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Epilogue and Some Conclusions

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10.1 Summary of PD Symptoms and the Influence on QoL

As it was extensively presented along Chapters 1 and 2, Parkinson’s Disease (PD) is a major, chronic, non-communicable disease and the second most frequent neurodegenerative disorder worldwide. There is currently no cure for PD, but treatments are available to help relieve the symptoms and maintain individual’s Quality of Life (QoL) at least for the first years.

It has been already debated the impact on the QoL of the Parkinson’s Disease due to an enormous number of motor and non-motor symptoms: bradykinesia, rigidity, tremor, postural instability, reduced gait speed, freezing of gait, sleep disturbances, depression, psychosis, autonomic and gastrointestinal dysfunction as well as dementia. As already explained, the majority of patients will develop an increasing number of more complex symptoms over time.

The treatment in the early stages of the disease, focused on the use of levodopa in pills, is very effective. Nevertheless, different problems related with the treatment may start to appear depending on the advance of the disease. Thus, it might be the case of motor complications: motor fluctuations such as the wearing-off phenomenon, involuntary movements known as dyskinesia, abnormal cramps and postures of the extremities and trunk known as dystonia, and a variety of complex fluctuations in other motor and non-motor functions. In these cases, the correct adjustment of the therapy is crucial

for avoiding to decrease the QoL of the patient. The motor symptoms are especially responsible of falls and gait impairments and negatively impact on QoL by reducing the ability to perform many activities of daily living. They are the major causes of institutionalisation and to lose the capability to live independently. Daily tasks at home: self-care, food preparation, hygiene, become difficult, as do many activities outside the home (shopping, visiting friends/family, leisure activities . . .).

The global management of this disease has to be based on a simultaneous treatment and consideration of different symptoms that usually are treated in different by different specialists. Unfortunately, many times no integration between data is made and there is a lack of information about the overall condition of the patient and, furthermore, there is not enough communication between the healthcare professionals treating the patient.

REMPARK system, discussed along the present document is a good example of the recent advances in technologies for people with neurological diseases, focused on the development and validation of tools, techniques and overall solutions for the effective management of PD. The system exhibits the combination of two technologies that promise to radically change the daily management of PD: the so-called wearables technology (WT) and the machine-learning based algorithmic approach. These technologies can provide objective, high frequency, sensitive and continuous data on motor and non-motor phenomena in PD. Thanks to the technology, it is possible to solve one on the major existing problem: the data acquisition over a continuous time period. An important aspect of a WT system is that it allows remote monitoring of symptoms with its obvious potential advantage for patients and health economics.

10.2 Existing Barriers of PD Management

In order to preserve their quality of life and allow them to live independently for longer while experiencing their burdens, PD patients fully resort on tailored treatments that can address the symptoms as they appear or prevent/delay the onset of other symptoms and co-morbidities. Emerging systems, like REMPARK, try to improve the efficacy of disease management and treatments in the current clinical practice that presents the following major obstacles:

- **Barrier 1: Lack of accuracy and completeness when reporting about own symptoms.** Due to the cognitive impairments, distress or the evasive nature of some of the symptoms caused by PD, the patients often

find difficulties or lack sufficient ability to provide reliable/consistent clinically relevant information about the symptoms they experience in order to optimise the treatment. In particular, often the patients are not aware of the onset of dyskinesia and sometimes it is even difficult for them to distinguish between ON/OFF periods. However, these are key information items for the doctor to adjust the treatments.

- **Barrier 2: Missing information about the PD symptoms and signs of disease progression at clinical level.** The current available means to report and monitor the symptoms are modest as compared to the huge challenge posed by the variety of PD symptoms and their fluctuations. The patient's visits and self-reporting may not throw reliable or complete evidence for the physician to cope with the entire picture and overall phenomena surrounding their patient's day-to-day. Most of the evidence used builds on reporting provided by the same patients and they often lack the ability to undertake this task.
- **Barrier 3: Compromised self-care and adherence to treatments.** Treatment regimens (medications, times, doses) and adherence to treatment are crucial for a correct PD management and the QoL of the patients. PD patients resort to prescribed regimes, but this seemingly simple commitment may represent a non-trivial feat, since patients must add on top of the overall burden the challenge of self-care, which is often difficult to achieve due to the many impairments and distresses linked to the disease. Cognitive deficits such as attention, communication, memory, and executive functions; depression and impulsive behaviours play a key role in the common lack of adherence and self-efficacy in co-management of the disease.
- **Barrier 4: Symptoms recognition in time to better administrate the medication dose.** Another related barrier is the capability of the professional to properly assess the number of OFF hours the patient has experienced to judge, based on that information, the therapeutic effect of the administered therapy, since it is based on daily or patient recall. Thus, the practitioner has difficulties for adjusting the continuous dose and control the administration of extra doses, mainly when an infusion pump therapy is used.
- **Barrier 5: Usability from the patient's point of view.** Some patients with Parkinson's have OFF phases so severe that they cannot even self-administrate extra doses. Patients with severe OFFs, which have no caregivers who can perform this task for them, often cannot choose the treatment with continuous infusion pumps.

