PERFORM: A system for the monitoring and management of persons with chronic motor neurodegenerative disorders

A study on Parkinson's Disease and Amyotrophic Lateral Sclerosis

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***Abstract*—In this work we describe a system for the monitoring and management of patients with neurodegenerative diseases, focusing on Parkinson's Disease and Amyotrophic Lateral Sclerosis. The system exploits a single wearable sensors' setting to detect and quantify all patient symptoms. An easy to use touchscreen interface allows patients and caregivers to provide additional useful information and assist patients to perform standard predefined tests which otherwise are performed in the clinician's office. The system exploits patient information to suggest appropriate treatment changes based on accumulated medical knowledge. In this paper the architecture of the system, as well as, its innovative features are presented.**

Continuous wearable patient monitoring system; treatment adjustment; Parkinsons' Disease; ALS;

I. INTRODUCTION

The proposed system addresses both monitoring and management of patients with chronic neurodegenerative diseases exhibiting motor disabilities. Such patients present various motor symptoms which are evolving with time. The monitoring of these symptoms and their evolution provides valuable information on the patient's health status and wellbeing. However, each symptom is expressed differently in each patient and the evolution of the disease is highly personalized. Accurate patient health assessment is a prerequisite for correct treatment evaluation and adjustment of therapy, according to patient characteristics. PERFORM continually monitors all patient's symptoms, and thus allows an accurate assessment of the patient's condition and disease's evolution. This is finally used, for the first time, to propose appropriate treatment changes which assist the treating clinician and the patient to maintain or improve when possible, the patient's quality of life for a prolonged period of time. It focuses on two such diseases: Parkinson's Disease (PD) and Amyotrophic Lateral Sclerosis (ALS).

PD main symptoms are tremor, dyskinsesia, bradykenisia and gait abnormalities, such as slower walking pace, shuffling, freezing, falls. Pharmacological treatment improves patient's status; however it also causes undesirable symptoms (e.g. on-off fluctuations) which require treatment adjustments.

ALS symptoms are impaired walking, breathing and generally every body function is affected due to muscle weakening. Treatment focuses on recognizing life-threatening situations and rapid disease evolution.

II. STATE OF THE ART

Over the past decades various methodologies and systems have been proposed for the monitoring and assessment of PD symptoms. Two trends can be distiguished.

The first, focuses on the study of specific motor tests, such as handwritting, inserting pegs and various games ([1], [2], [3], [4], [5], [6]). In these studies, the researchers monitor and analyse the patient movements during a specific well defined motion test. The analysis of the collected signals or images, allows them to quantify the condition of the patient, usually tremor and bradykinesia.

The second trend focuses on the study of specific symptoms during daily patient activities. The researchers suggest the use of different types of wearable systems that can be used at home and record patient signals for several hours during the day.

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Various symptoms and conditions has been investigated. H. Russmann et al. [7] and N. Saito et al. [8] focused on the investigation of various PD gait parameters. E. Van Someren et al. ([9], [10], [11]) and M. Yang et al. [12] studied the detection and quantification of PD tremor. P. Burkhard et al. [13] and N. Keijsers et al. ([14], [15]) investigated the detection and quantificication of levodopa induced dyskinesia. A. Salarian et al. ([16], [17]) and J. Giuffrida et al. [18] studied both tremor and bradykinesia usign each, their own wearable system. Recently various researchers have focused on the study of systems that could be used for the overall motor patient assessment and the adjustment of therapy. A. Antonini et al. [19] proved that such systems can be accepted by the PD patient. In their approach the signals were collected at home and sent to a hospital through the available telephone line, and were analysed there. C. De Luca et al. [20] proposed a wearable system exploiting the combination of EMG and acceleration signals that will be used to invesitgate tremor, bradykinesia, on/off flunctuation and the adaptation of therapy. Initial results indicate that the system can be used to recognise patient on/off conditions while the patient is performing specific well defined motion tests (e.g. Finger-to-Nose, Sit-Stand-Walk). Most recently, S. Patel et al. [21] focused their investigation on the use of a minimum set of features to detect and quantify tremor, bradykinesia and dyskinesia for specific well defined motion tests. The researchers proved that the suggested algorithms use minimum resources, and thus can be incorporated into a wearable device instant of being transmitted and analysed remotely.

On the other hand, ALS has only been investigated recently in L. Fuyuan et al. [22]. The researchers studied gait rhythm abnormalities for three categories of neurodegenerative diseases, among which PD and ALS using a wearable device.

