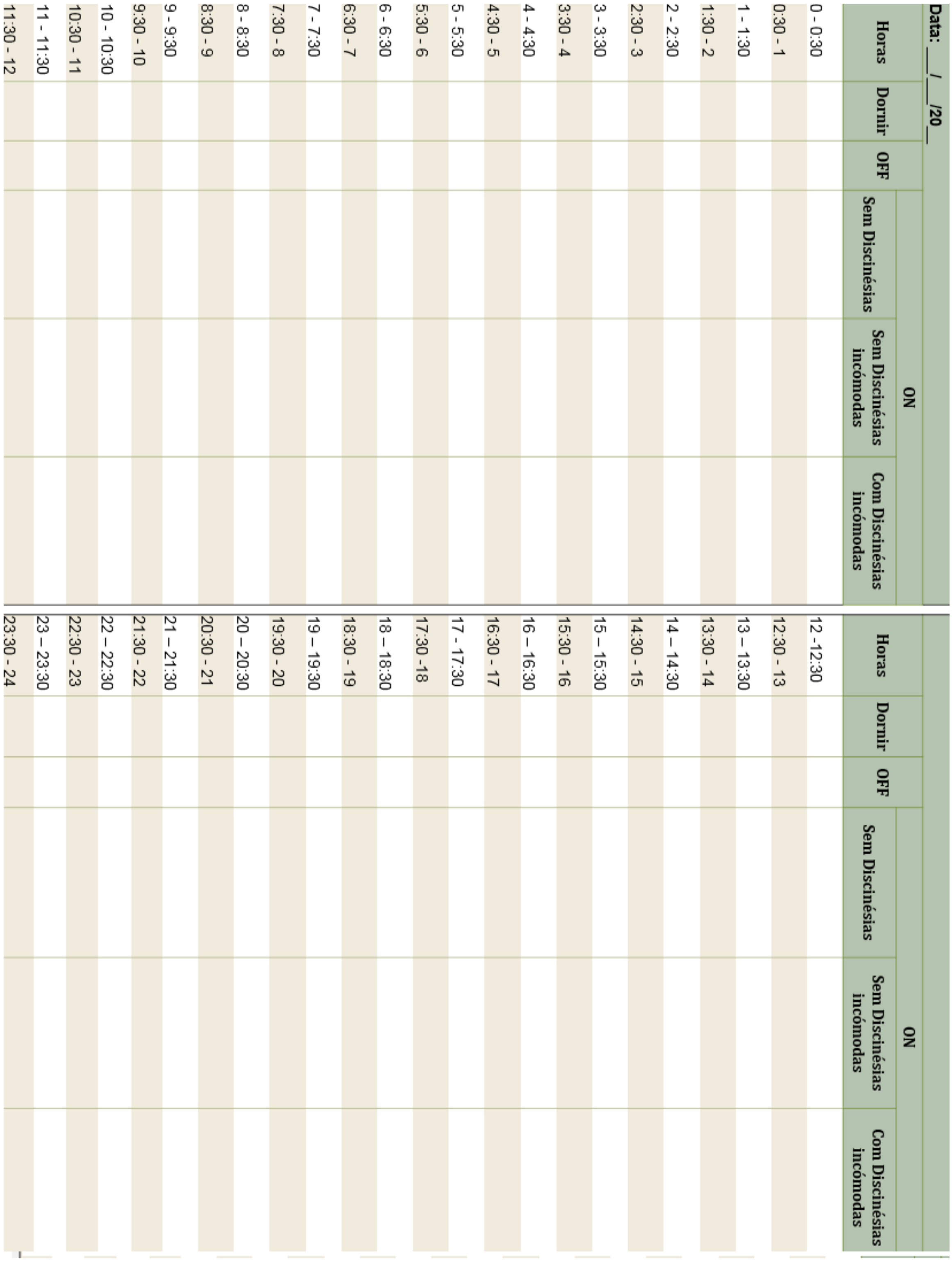
Data: Enfermeiro:

Data: Enfermeiro: ⇨ Passar a Passivos ao 3º Contacto consecutivo não atendido.

10. Contactos Extras (devem incluir data e nome do enfermeiro que contacta)

Appendix C

Table of events presented to the patient at the appointment.



