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Introductory Chapter: Targeting Unmet Needs in Parkinson's Disease

Sara Palermo, Rosalba Morese and Mario Stanziano

1. Introduction

About 20 years ago, actor Michael J. Fox—well known for the trilogy “Back to the Future” and at the time at the height of his success and of his youth—declared to the public that he had received the unexpected diagnosis of Parkinson's disease (PD) 7 years before. On the same occasion, Michael announced the decision to put his image at the service of what would become one of the most lasting and decisive campaigns of hope, information, awareness, and fundraising for research in the fight against PD. About 20 years later, what progress has actually been made?

As is known, Parkinson's disease does not yet have a cure. The fundamental therapy is still the pharmacological one, which is implemented today with the administration of various active ingredients in addition to levodopa which remains the most powerful drug, but which presents marked side effects after a few years. 2018 was a special year for people with Parkinson's and their loved ones. It started in January with the shocking news of the decision by the pharmaceutical company Pfizer to suspend all research related to treatments for Parkinson's and Alzheimer's because they were too expensive, to continue with the announcement by researchers at Johns Hopkins University to have obtained results, still preliminary but extremely encouraging, with the drug called NLY01. With regard to non-pharmacological interventions, we note the progress of neuronal stem cell experimentation carried out in Australia by the International Stem Cell Corporation (ISCO), which, according to what the company reported, looks very promising. These are the first steps and the path will still be long, but these are just some of the researches that keep hope for the future alive.

Innovative ideas and therapies for PD go far beyond a single drug or stem cell. There is a broader and more exciting picture. Innovative ideas include drugs, cells, vaccine, ICT-IoT devices, genetics, social care, and cognitive-behavioral enhancement. The most recent therapeutic approaches have highlighted the importance of the multidisciplinary perspective and the usefulness of rehabilitation, both in its “classic” form as physiotherapy and in one or more of the so-called “complementary therapies” (indicating that they complement but do not replace approaches that are more conventional). Patients and their families should be kept informed and updated on all potential innovative therapies. Above all, their needs should be at the center of the healthcare process and the research initiatives. Some of the most frequent questions we receive from parkinsonian patients and families are “How can I be cured?” “What will be the next breakthrough?” and “For everything else what do I do now?”

Because of the complexity of the disease, each patient has a different combination of motor and non-motor symptoms, of difficulties in daily life. This complexity therefore means that the answer to the next possible innovative therapy will vary from patient to patient—and could be an innovation in care, as well as, possibly, a new ICT-IoT device or a new cocktail of drugs. We will need to expand our notion of innovation, and we will need to exploit this knowledge to reduce the burden of Parkinson's patients. This introductory chapter therefore aims to answer the fundamental question: *What are the unmet needs in Parkinson's disease?*

2. Unmet needs in Parkinson's disease: new horizons in the clinic and in research

PD patients fight against a range of physical motor symptoms including slowness of movement, rigidity, tremor, and postural instability. However, this is not the full story. They also experience many other non-motor symptoms, which affect their daily living, sometimes in ways that are just as important to them as the cardinal motor symptoms of the disease.

The awareness has now been reached that non-motor symptoms burden is a key determinant of quality of life of patients and their primary caregivers [1, 2].

Treating these kinds of symptoms that negatively influence the lives of patients—and in particular those that are responsive to the dopaminergic replacement therapy—automatically translates into improvements in quality of life and reduction of the associated burden [3].

However, clinicians often regard non-motor symptoms and their management as peripheral to that of the motor symptoms. Just for an example, the 2011 Parkinson's UK report showed non-motor symptoms recorded in only 21% of elderly care and 9% of neurology services in the UK.

Nevertheless, Hatano and collaborators [4] suggested that PD patients have unmet needs in their treatment and standards of care already in 2009. In particular, the authors suggested focusing on the development of better treatment for motor symptoms, the development of new treatments for non-motor symptoms and improved two-way communication between patient and physician.

Chaudhuri et al. reported a few years later: “Key medical unmet needs in PD include the need for better animal models replicating the parkinsonian process, slowing of disease progression/neuroprotection, improved biomarkers (imaging, genetic, clinical or other modality), improved 24-h control of motor fluctuations in moderate to advanced disease and more effective treatment of non-motor symptoms (NMS). Nocturnal symptoms as well as early morning fluctuations remain also neglected” ([5], p. 52). To confirm the above, in their study on Palliative Needs of Parkinson's Patients, Prizer and colleagues [6] have shown that among the palliative needs most frequently reported by patients, there were: healthcare education, care coordination, support groups, spirituality/religion, and the greater presence of the neurologist.

How to address the unmet needs of people living with Parkinson's disease? We need a person-centered perspective.

It is proposed this year an interesting approach called the “Voice of the Customer” [7], which includes three successive phases of gathering information on the real needs due to the experience of the disease: (1) capturing patient needs by means of semi-structured interviews with patients, relatives, and healthcare providers in their private environment; (2) preparing a comprehensive summary of the contents discussed in the interviews; and (3) prioritizing needs in a consensus meeting, in which all parties participate. Vlaanderen and collaborators [7] suggested that patients were more concerned about the impact of PD on their daily

lives than about the bio-medical aspects of the disease. The authors have found that top unmet needs of the parties involved were: more self-management; better interdisciplinary collaboration between different healthcare professionals; more time to discuss the future and possible scenarios; and a healthcare professional acting as a single point of access, acting as personal case manager, either to solve problems directly or to direct patients to the professional best equipped to address the problem at hand.

Another useful tool could be the *Parkinson's Well-Being Map™*—developed in partnership with the European Parkinson's Disease Association (EPDA), the Cure Parkinson's Trust, and the Spanish Federation of Parkinson's Disease—which takes a holistic approach, allowing patients to track both motor and underlying symptoms. The map helps PD patients to prepare for consultations with their healthcare team, so that they can help to understand how living with Parkinson's disease affects them. The map covers all aspects of Parkinson's, so that a patient can highlight the symptoms that are of most concern to him/her and list the most important questions to ask at his/her next consultation. It was made available free online and in paper form.

Approaches of this kind can help clinicians and researchers to better plan their activities so that in the future, gaps in the current methods of management are filled and research topics are expanded based on a patient-centered approach.

3. The nature and purpose of the book

The volume aims to bring together in a single publication the knowledge on the topic of diagnosis, characterization of the clinical and neuropsychological profile in Parkinson's disease. The strong impulse given to research on this topic has produced in recent years a large literature that documents the high level of complexity of the issue, for which a reasoned multidimensional analysis able to integrate expertise of different disciplines (neurology, neuropsychology, neuroradiology, and clinical neuroscience) is necessary.

The volume illustrates the neuropathological characteristics that define Parkinson's disease. Subsequent contributions focus on the diagnostic characterization and monitoring of Parkinson's disease, considering also the contribution of neuropsychology, morphological and functional imaging techniques.

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