Our approach is based on the most recent results from other reserch teams ([13]-[22]), and proposes a system that can be adapted to both PD and ALS. However, our focus is on the detection and quantification of all patient symptoms during daily activities using a single set of wearable sensors. The designed system is lighted weighted and patients are willing to wear it for continuous daily sessions, thus allowing 24h monitoring for all symptoms, which is proposed for the first time. This allows continuous patient status evaluation in combination with patient and caregiver provided information, and enables for the first time the provision of experts systems which sugesst appropriate treatment changes and support the patient management procedure.

III. SYSTEM ARCHITECTURE

A. *System Actors*

The main users of the system are the patient and the treating clinician, who is usually a specialised neurologist. Moreover, in chronic neurodegenerative diseases, the patient's family or a professional caregiver are also involved in the patient management process. The management process itself, presents significant differences among European Countries, as different healthcare system structures designate different roles in the involved healthcare actors. In some European Countries, apart from specialised neurologists, general practitioners are also involved in the patient following up process. Thus, PERFORM actors are:

Patient: Its motor status is being monitored by the system. The patient may also provide additional information and receives system's feedback after clinician's permission. PD patients are usually 60+ years old and have minimum familiarity with computers and information technology. ALS is not an age-related disease, thus patients present similar technology familiarity characteristics as the general population.

Caregiver: Either being a family member or a professional, the caregiver provides information on the patient status and patient problems.

Treating Clinician: It is normally a specialised neurologist who follows up the patient and is responsible to adjust the therapy plan and the follow-up plan, according to patient characteristics and reported problems.

General Practitioner: In some European Countries, the general practitioner follows up the patient according to the follow-up plan provided by the treating clinician. If the General Practitioner observes abnormalities, it instructs further patient examinations and requests advice from the treating clinician.

B. *Overall System Description*

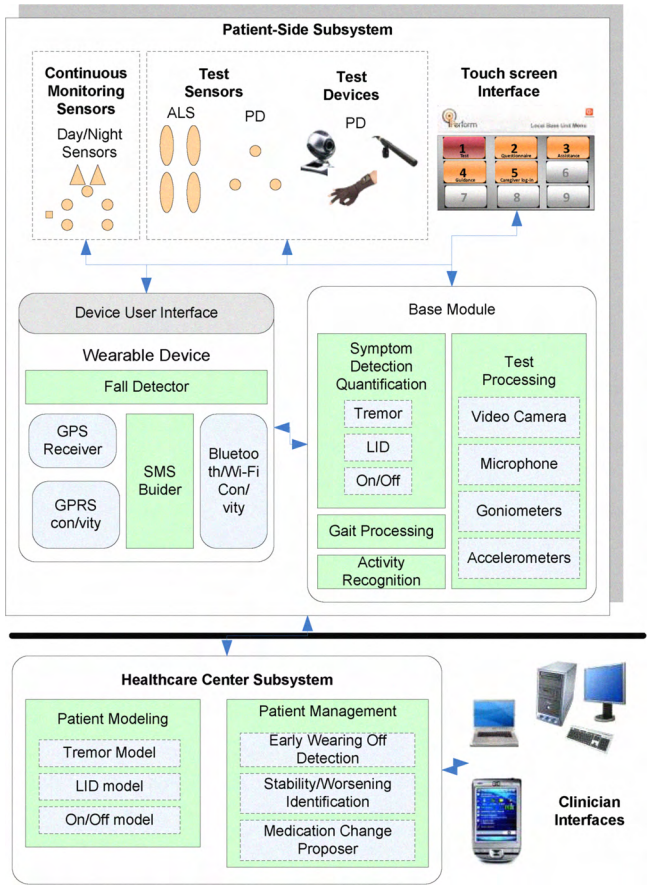

Figure 1. Overall System Architecture

The proposed system consists of two subsystems (Fig. 1): the patient-side subsystem and the healthcare center subsystem.

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The patient-side subsystem is responsible for the identification and quantification of the patient symptoms, and the recording of other useful information for the evaluation of the patient status. Both patients and caregivers access PERFORM through the patient-side subsystem. The healthcare center subsystem evaluates the patient's disease characteristics and their evolution through time and suggests appropriate treatment changes. Both the treating clinician and the general practitioner access PERFORM through the healthcare center subsystem.