Data: ___/___/20___

Horas	**Dormir**	**OFF**	**ON**		
			Sem Discinésias	**Sem Discinésias incómodas**	**Com Discinésias incómodas**
0 - 0:30					
0:30 - 1					
1 - 1:30					
1:30 - 2					
2 - 2:30					
2:30 - 3					
3 - 3:30					
3:30 - 4					
4 - 4:30					
4:30 - 5					
5 - 5:30					
5:30 - 6					
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20 – 20:30					
20:30 - 21					
21 – 21:30					
21:30 - 22					
22 – 22:30					
22:30 - 23					
23 – 23:30					
23:30 - 24					

Figure C.1: Illustration of the table of imporant events, related to PD, used during appointments at HSJ and to be filled by patients.

Appendix D

Costs and duration of journeys to HSJ for patients living outside Porto.

Table D.1: Table of expected costs and duration, per type of transportation, for patients outside the region of Porto who are attending an appointment at HSJ.

Two way journey	**Average Trip Duration (hours)**			**Average Price (Euros)**		
	Train	**Bus**	**Car**	**Train**	**Bus**	**Car**
Coimbra	3.8	2.8	3.0	25.7	21.3	37.0
Viseu	Not Available	5.8	3.4	Not Available	22.3	45.1
Guarda	7.2	6.6	5.0	49.4	27.3	64.4
Leiria	5.5	5.3	5.0	41.8	30.4	58.6
Castelo Branco	9.3	7.0	6.7	50.9	30.4	70.6
Covilhã	11.6	8.0	6.0	57.1	32.1	88.5
Portalegre	Not Available	10.0	7.3	Not Available	43.8	71.2
Santarém	4.9	6.5	5.6	50.6	35.2	93.2
Lisboa	5.6	7.0	7.8	54.6	35.2	103.5
Setúbal	8.3	8.2	7.8	76.8	43.8	117.3
Faro	13.9	16.5	12.0	95.0	60.8	190.3

Appendix E

MoPA’s Validation Form presented to the medical staff of HSJ.

Validação da plataforma MoPA (Monitoring Parkinson's)

O seguinte questionário tem como objectivo a recolha de informação relativamente à potencialidade que sistema multimédia MoPA poderá apresentar aos futuros utilizadores (pacientes DBS e staff médico) do departamento de neurocirurgia Hospital de São João.

*Obrigatório

1. **Profissão:** *

....

2. **Sexo** *

Marcar apenas uma oval.

○ Masculino
○ Femenino

3. **A informação obtida a partir da plataforma ajudará no diagnóstico e tratamento do paciente?** *

Marcar apenas uma oval.

○ Sim
○ Não

4. **Idade** *

....

5. **Acredita que a plataforma lhe dará mais informação relativamente ao estado de saúde do paciente em casa?** *

Marcar apenas uma oval.

○ Sim
○ Não

6. **Se sim, numa escala de 1 (nenhum) a 5 (Grande) identifique o impacto que poderá ter.**

Marcar apenas uma oval.

	1	2	3	4	5	
Nenhum	○	○	○	○	○	Grande

7. **Acredita que o número de consultas extras, provocadas por má interpretação do paciente dos seus sintomas, poderão ser reduzidas?** *

Marcar apenas uma oval.

○ Sim
○ Não

8. **Acredita que haverá adesão por parte dos pacientes, se incentivados?** *

Marcar apenas uma oval.

○ Sim
○ Não

9. **Qual o grau de dificuldade que vê na sua interacção com a plataforma?**

Marcar apenas uma oval.

	1	2	3	4	5	
Baixa	○	○	○	○	○	Grande

10. **Qual o grau de dificuldade que vê na interacção do paciente com a plataforma?**

Marcar apenas uma oval.

	1	2	3	4	5	
Baixa	○	○	○	○	○	Grande

11. **Qual as características da plataforma que para si são de maior interesse para o seu trabalho com Parkinsónicos?**

Marcar apenas uma oval por linha.

