

# Problems of Parkinson's disease in the Arab world

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## ABSTRACT

Problems of Parkinson's Disease within the Arab world are discussed and a number of solutions are presented that will help in the management of Idiopathic Parkinson's Disease. The problems discussed are problems related to the diagnosis whereby no individual clinical feature has sufficient sensitivity and specificity to serve as the sole basis for distinguishing Parkinson's disease from other diseases with Parkinsonian features. Problems related to the Unified Parkinson's Disease Rating Scale are also discussed and convey a multitude of problems culturally distinct to the Arab world. Problems related to the medical treatment, selection of patients for surgery, the surgery itself and the surgeon, programming and rehabilitation are discussed in detail.

**Keywords:** Parkinson's Disease, Unified Parkinson's Disease Rating Scale, surgery.

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The management of Idiopathic Parkinson's disease still poses a major challenge despite recent advances in neurophysiology, neurochemistry, development of new criteria for the diagnosis of Parkinson's disease (PD), tremendous progress in genetic studies as well as in the medical and surgical treatments. This challenge is not only based on the understanding of the disease or the recent development in its treatment, but also on socio-cultural factors that are directly related to the population under treatment. In this paper some of the problems of PD in the Arab world are discussed. A number of possible solutions that would help in the management of Idiopathic Parkinson's disease are also presented, some of which are based on the recommendations of the April 2000 congress of the Pan Arab Union of Neurological Sciences (PAUNS) held in Beirut. Special attention is paid to the following problems: problems related to the diagnosis; problems related to the Unified Parkinson's Disease Rating Scale (UPDRS); problems related to the medical treatment; selection of patients for surgery; the surgery itself and the surgeon; programming and rehabilitation.

**Problems related to the diagnosis.** Only about 75-90% of clinically diagnosed PD cases are confirmed at autopsy, largely because the cardinal signs can

occur in conditions other than PD.<sup>1-8</sup> The diagnosis is based on the results of clinical assessments as there is no diagnostic biological marker for PD. Studies that require only inclusion of early cases of PD present a diagnostic challenge.<sup>7-9</sup> Previous studies concluded that initial diagnoses of PD made by general neurologists were incorrect in 24-35% of the cases when patients were examined at autopsy. Experts in movement disorders are expected to have greater accuracy of initial diagnosis of PD.<sup>10</sup> There is not yet a single feature that has sufficient sensitivity and specificity to serve as the sole bases for distinguishing PD from other diseases with Parkinsonian features such as Multiple System Atrophy (MSA), and Progressive Supranuclear Palsy (PSP). Criteria based on the combination of clinical features improves diagnostic accuracy, but no criteria yet proposed has achieved a sufficiently positive predictive value to eliminate the need for autopsy confirmation.<sup>8,11,12</sup> In addition, the response to L-Dopa, particularly in the early stages of the disease, is not specific for PD. For example, Dopa responsiveness and even motor fluctuations may be seen in MSA and PSP.<sup>11,13-19</sup> However, Positron Emission Tomography (PET) is a test that definitely can give the diagnosis particularly in the early stages of the disease, studying glucose metabolism or a so-

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called Nomifensin PET test. Metabolic imaging with fluorodeoxyglucose F 18 PET can discriminate patients with PD from normal subjects and from patients with atypical Parkinsonism. Such findings also correlate with the severity of the disease.<sup>1</sup> Unfortunately PET scan is not readily available in the Arab world. The lack of experience and training in this field in the Arab world in general and the absence of specialized units further limits the experience and training possibilities. Additionally, there is a lack of Movement Disorders neurologists with special interest and expertise.

**Problems related to the Unified Parkinson's Disease Rating Scale (UPDRS).** The UPDRS is a valuable tool for following disease progression and the efficacy of therapy.<sup>20</sup> However, there are several items of the UPDRS examination for which written instructions are vague. In addition, some of the questions were difficult to grasp and comprehend by the patients. Some of the answers given by the patients were not specific enough to allow the instructor to reach a conclusive result. Trained staff in off-medication and in best-on-medication conditions should make the UPDRS. This is very difficult to perform in a busy clinic since it takes up staff time and requires compliance and cooperation. Many of these problems may often be overcome by increasing the awareness of the patient about the nature of the disease and the UPDRS at the early stages of the disease. Another problem that the practitioner faces in the Arab world is cultural. Patients do not appreciate the degree of accuracy and specificity required. This entails that the practitioner has to spend a long time in advising patients on the importance of being accurate to better assess their case. In conclusion, UPDRS need to be reassessed for practical applications in the Arab world; translated by neurologists who are familiar with it and its application and validated in a pilot study. In addition, such a "translated scale" needs to be made available in a standard form at different institutions and countries in the Arab world to ensure that its application is consistent and uniform.