C. *Patient Side Subsystem*

The patient-side subsystem composes of the following modules:

1) Continuous Monitoring Module (available only for PD). It is used to monitor the patient motor status throughout the day. It is composed of two sub-modules:

a) Day Monitoring Submodule. It consists of five accelerometers and a wearable device. The wearable device processes the recorded signals and detects patient falls in real-time. If the patient remains on the ground for a substantial timeperiod, the device alerts the designated caregiver. If the caregiver fails to acknowledge the alert within a predefined time-limit, the system informs emergency services of the event and the location of the patient. The sensors' position (Fig. 2a), was chosen after carefull examination and research on the targeted disease symptoms. In Table I, the association of each symptom with the relevant sub-set of sensors is presented. All sensors can store locally the recorded data and wirelessly transmit them to the wearable device.

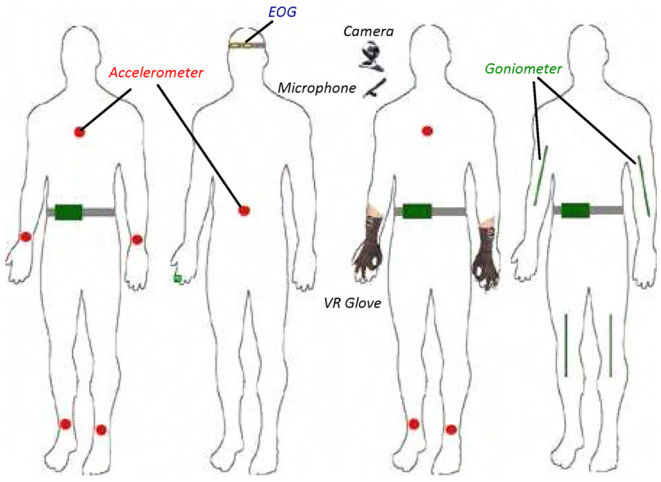

Figure 2. Sensor's Positioning: (a) Day Monitoring System, (b) Night Monitoring System, (c) PD tests system, (d) ALS tests system.

b) Night Monitoring Submodule. It consists of one accelerometer, two Electroculogram (EOG) sensors and a wearable device which records the relevant signals and performs the signal pre-processing. The sensors are positioned as it is shown in Fig. 2b. When the wearable device recognises that the patient is at the stage of REM sleep (from EOG processing), it initiates recording from the four accelerometers and detects patient movements. It is known that humans do not move during REM sleep, but this protective human mechanism is not functioning properly in PD patients.

Special attention is given to the sensors usage and the easy set up by the patients and the caregivers. Sensors which are placed on the trunk or waist are attached to patient clothing and placed within small sized pockets. Zippers allow easy sensor attachment/detachment. Arm and Leg sensors are placed on elastic wrist bands with velcro extensions which allow the firm placement of the sensor.

TABLE I. SYMPTOMS & CORRESPONDING SENSORS

Movement/Symptom	Relevant Sensor	Measured Features
Day Monitoring		
Patient Movement in Space	Trunk Accelerometer	Locomotion Speed
Posture	Trunk Accelerometer	Degrees of inclination
Feet Movement	2 Leg Accelerometers	Step Length, Step Frequency, Height of Feet above ground
Arm Movement	2 Hand Accelerometers	Angle Amplitude
Tremor	2 Hand Accelerometers and 2 Leg Accelerometers	Duration Amplitude Frequency
Levodopa Induced Dyskinesia	All accelerometers	Duration, Severity
Fall	Trunk Accelerometer	Fall Detection
Freezing	All accelerometers	Detection/Duration
On/Off condition	Trunk Accelerometer	Duration Severity
Activity	All Accelerometers	Walking, Sitting, Lying, Standing, Freezing
Night Monitoring		
REM sleep	2 EOG sensors	REM phase detection
Oxygen Saturation	Finger Pulse Oximeter	Oxygen Saturation Value
Patient Movements	2 Leg Accelerometers and 2 Hand Accelerometers	Detection of Movement Duration

TABLE II. TESTS, TEST DEVICES & RESULTS

Test	Device	Measured Features
PD		
Finger Tapping	Virtual Reality Glove	Taps/ sec
Fist opening/closing	Virtual Reality Glove	Movements/ sec
Alternating Hand Movement	Virtual Reality Glove	Movements /sec
Feet Taping	2 Leg accelerometers	Taps/ sec
Posture	Trunk accelerometer	Degrees of inclination
Facial Expression	Video camera	Detection of neutral face
Speech	Microphone	Detection of Hypophonia
ALS		
Hand Grip	Grip force sensor	Pressure
Arm Raise	2 arm goniometers	Angle Amplitute
Leg Raise	2 leg goniometers	Angle Amplitute
Ankle Flexion	2 arm goniometers	Angle Amplitute
Knee Flexion	2 leg goniometers	Angle Amplitute
Spirometer	Spirometer	Air volume

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2) Test Module. It consists of a set of devices used to record patient information, while the patient is performing specific tests, as normally done at the clinician's office during an examination. The patient wears the test devices and performs the tests as instructed from the visual interface of the base module. The test module records the performed activities and identifies any abnormalities, such as wrong sensor or patient position. Finally, it processes the recorded data and extracts the information presented in Table II, for each test.