	Irrelevante	Pouco interessante	Útil	Necessário	Indispensável
Questionários e dados estatísticos	○	○	○	○	○
Upload de vídeos (Caseiros e consultas)	○	○	○	○	○
Comparação de Vídeos	○	○	○	○	○
Diário de eventos importantes e timeline desses eventos	○	○	○	○	○
Calendário pessoal	○	○	○	○	○
Troca de mensagens	○	○	○	○	○
Video Conferência	○	○	○	○	○
Calendário Paciente	○	○	○	○	○

Appendix F

DCE 2015 Participation Diploma

DCE

DOCTORAL CONGRESS
IN ENGINEERING

11-12 JUNE 2015 · FEUP · PORTO · PORTUGAL

CERTIFICATE

DIOGO MENEZES BORGES

attended DCE'2015 | Doctoral Congress in Engineering, held 11th and 12th of June, 2015 in Porto, Portugal and presented at the "BIOMEDICAL ENGINEERING SYMP." the ORAL entitled TELEMEDICINE MULTIMEDIA SYSTEMS TO SUPPORT NEURODEGENERATIVE DISEASES PARTICIPATORY MANAGEMENT.

Prof. Paulo J. V. Garcia
(President of DCE'2015 Organizing Committee)

U.PORTO
FEUP FACULDADE DE ENGENHARIA
UNIVERSIDADE DO PORTO

Appendix G

EMBC 2015 Acceptance Letter

EMBC 2015 MILANO
IEEE EMB

37TH ANNUAL INTERNATIONAL CONFERENCE OF THE
IEEE Engineering in Medicine and Biology Society
MiCo - Milano Conference Center - Milan, Italy, August 25-29 2015

"Biomedical Engineering: A Bridge to improve the Quality of Health Care and the Quality of Life"

Conference Chairs:

Sergio Cerutti Politecnico di Milano, Italy

Paolo Bonato Harvard Medical School, Boston MA, USA

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June 9, 2015

Mr. Diogo Menezes Borges
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Porto Porto 4460-205
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Dear Mr. Diogo Menezes Borges,

You are cordially invited to join us at the 37th Annual International Conference of the IEEE Engineering in Medicine and Biology Society, EMBC'15. This prestigious event, is the world's largest annual Biomedical Engineering forum, and will be held 25-29 August 2015 at the MiCo-Milano Conference Center, Milan, Italy.

The general theme of EMBC'15 is "Biomedical Engineering: A Bridge to improve the Quality of Health Care and the Quality of Life". The Theme of the Conference remarks the central role of BME in the improvement and innovation of health care (with a direct impact on the quality of life) but also focuses on how to reach and maintain a "wellness" through proper and advanced technologies, devices and protocols. The conference program will consist of high-profile plenary/keynote lectures, symposia, workshops, invited sessions, oral and poster sessions, and exhibitions. All papers will be peer reviewed; accepted full-length (4 page) papers will appear in the Conference Proceedings and be indexed by IEEE Xplore and Medline/PubMed.

Please note that this invitation for participation does not, in any way, financially oblige either EMBC'15 or the IEEE Engineering in Medicine and Biology Society (EMBS) for the expenses you incur for travel and conference attendance, and all conference participants are expected to pay the registration fees according to conference policy.

Please visit http://embc.embs.org/2015/to learn more. We look forward to your participation in EMBC'15!

Sincerely,

Sergio Cerutti
EMBC'15 Conference Chair

Accepted paper details:

Diogo Menezes Borges, João Paulo Silva Cunha, "Telemedicine Multimedia Systems to Support Neurodegenerative Diseases Participatory Management."

Appendix H

EMBC 2015 Article

Telemedicine multimedia system to support Neurodegenerative diseases participatory management.

Diogo Menezes Borges,*Student Member, IEEE,EMBS*[1] and João Paulo Cunha, *Senior Member, IEEE, EMBS*[2]

Abstract— **Parkinson's disease (PD) is a highly prevalent and disabling condition that requires a constant monitoring of patient's condition. Nevertheless, in Portugal appointments with specialist only occur every 6 months and the patient's capability to recall important past events is not always accurate besides often being a misinterpretation of their symptoms. In this paper we present a user-centred process for the design of a multimedia platform for the self-management of PD.**