**Problems related to the medical treatment.** The introduction of L-Dopa more than 30 years ago revolutionized the management of PD. However, soon after its use it became apparent that the drug offered only symptomatic relief and did not affect the underlying pathology. Moreover, chronic use of the drug was associated with a wide range of adverse effects. Current strategies seek to delay long-term complications of treatment for as long as possible. However, once they appear, most adverse effects are amenable to some form of management. Clinical studies have shown that after 5 years the majority of these patients suffer from motor and psychological complications. The motor complications included involuntary movements such as dyskinesia, freezing,

dystonia and motor fluctuations such as on-off phenomena, wearing off and delay or absence of L-Dopa action. The psychological complications include hallucinations and psychosis. These adverse effects can be reduced by delaying the use of L-Dopa particularly in young patients. The least effective dose of L-Dopa can be controlled by using Dopamine agonist and Amantadine or Catechol-O-Methyl Transferases (COMT) inhibitor for motor complications. Atypical neuroleptics such as Clozapine, Risperdol, Soliten or Olanzapin are found to be effective in the management of hallucinations. The dopamine agonist in some occasions may be used as an alternative to surgery. However, high cost and non-availability of some of these relatively new drugs are major drawbacks to their use. Accordingly, a number of therapeutic strategies are available for the treatment of PD. The final choice of therapy depends on the individual circumstances and requirements of the patients. It should balance the tolerance for adverse effects with the amount of symptomatic relief required. Unfortunately, in the Arab world this is not effectively applied for several reasons: 1) poor compliance to medication; 2) the lack of effective health education in the Arab world to explain to the patient that PD is chronic, life long, progressive incurable condition and that a person's life can be improved by medication, regular physiotherapy and eventually surgery in selected areas; 3) the patients, when they finally approach the specialist are usually on the wrong medications, taking inadequate treatment, or changing medication rapidly; 4) build up and improvement of medical management knowledge requires continuous education to comprehend the complexity of the problems and to establish a treatment tailored to the particular patient's need at different stages of his or her disease. This also requires specialized units or centers for PD and other movement disorders. These centers are just being established in the Arab world.

**Selection of patients to surgery.** One should be strict with the inclusion and the exclusion criteria, stressing the following: the patient should understand that whatever the type of surgery, it is only a symptomatic treatment and not the cure. It is a complement and not a substitute for medication; symptoms cannot be controlled by adequately adjusted medical therapy (medication efficacy exhausted); medication side effects cannot be treated, presence of a motor handicap; the psychological state of the patient and compliance with the medication prior to surgery.

**The surgery and the surgeon. The surgery.** The surgery should be tailored to the symptoms. Thalamic stimulation or lesioning is best for essential tremor. Pallidotomy or Bilateral Deep Brain Stimulation (DBS) for the Pallidum is most suited for Dystonia. Current knowledge indicates that for all

the other symptoms in PD requiring surgery, bilateral DBS in Subthalamic Nucleus (STN) is the appropriate choice. Today, there is a passion for DBS in general and for DBS in STN in particular. It is an effective surgical method but the cost is prohibitive, needless to say that the stimulators should be replaced every 4-5 years. However, Thalamotomy and Pallidotomy can be the methods of choice in dealing with dyskinesia, dystonia, rigidity and tremor.

**The surgeon.** Specialized and extensive training and experience are essential to prepare a competent surgeon. It is not enough to buy a stereotactic frame and start doing surgery. Furthermore, the confidence of the surgeon and surgical team in the used intraoperative physiological assessment of target is very important. It is not enough to buy a microelectrode system and start doing the surgery if no major experience is gained in the interpretation and the use of these systems. On the other hand, groups like those of Laitinen, Hariz, Rehnroos and Augustinsson in Sweden, Cosgrove at Harvard, Kondziolka in Pittsburgh, and DeSallees at UCLA for example have quite good results and zero mortality in their stereotactic experience since 1985.<sup>21-25</sup> None of these groups use microelectrodes but rather they employ a meticulous macrostimulation during surgery.

**Programming.** This is a very laborious procedure, especially in pallidal and STN DBS. It needs frequent and long visits of patients to the doctor, and this is costly. Without adequate and tight programming, DBS is of no use for the patient and a waste of money. In fact, once you have 100 or more patients going on DBS, you have no time to do anything else and further recruitment of neurologists or specialist dedicated to programming and follow-up of DBS patients will be needed.

**Rehabilitation.** The establishment of rehabilitation centers for PD patients is a major requirement for the management of PD patients at all stages of the disease. Physiotherapists, occupational therapists, speech therapists, psychologists, social workers and PD nurses for example are all very important supportive staff for the comprehensive care of PD patients. In Jordan, we received several groups from Austria and Germany travelling to camps and hotels in the Dead Sea. These groups participate in preset programs with different sports activities with the objective of improving the mobility, mood and well being of PD patients.

**Efforts in Jordan (1999).** Because of all these problems in Jordan, the Jordanian Medical Association established a committee of related specialists to which a patient is referred for selection to surgery. The function of this committee is to: validate the diagnosis of idiopathic PD; perform a thorough review of the medication used prior to surgery, establish that the medication efficacy in the

treatment has been exhausted or that the side effects cannot be treated or that the patient is no longer able to tolerate it, decide on the type of surgery, Lesioning/DBS; delegate a neurologist/neurophysiologist to attend the surgery to document the changes in the symptoms and signs, to assess the electrical activity if micro recording is available, and to participate in the follow-up and post-surgery drug adjustment and programming.

**Efforts of the PAUNS (2000).** The Pan Arab Union of Neurological Sciences (PAUNS) recently formed the "PD and Movement Disorder special committee" to manage these problems. Some of the main functions of this committee are to: provide guidelines for the treatment of PD and other movement disorders; discuss problems as they arise during periodic meetings; join the international PD and Movement Disorder Societies and affiliate with major centers; develop an Arab database of specialists and patients in this field; publish awareness/educational material for both patients and General Practitioners; do research work in the field with the help of established centers; form committees to monitor referral of patients to surgery in various Arab countries and to follow-up on the results of the surgery and to encourage the formation of special units/centers for PD and movement disorders.

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