3) Base Module. It is the core module of the patient-side subsystem including the patient interface for additional patient information, the communication services with the healthcare center, and the symptom detection and quantification submodules.

a) Patient Interface. Emphasis is given in designing an easy to use interface for the patient, considering the patient motor inabilities and limited computer familiarity. The designed interface inherits the "feel and touch" of the phone dialing pad, and all system choices are based on it. Patients use the interface to declare their subjective estimation of their own status, to gain access to relevant disease information, to receive instructions on life-style interventions and on the execution of tests. Moreover, PD patients declare medication intake and food intake information, which is usefull for the patient status assessment.

b) Communication. The Base module supports bluetooth and zigbee communicaion with the continuous monitoring system, and fixed line communication to the hospital center, over ISDN and xDSL.

c) Symptom Detection (only for PD). This submodule processes received patient signals and detects the targeted patient symptoms (tremor, levodopa induced dyskinesia, off state). For each symptom a dedicated submodule processes the relevant signals (Table I), detects the symptom episode and quantifies it into a severity scale from 1 to 4, according to the UPDRS scaling for PD patients [23]. Other features such as duration, frequency and amplitute might also be provided for further clinician review and system evaluation.

Our ultimate target is to develop algorithms which require minimum computational resources and thus can be integrated into the wearable device, and be removed from the base module.

D. Healthcare Center Subsystem

The healthcare center subsystem is composed of the following modules:

1) Patient Modelling Module (available only for PD). This module exploits the recorded patient information to build a patient symptom profile. For each main symptom (tremor, levodopa induced dyskinesia and on-off states), it produces a patient profile which describes the patient's common symptom features. When a new patient recording is processed, it is checked against the patient symptom profile. If significant differences are found, it might be due to two reasons: either a temporarly patient behavior abnormality or a change to the patient profile. In the last case, the system checks if a substantial number of similar situations are identified for the last time period for the specific patient and indicates an alert.

2) Patient Management Module. This module considers the detected symptoms and their characteristics, combines them with other recorded information and suggests appropriate treatment changes based on the accumulated specialists knowledge on the management of PD and ALS. The expert systems used in these cases will be coupled with a data-mining module, which will identify potentially usefull symptom-evolution-therapy associations. The newly found associations will be presented to the specialist who will decide their incorporation into the system's knowledge.

3) Medical Interface. The system can be accessed either locally or remotely by the treating clinician and the general practitioner, using either a large screen access device (e.g. PC, laptop) or a small sceen access device (e.g. PDA). Clinicians will be directed to the home system screen which presents the produced patient alerts, and through it to the patient-specific screen which will provide the information needed to evaluate visually the patient condition. On request, the actual recorded signal and tests will be downloaded from the patient-side to the healthcare center for review. The focus is on the provision of an adequate patient status visual description within one screen, minimising the time spend by a clinician. Clinicians will access the system periodically to check patient status, but the option to be alerted when patient status changes is also available.

4) Communication. The system will support monitoring of 1000 patients at the same time. All patient-side data (signal features and patient inserted information) will be transmitted to the health-care subsystem once a day, through a fixed line communication network.

5) Access/Security. An RBAC policy will be implemented allowing for the viewing of permitted patient information. Patients's will be able to suspend access to their data.

IV. CONCLUSIONS

In this work, we presented a modular system architecture for integrated patient monitoring and management which can be adapted to the needs of any motor neurodegenerative disease. The system is currently addressing PD and ALS, covering two major categories of motor diseases: diseases which present motor fluctuation throughout the day and thus require continuous monitoring, and diseases which are stable throughout the day, and thus can be evaluated at periodic intervals with standardised motor tests. For both categories, disease symptoms are changing with time and treatment adjustments are necessary. The system continually detects and assesses the severity of all disease symptoms, thus making it possible for the first time to propose suitable interventions to maintain patient status at the desirable level. Attention is given to usability issues for both patients and clinicians, proposing a system that can be easily incorporating into their daily lifes. Future work focuses on the research, development and testing of the symtpoms detection and quantification algorithms, as well as the expert systems to support the patient management procedure.

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