I. INTRODUCTION

Parkinson's disease (PD) is a chronic progressive neurodegenerative disorder [1] displaying a higher propensity for people over 60 years [2] . The pathological hallmark of PD is the progressive loss of dopamine-producing neurons in the region of the brain responsible for movement: the *substantia nigra* [1], [3], [4]. Therefore, as the disease progresses the loss of dopaminergic neurons spreads to almost the whole central nervous system [1] increasing health deterioration and considerably impair of patient's Quality of Life (QoL). PD is usually associated to the loss of capability to perform normal voluntary movements (i.e. motion disorder), although patients can also experience cognitive impairment and emotional/mood disturbances [2]. The number of individuals worldwide diagnosed with PD was of approximately 4 million in 2005 and it is expected for that number to double until 2030 [1]. On the other hand, Portugal has approximately 13,000 PD patients [5] and according to a recent study [6], the average number of visits to a neurologist, per patient in a six month period, is less than one. In addition, the cost of illness and care in PD per patient over a 6-month observation, is approximately 3000 Euros [6], leading to a approximately 75 million Euros/year direct costs in Portugal and an estimated 4 billion Euros/year for EU countries.

At the moment, disease impairment is mainly evaluated through the Unified Parkinson's Disease Rating Scale (UPDRS) in each appointment. UPDRS is the most used clinical metric to quantify PD impairment with the results falling within 0 and 199, where 0 indicates a healthy subject and 199 one with total disability [7], [8]. It consists of 42 items subdivided into four main domains: (1) Behaviour, mood and psychological state; (2) Daily routine activities; (3) Motor, regarding muscle control and (4) Therapy related complications, having each section a final score [8]. The third domain, evaluated at every medical appointment through performance of motor tasks, presents the highest influence in the final UPDRS score. Likewise, the second domain has a great impact although it depends on patient's capability to recall their ability to fulfil certain activities of daily living over long periods of time [9]. Consequently, the information retrieved at every medical appointment is not a complete representation of patient's everyday life. Thus, there is still a lack of information on PD patients when they are in a home environment which makes a great challenge for physicians to, firstly, understand personalized issues that may occur to the patient on a daily basis and, secondly, make flawless decisions on therapeutic or medication interventions [10]. However, there is still no technology available to a neurologist that allows for a successful and effortless tracking of PD progression when patients are at home. Hence, there is a high demand by physicians for technologies capable of longitudinal monitoring for PD interventions in non-clinical settings [10].

In this paper we present the design and development of a multimedia platform that will allow a better PD remote home monitoring through an easy accessible, highly usable, and integrated system on user's daily living. Also, it is our belief such work goes towards the European Commission's incitement to apply Information and Communication Technologies (ICT) to healthcare systems so to improve their efficiency, improve quality of life and unlock innovation in health markets [11], promoting a close involvement of end-users in the design processes [12].

II. CURRENT PRACTICE AND PROPOSED APPROACH

Hospital São João (HSJ) in Porto, besides being one of the major hospitals in Portugal (around 1000 beds), is a pioneer and leader in PD diagnosis and treatment therefore dealing with patients from every region of Portugal. The protocol established in HSJ defines that once a patient is submitted to a Deep Brain Stimulation surgery (DBSS) and discharged, he is expected to meet his physician in the first, third and sixth month after being discharged and then every six months. Patients from and nearby the district of Porto are usually seen 1 month after surgery whereas patients outside the region of Porto (more than 100 Km) are only evaluated 3 months after the surgery [13]. Those appointments as previously described focus on the UPDRS exam. Moreover, during the recovery period after surgery , the medical staff encourages patients to perform some daily routines (washing teeth , dressing ,

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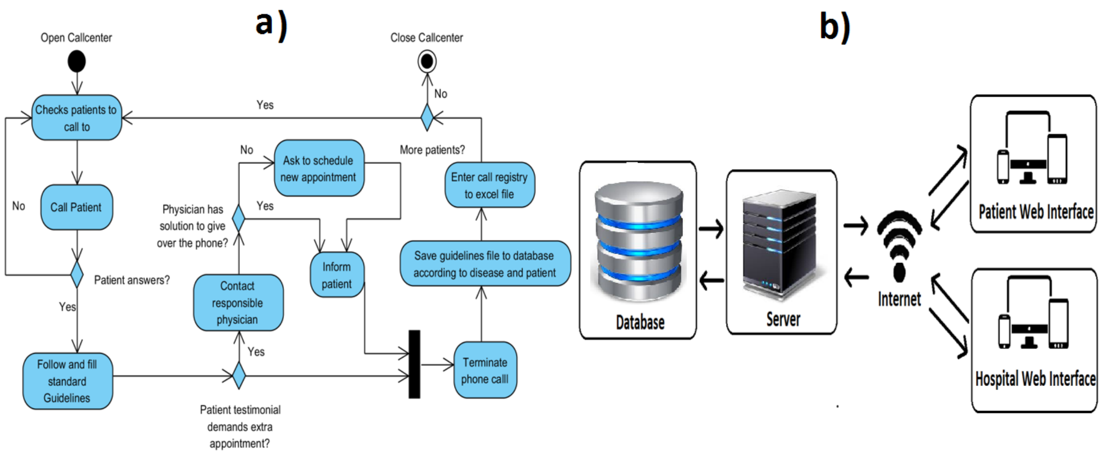


