Chapter 6. Recommendations for Future Research

The following recommendations would enable researchers to generate useful data to support answers to the questions posed in this report.

Standardize methods of reporting results.

Standardization of reporting results facilitates inter-study comparisons. Given the unlikely probability that any one study will conclusively demonstrate the efficacy of a given treatment, it becomes very important for authors to make sure that their results are both clear and complete enough to allow future synthesis with other important studies in the field.

The reliability and validity of the UPDRS has been widely documented, and it is currently the most common instrument used to measure the progression of PD. Investigators should report baseline, endpoint, and change in UPDRS scores, along with their respective standard deviations. While some researchers only report the motor subscore, and it is important that the ADL score be reported as well. Many researchers reported much of this data in figures, making estimates of means imprecise, and estimation of standard deviations almost impossible. Unless researchers report change score standard deviations, the added certainty those researchers achieve by controlling for an individual's pre-test data will not be directly available to future researchers.

The CAPIT committee recommended that surgical studies report UPDRS scores ("off" and "on"), H&Y stages ("off" and "on"), Dyskinesia Rating Scale ("on"), timed tests of motor function ("off" and "on)," and self-reporting diary. We enthusiastically endorse these recommendations, for studies of pharmacological and ancillary as well as surgical treatments, because standardized reporting of baseline and outcome data can only enhance the ability to build an evidence base regarding the optimal treatment of PD.

Duration and severity of "on" and "off" periods are useful parameters to follow, particularly in patients with advanced PD. These could not be meta-analyzed, due to the widely divergent methods used in reporting. "On" and "off" time should be consistently reported, using a standardized method.

Patient withdrawal should preferably be modeled using the sophisticated statistical methods currently published and in development for the problem;[306] when these methods cannot be employed, researchers should use ITT/LOCF and record whether they do so. When researchers deem LOCF findings inappropriate, they should explain how they are accounting for patient withdrawal and whether their findings are sensitive to how patient withdrawal is handled.

Adequately power studies.

Many of the studies meta-analyzed had very small sample sizes. While one of the benefits of meta-analysis is that a synthesis of inadequately powered studies can yield interesting findings, such meta-analyses require large numbers of studies in order to make conclusive findings. Researchers should make sure to power their efficacy studies appropriately.

Report L-dopa usage.

The number of patients who receive L-dopa, and their doses, should be clearly stated. Many studies mentioned whether L-dopa treatment was allowed, and failed to report how many patients needed such treatment, or what their average dose was. Given that most treatments incorporate L-dopa into the regimen, and given that an important treatment outcome is whether an additional drug allows for a decrease in L-dopa dose, data regarding actual L-dopa usage are quite important in evaluation.

Include patients with comorbidities in clinical trials.

In clinical practice, clinicians see patients with numerous comorbidities in addition to PD. As nearly all of the studies excluded patients with serious illnesses, the generalizability of study results is limited.

Include more elderly patients and members of different racial and ethnic groups in clinical trials.

As the body of evidence increases in size, the power to detect difference in efficacy of treatment based on certain characteristics increases. More detailed description of patients enrolled in studies could help researchers to identify which treatments may be more efficacious in patients of different age, gender, or ethnic background.

Perform studies that include patients with younger onset of disease.

Only three of the 356 treatment arms in the database reported mean age of disease onset as less than 50. While PD is mainly a disease of the elderly, it does occur in young patients as well, and it would be inappropriate to assume that patients with early onset of PD should necessarily be treated the same as patients with older onset of PD. More studies of younger patients are needed to determine whether different treatment is appropriate in this population.

Evaluate use of combinations of tests in diagnosing PD.

Preliminary evidence suggests that the PD test battery may be helpful in diagnosing PD. More research should be done looking at combinations of tests for diagnosing PD.

Improve quality and duration of studies of ancillary treatments for PD.

Further studies of PT, OT, speech therapy, and other nonpharmacologic and nonsurgical modalities should be of longer duration and should measure standardized, clinically meaningful outcomes.

Report family perceptions relating to patient care.

Families are one of the most important resources for managing patients. They play an important role in the results of an intervention by their participation as well as their interpretation

of the success. Family caregiver perceptions should be included in research as an independent variable and should be included systematically as an important endpoint.

Continue research on genetic components of PD risk.

Important new developments in genetic susceptibility for PD are likely to have a major impact on the diagnosis and management of PD. Information on these topics should be collected and included in an update of this systematic review. Studies of genetic abnormalities in PD patients should continue, to help identify which patients are appropriate for genetic testing.

Perform long-term studies on efficacy of surgical procedures.

The literature indicates that research is needed on the efficacy of surgical outcomes in patients 65 years of age and over. The literature also indicates that research is needed to evaluate long-term efficacy and safety in the areas of DBS and tissue transplantation.