EDITORIAL

# "Stiff in the Closet" – Who Provides Care for Parkinsonian Patients?

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Parkinson's disease is an exceedingly common disorder, estimated to affect nearly 2% of the population over age 65, and up to 100,000 Canadians. Direct costs of the illness are enormous, and the indirect costs, including loss of independence, lack of employability, requirement for institutionalization and impact of caregivers is virtually incalculable.

Although identification of the cause(s) for Parkinson's disease remain(s) elusive, current interest is focused on an interaction between genetically determined susceptibility and exposure to as yet unidentified environmental risk factors. Aberrant cellular protein handling, oxidative stress, mitochondrial dysfunction and excitotoxicity may all play a role; none of these is mutually exclusive of the others, and all may result in apoptotic cell death of nigral dopaminergic neurons.

Although there is much hope for neuroprotective treatments that would slow disease progression, there is no firm evidence to date for such an effect – a somber reminder of the work that remains to be done. Thus, current treatment is directed towards symptom relief and should only be initiated when dictated by disability; something that is highly individual in its definition. There is no question that the single most effective drug for treating the symptoms of Parkinson's disease is levodopa, and this remains the gold standard against which all other treatments must be measured. However, although highly effective, the long-term use of levodopa is associated with numerous complications, including fluctuations in motor response and sometimes disabling dyskinesias. Recent multi-centre studies suggest that these complications can be forestalled by initiating therapy with one of the novel dopamine agonists.[1,2] A longer term, admittedly unblinded study found that disability was better controlled by levodopa and that when the analysis was restricted to dyskinesias of moderate to severe intensity, there was no significant advantage of agonist use.[3] Many questions remain unanswered. Does early use of a dopamine agonist confer long-term advantages in terms of sustained avoidance of dyskinesias, or even perhaps reduced rate of disease progression compared to levodopa?[4,5] Are the new agonists any better than the older ones? What about initiation of therapy with amantadine, using either levodopa or a dopamine agonist as adjunctive therapy when indicated? Are some drugs more prone than others to produce problems with sleep?[6,7] Is there a role for inhibition of catechol-O-methyltransferase in patients with a stable response to levodopa, or even at the time of initiating levodopa therapy? Who should be considered a candidate for stereotactic surgery? Might high frequency stimulation of the subthalamic nucleus have a disease (not just symptom) modifying effect? These questions are nearly impossible for even the expert to answer and may apply to the care of patients in early stages of disease. In later stages, numerous complications, including autonomic dysfunction, swallowing and speech disturbances, postural instability, psychosis and cognitive decline, can represent an extraordinary challenge to even a highly skilled, multi-disciplinary team. One might therefore be forgiven for assuming that the diagnosis and management of this complex disorder would best be undertaken in centres with established special interest and expertise.

On this background, Guttman and his colleagues have posed the simple question of who is providing the care. Their findings, reported in this issue of the Canadian Journal of Neurological Sciences[8] provide food for thought. Taking advantage of their access to a linked data set, they estimate a prevalence of more than 15,000 cases of parkinsonism in the province of Ontario. This figure is admittedly a gross approximation, subject to errors in diagnosis, inclusion of other causes of parkinsonism, errors derived from the use of 'anti-parkinson' medications for other purposes, and errors resulting from the assumption that medication use in the over 65 population reflects patterns of use in younger individuals. However, even allowing for these deficiencies, it is worth noting that the figure would be in rough agreement with other estimates of prevalence.[9]

More striking, however, is the observation that fewer than 60% of the patients identified ever saw a neurologist over the six years addressed by the study. Given the recognized high rate of misdiagnosis, let alone the numerous questions regarding optimal therapy in the early stages of disease, this raises serious questions as to the quality of care being provided. The high rate of complications associated with advanced disease and the considerable difficulty in their management are even more disturbing. If experts with extensive training and the day-to-day experience of managing hundreds of patients with Parkinson's disease admit to feeling challenged, what is the likelihood that optimal care will be provided by practitioners with no more than a passing interest in the condition, and a cumulative experience of two to three cases? What is the likelihood that patients seen in such settings will gain access to a multidisciplinary care team where appropriate?

It should not, however, be assumed that the care provided by such 'experts'necessarily results in a better overall outcome, or at least in more efficient delivery of care. Relatively minor improvements might potentially be offset by an increased tendency to use newer, more expensive medications, or to refer patients for costly stereotactic surgical procedures. The authors do not indicate whether neurologist utilization rates reflected geographic availability – one assumes that this must be the case for at least some patients.

The study by Guttman et al[8] highlights the need to carefully and honestly scrutinize the care we provide, with a view to ensuring that patients receive care that genuinely improves their quality of life and productivity, and that this is done in a fiscally responsible fashion. This may require the use of outcome measures that more meaningfully reflect disease impact than do the scales widely applied to short-term clinical trials. If such

studies indicate improved outcomes when patients are assessed and regularly followed at specialized clinics, it would not be a stretch to imagine that similar issues might apply to other neurological and non-neurological conditions. The implications for health care policy and the assurance that quality care is universally accessible are enormous. Neurologists should welcome the opportunity to participate in this process.

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## References

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