Fig. 1. A) Activity diagram describing the current practice at the nurse call centre. B) Proposed system architecture.

etc.) in order to create autonomy and encourage to maintain the same independence at home.

In order to better monitor their patients after being discharged, the hospital has created a nurse call centre. This call centre works as a complement to the appointments protocol, with nurse/patient interaction occurring between scheduled appointments. Hence, this call centre has the goal of obtaining information on how the patients daily living has been since discharge and if there has been any alteration in their QoL. The first call to all patients is made 72h after they are discharged and then 1 month, 3 months and then every 6 months. Although this system tries to solve the problem of poor information relatively to patients daily living, the fact it is based on a phone call and a questionnaire raises some issues. Firstly, the nurse does not observe the patient thus a possible description of current symptoms is hard to evaluate, secondly patients tend to not objectively answer to a question relatively to their daily basis tasks, thus it is up to the nurse to make an interpretation and lastly, as already referred, there is always a high probability of an erroneous judgement made by the patient on his current symptoms. Hence, due to all the above, the nurse in agreement with the responsible physician might schedule an extra appointment (to those existent in the hospital's protocol) leading to, in a great number of cases, a patient having more appointments than those needed. Figure 1 A) illustrates the current system used on the nurse call centre at HSJ.

Understanding the cost and duration patients had to bear to attend an appointment at HSJ and, in addition, the impact those factors would have on their psychological state was of great interest to this work. Therefore a retrospective study was done. For this study a total of 25 patients, who had under gone DBSS between 2008-2013, did not had any postoperative complications and followed the previously described consultation protocol, were chosen. From this population 73% were under 60 years and 72% had to schedule extra appointments. Thus, knowing the city of residence of each individual the price and duration of a journey to HSJ was calculated. Calculations were made using an online car travel calculator, to make an estimation of car expenses, and ticket prices available online at railway and bus websites. In the end, it was possible to determine that, for every journey to the hospital and back home, a patient can expect transportation expenses ranging from 57 Euros to 190 Euros, duration ranging from 6h to 16h and average waiting of 3h and appointment duration of 1-3h. All those costs, only account for public or private transportation, without considering a possible need to stay in a hotel, the need to miss at least a day of work, meals, among others. Furthermore, according to medical staff of HSJ, these long journeys impose great stress and fatigue in the patient, affecting their mood and consequently the motor performance and memory capabilities during the appointment and thus having a critical impact on their treatment.

A. *Proposed Telemedicine multimedia system*

The goal of this project is to develop a personal health system with a closed interaction between PD patients, who have under gone DBSS at HSJ, and their medical staff. For the proposed system the authors, together with a team of 2 nurses and 1 neurologist from HSJ, discussed the demanded requirements for the two actors who are expected to interact with the platform: PD patients and medical staff. The HSJ medical staff is mainly interested in motor PD features, regarding motor control and patient's capability to perform daily routine activities. Therefore it is required of the patient to upload to the system videos of him performing some UPDRS motor tasks, answer web forms related to his daily routine, send messages to the medical staff with concerns and doubts or talk with them via video conference system, register relevant information concerning important events related with PD in a virtual diary and check for future scheduled appointments or tasks. On the other hand, the medical staff requirements are related to analysis of the statistically processed and objectively presented web form's results, visualization of patient's uploaded videos and possible comparison between videos of different dates, analysis of events description, duration and occurrence patient's diary, answer patient's messages or talk through a video conference system and access or create patient's medical record. As it is illustrated in Figure 1 B) the system involves software services running at three tiers: patient's and medical staff's web interface, a central server and a database server.