10.3 The Role of the REMPARK System in the Context

REMPARK system was proposed and has been developed as a personal health system for the remote and autonomous management of PD. It is composed of wearable sensors for the detection and measurement of motor symptoms, a high level analytical layer and decision support tool, and a care platform (DMS) for professional care providers, patients and family. It enables the real-time, continuous and quantitative identification of the patient's motor symptoms in ambulatory conditions. The novelty and added value of REMPARK relies on using just one inertial sensor located and fixed to the patient's waist and a mobile interface to constantly read and send to the remote server a wealth of key relevant motor symptoms related to PD.

After symptoms' identification, the system is also able to provide some degree of actuation, like gait guidance mainly with an auditory cueing system, automatic fall detection and alarms, and assistance for self-management during daily life activities. Further development of the system should also include an automatic control of an infusion pump for a more accurate dosage or a delivery of an extra dose, when necessary.

The remote computing platform underneath REMPARK provides automatic data storage, processing, analysis and visualization tool so that other relevant actors, doctors and caregivers, can be included in the loop and can provide the best-informed, evidence-based and personalized action for therapy and healthcare management. In particular, REMPARK can be used to extract indicators of the disease evolution and open the possibility of a better adjust of the medication and treatments.

One of the main advantages of REMPARK is its alignment with the actual evolution of the care models, that are moving from reactive to proactive approach. The strength of the system relies on the ability to obtain, analyse and integrate data from different sources: sensors, patient reported data and healthcare professionals.

The system is able to receive the data transmitted from the sensors. For each individual patient, it is possible to define a range of normal values, permitting to stablish some levels of alarms according the thresholds defined by the professionals. Any deviation from normal event creates an alert on the system and consequently there is a reactive intervention. The DMS includes a shift management module that manages the tasks and users that are at each shift. The shift manager can see the workload and type of activities done in the centre for efficient management of the care process.

The REMPARK system is an interesting solution that includes a wide range of functionalities for delivering comprehensive and customizable integrated

care by a multidisciplinary team, but it also enables the treating physician to maintain a supervision of the patient throughout the journey; from patient disease diagnosis, through treatment plan definition, customizing specific protocols. One of the main problem in most existing systems for disease management is that the patient's data used for treatment is collected on the system overtime and is not updated by other systems that are used for treating the patient. This problem is particularly relevant when the patients are affected by a multimorbidity.

Multimorbidity is commonly defined as the presence of two or more chronic medical conditions in an individual and it can present several challenges in care particularly with higher numbers of coexisting conditions and related polypharmacy. For this reason the patient is treated by the neurologist for the PD and in parallel he is treated by the general physician in the community for other health conditions. Typically, a complete integration between data doesn't exist and there is a lack of information about the overall condition of the patient. Furthermore, the communication between the healthcare professionals treating the patient is quite limited. This way of delivering care results in a fragmentation, some duplication and lacks of coordination.

REMPARK, offers an integrated environment for data and knowledge sharing for all care providers and also it provides clinical guidelines and a decision support tool for healthcare providers helping in management of patient's disease. This tool enables treating several conditions at the same time in a coordinated way avoiding the interaction among drugs and the negative impact on the patients compliance.

Another additional value is the available integrated platform, allowing the stablishment of improved communication channels among patients and professionals (doctor, nurse, etc.)

Some advantages for the patients are the increase of their treatment performance scores, the improvement of the patients' empowerment and a good degree of satisfaction.

10.4 Limitations of the REMPARK System

The characteristics and advantages of REMPARK system would contribute, for sure, to the mitigation of the barriers analysed in the Section 10.2. It is obvious that some limitations exist, and because a main part of REMPARK is the sensor (a wearable device) for the detection and measurement of the motor symptoms related with PD, part of the inherent limitations are in line

with those of different wearable products developed for their use in e-Health domains.

There is a need to improve the cost-to-benefit ratio of WT strategies and their effectiveness for chronic disease and rehabilitation therapy management. Innovative research is still needed to continue developing the best combination of wellness, special needs and technologies in order to assist and maintain the preferred QoL for individuals with chronic disabilities and older adults.

A further limitation is the need of a refinement of the technology to correctly measure and monitoring non-motor symptomatology of the disease. Patient priorities and sources of disability often arise from non-motor deficits, such as: depression, anxiety, fatigue, orthostatic hypotension, sleep disturbance. There is a need for developing unobtrusive systems to monitor non-motor end points in the home environments and community settings. As it has been presented along the chapters, REMPARK was designed as a complete system, where in a limited way, the consideration of the non-motor symptoms was already included and worked-on. Further versions of REMPARK system must, for sure, consider and emphasize these aspects.