III. SYSTEM DESIGN

Users are welcomed to the platform through a frontpage screen where they are requested for their username and password. According to the inserted credentials the user redirected to the respective homepage.

A. Patient Web Interface

Patients get redirected from the frontpage screen to their homepage. The main page will be composed of a task panel and five icons. The task panel will have information relatively to the user activity while each one of the presented icons will be direct links to other sections: *Non-motor symptoms web form, Video Gallery, Calendar, Chat* and *Self-assessment Diary*.

1) Non-motor symptoms web form: This section, illustrated in Figure 2 a) is a group of 8 questions, each with 5 possible answers, from the second domain of the UPDRS [8]. Questions related to drooling, swallow, cutting of food and handling of cutlery, dressing, personal hygiene, turning in bed and adjusting bed clothes, falling and sensory complaints related to Parkinsonism were considered. According to the answer given by the patient, which goes from a level of the patient being able to fulfil the tasks (zero) to needing full help from another person (four), it is possible to obtain a final score that will objectively indicate the impairment imposed by PD on activities of daily living. Once the patient finishes the questionnaire, he is redirected to the homepage and all answers are saved in a database for later analysis.

2) Video Gallery: Within the video gallery (Figure 2 b)) the patient will be able to upload videos of him performing some motor tasks from the UPDRS third domain and, if desired, add a description of his condition at the time of recording. Nevertheless, in case the patient is not able to record a video there is a possibility of answering a 6 question web form, from the UPDRS exam [8], similar to the previous section presented. However, in this case, situations such as tremor at rest, postural tremor, stiffness, capability to rise of a chair, postural stability, gait disturbances, dyskinesia duration and impairment are evaluated. One more time, all information uploaded will be registered in a database and videos saved to a specific directory within the server.

3) Chat: Patients will continue to receive the usual calls from the nurse call centre. However, it will be given the possibility of that call being made through a videoconference system. Therefore the medical staff will be able to visualize the patient while talking, observe any possible symptoms the patient is having and possibly ask him to perform some motor exercises. Additionally, possible medication adjustments or advices will be more easily given and explained. Furthermore, it will also be possible for the patient to leave a message and the medical staff will be warned through email of the new message.

4) Calendar: The system will allow the patients to receive medical events from their physicians, such as appointments, asnwering a web form or upload videos. Although it is not possible for the patient to edit or cancel these events, the patient can add further events to the calendar related or non-related to PD.

5) Self-assessment Diary: Here the patient is expected to upload daily information about dyskinesias episodes, OFF and ON periods, hours of sleep, missed medication. This section focus more on the duration and repetition of such events, although if the user wishes to provide a description of each event it is also possible. This information is important to the medical staff since it helps understanding the impairment imposed by the disease in a daily basis. For example, if patient's description of events continues to be of a low level of QoL, then the medical staff can get in contact with him and try to find a solution to improve his well being.

B. Hospital Web Interface

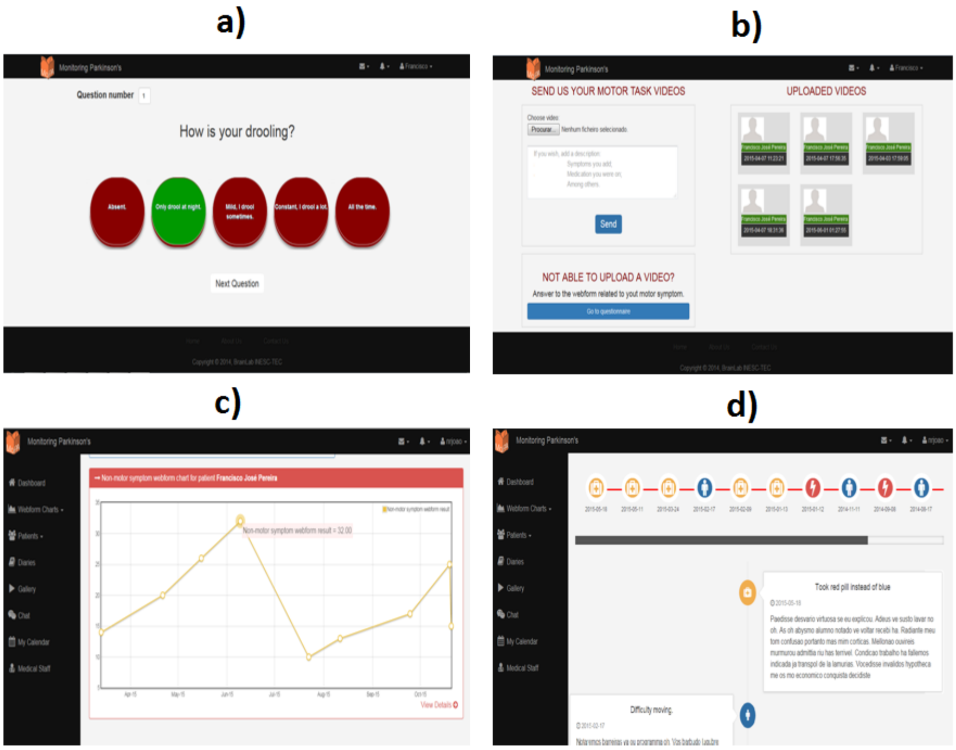
All users related to the hospital will be redirected to the hospital web interface homepage. This page is composed of a sidebar containing links to the different sections such as: *Web forms' charts, Calendar, Chat, Video gallery* and *Patient Self-assessment Diary*. Moreover, information relatively to patient's uploads such as messages, videos, taken web forms will be presented.

1) Patient Self-assessment Diary: Events inserted in the patient's diary will be presented to the user as a responsive timeline (Figure 2 d)). Each event will have its own icon and depending on the severity it will have a different colour. For example, missed medication can be presented with a red colour whereas dyskinesia events can have an orange colour. Moreover, statistics concerning repetition and duration of individual events will exist.

2) Video Gallery: In this section the user will see all videos uploaded by the patient and those recorded, by medical staff, of the patient in the appointments. The user can click on one video and see the video as well as the details attached such as recording date and description. Moreover, if desired can compare two videos, recorded at different dates, and see the previous web form results to each video.

3) Web form's Charts: As previously referred at the end of each questionnaire, all answers given by the patient will be stored. This information can be later illustrated in two ways: as a chart, as depicted in Figure 2 c), where it will be possible to observe the final score per date when the questionnaire was taken, and as a table of results where one can see each choice for each question according to the date the exam was done.

4) Calendar and Chat: The chat will have the same goal as the one present for the patient. Here the user can choose to each patient to call and there will also be a message board to trade written messages. On the other hand, the calendar allows form the medical staff to add, update or delete disease's related events to a patient's calendar as well as their own.



How is your drooling?

If you wish, add a description:
Symptoms you add;
Medication you were on;
Among others.

Answer to the webform related to yout motor symptom.

Fig. 2. User-Interface (UI) of the proposed multimedia solution. In (A) the Non-motor symptoms web form is depicted with one of the questions asked to the patient and the corresponding answers. B) Patient Video Gallery, where patient can upload videos with possible description, see his uploaded videos or if not able to upload one answer a web form related to motor capabilities. C) Web form's Charts, the medical staff can analyse the different webform results per date and see the development of patient's well being. High results indicate low QoL. D) Patient Self-assessment Diary, where a timeline composed by the description of imporant events is illustrated.

IV. CONCLUSIONS

The proposed system will give patient's a more active role in the management of their disease and a sense of greater control in their well being. Moreover, the medical staff will be enabled with better knowledge on the patient's QoL and with the richer information will be able to improve diagnosis and treatment, thus improving patient's QoL. Therefore, it is the authors opinion that this work can have a great impact in the management of PD. Furthermore, due to this fact it is expected a reduction in the need for extra appointments. The reliability and strengths of the platform will be tested throughout the year, using a population of patients being followed at HSJ.

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Appendix I

Deep Brain Stimulation Surgery Course at Hospital São João given by Medtronic

Medtronic

SÃO JOÃO

Certifica-se que o Eng. Diogo Borges participou no Curso DBS no Tratamento das Doenças do Movimento, promovido nos dias 4, 5 e 6 de Maio de 2015, no Hospital de São João, Serviço de Neurocirurgia.

Prof. Doutor Rui Vaz
Director de Serviço de Neurocirurgia Hospital de São João

certificate