Usability of the REMPARK system was a challenge from the beginning of the project and quite good results are reported in Chapter 9. A problem that the consortium was working-on and tried to solve is the PD patient's adapted smartphone interface. The special adapted interface (see Chapter 6) is a good point for the usability and acceptability of the system.

After the REMPARK project finalization, relevant experiences would be used for an improved version of the different parts of the system, but always some common issues related with the acceptability of wearables in general would be encountered.

Systems are often not as user friendly or compelling to adopt as they should be. Currently, patient and care giver engagement with wearable and mobile technology is modest, as shown by recent studies.

A lack of motivation to use wearables and monitoring systems should not be underestimated, particularly in the absence of meaningful feedback provided to their users. Preliminary evidence suggests that patient empowerment and their inclusion as active players in the development of research activities may favourably impact on compliance. As a preliminary conclusion, it could be established that additional research is needed to determine the characteristics and the feasibility of wearable systems for long-term monitoring of motor and non-motor symptoms that would be acceptable to patients.

10.5 Clinical Applicability of the REMPARK System

The power and usefulness of the devices and systems based on ICT technologies are still under-recognized by a part of the physicians and professionals participating in the treatment and management of the PD patients. Its potential, considered as an aid to the patients, is also under-exploited.

In the case of REMPARK, the system is based on non-obtrusive elements worn by the patient: the waist inertial sensor, a smartphone and an auditory cueing system. The elements seamlessly communicate with each other and with the server platforms providing further service and capabilities. REMPARK is an interoperable standalone solution that can be easily integrated in Hospital Management Systems and external eHealth services operated by third parties.

The REMPARK system core is a sensor device placed on the patient's waist that it is able, as it has been already explained, to identify and quantify the main motor symptoms of PD (bradykinesia, dyskinesia and FOG) in real time. This sensor also recognizes and registers the patient's motor fluctuations (ON and OFF motor states) in ambulatory conditions in a very reliable and automatic way while patients are performing their normal activities. Finally, the device wirelessly transmits this information to a server.

Furthermore, the use of these devices with the described characteristics would enable the doctors to accurately personalize medication intakes and, thus, improve the patient's response to the treatment. A system with the REMPARK characteristics would result an invaluable tool in the diagnosis and management of PD. A correct detection of the symptoms would help to, on one hand, enhance the effectiveness of the oral medication through a better regimen adjustment; on the other hand, to automatically control the administration of an extra dose when the patients are using infusion pumps (apomorphine or duodopa). These new approaches are aimed at significantly improve the QoL of patients and, it will allow a deeper understanding of the personalized evolution of the disease.

An additional benefit is represented by the contribution of the system to the real and effective implementation of a multidisciplinary care. In fact, clinical experience suggests that optimal management requires a multidisciplinary approach, with multifactorial health plans tailored to the needs of each individual patient. In case of PD patients, the multidisciplinary team includes physiotherapists, occupational and speech-language therapists, dieticians and social workers.

The use of systems highly based on ICT technology, like REMPARK, contributes to alleviate and facilitate the organization of the multidisciplinary approach improving communication between the different health professionals, the patients and the caregiver.

Another area that would benefit from a tool, like the sensor developed in REMPARK is the clinical and epidemiological research. This kind of studies are expensive and highly laborious. Sometimes, they suffer economic limitations that can affect the methodological rigor of the studies carried out. In general, the studies based on movement disorders are especially complicated, on the one hand by the lack of well-established markers to establish a clear diagnosis and, on the other hand, by the lack of uniformity in diagnostic criteria.

Finally, it must be pointed out that REMPARK system technological innovation can be an interesting challenge for companies developing business based on the commercialization of new e-health home based services for PD patients. Such tools would provide the unique opportunity to objectively monitor and control the treatment efficacy of any given therapy on an individual basis, which would sustainably change traditional health care methods.

10.6 As a Concluding Remark

We can conclude that REMPARK system is a big step to a new approach to a new approach of the PD treatment where the technology contribution is helping to provide a different and complimentary view of the symptoms of the disease by offering clinicians a complete map and evolution.

The provided information will not only be useful from a diagnosis but rather would contribute to a better and more effective management of the disease.

This kind of systems, when completely developed, will be relevant because the possible supervision and measurement of the evolution of the symptoms and the appearance of new ones. This will permit a rapid action when necessary, facilitating among others the establishment of preventive polices according patients' individual needs.

References

- [1] Chang P. Wray L. Lin Y. Social Relationships, Leisure Activity, and Health in Older Adults, *Health Psychology*, American Psychological Association, 2014, Vol. 33, No. 6, 516–523.
- [2] Wallace E. et al., Managing patients with multimorbidity in primary care. *BMJ* 2015;350:h176.