



Neurology Care Line

PADRECC Pathways

Houston Parkinson's Disease Research, Education and Clinical Center
Vol 3, No. 2, Fall 2004

Parkinson's Disease Research Update

Onset and Progression of PD in Familial and Sporadic Cases

A recent study in Israel suggests that the disease course for Parkinson's disease (PD) patients with and without a genetic background might be different. Patients with young onset who reported another PD family member were tested for genetic mutations. For patients with a family history of PD, the age of disease onset was younger, but motor and mental change declined less when compared to those without a family history of PD.

Facial Expression and PD

New professionals appeared to be less informed about the lack of facial expression in persons with PD when compared to more experienced professionals. More recent graduates thought that those with less expression in their faces were quieter and more reserved, anxious, and nervous; both groups believed that the patients were less agreeable. Professionals need to be educated about these secondary symptoms and not jump to conclusions about the personality of PD persons.

PD Risk Higher for Men

The observation that PD affects

more men than women has a long history dating back several hundred years. The most likely culprit for a gender gap may be a genetic mutation passed down by mothers. Another theory suggests that the male lifestyle (pesticide exposure and head injury) may account for the difference and that estrogen may protect women against neurological diseases.

Parkinson's Disease and Twins

Over 33,000 twins from the Swedish Twin Registry were interviewed by phone about their histories of PD and movement disorders. Two hundred forty-seven twins reported a PD diagnosis and 517 others reported parkinsonian symptoms or the use of antiparkinsonian medications. The findings suggest that compared with other complex diseases, the importance of genetic factors in PD is probably low.

Scientists Study Sleep and Brain Chemicals

VA researchers discovered that three brain chemicals help regulate sleep for Doberman pinchers. Serotonin and norepinephrine affect muscle tone and keep the body still at night, while histamine controls wakefulness.

These biological findings may help guide the development of new drugs to induce sleep or maintain alertness.

Number of PADRECC Veterans Continues to Increase

Since 2001, the Houston PADRECC has evaluated nearly 750 new patients at the Michael E. DeBakey Veterans Affairs Medical Center (MEDVAMC). Patients seen include those with Parkinson's disease (58%), parkinsonism (8%), essential tremor (14%), atypical tremor (7%), and other related movement disorders (13%). The PADRECC patient population is approximately 97% male; the ethnic composition is 82% Caucasian, 11% African American, 6% Hispanic/Latino, less than 1% Asian/Pacific Islander, and less than 1% Native American. The average age at initial visit is 70 years. Approximately 96% of PADRECC patients come from Texas, with the remainder from LA, MS, OK, KS, AL, AR, HI, MN, NM, and NY.

Above summaries adapted from *eCommunicative* (Naomi Nelson, editor), a PADRECC Internet publication for health care professionals. References for above

Nurses' Corner

Often Parkinson's patients complain of upset stomach or nausea after taking their *carbidopa/levodopa* (*Sinemet*), a common side effect of the medication. The vomiting center resides in the *area postrema* of the brain stem. It detects toxins or poisons in the circulation and stimulates vomiting to rid the body of the transgressor. The vomiting center is not accustomed to seeing *levodopa* in the circulation and treats it as an offender.

When the *carbidopa/levodopa* is in the bloodstream for approximately 30 minutes, the vomiting center may be activated. The patient may experience a metallic taste in the mouth, dizziness, nausea, and vomiting.

Two factors allow patients to overcome most of these problems: 1) After repeated exposure to *levodopa* the vomiting center gradually becomes accustomed to its presence and no longer responds. 2) The vomiting center is most likely to react when the level of *carbidopa/levodopa* rises rapidly in the blood (large doses of medication). Smaller doses taken after meals slow the absorption.

Most patients complain of these problems after a breakfast of juice, coffee, and toast. This isn't enough food to slow the absorption, which would inhibit the vomiting center from activating. In fact, the caffeine in coffee can actually stimulate the vomiting

center.

For patients who experience nausea in the morning, we recommend solid foods with some protein and decaffeinated coffee or tea. If necessary, your physician might reduce the breakfast dose of *carbidopa/levodopa*. If this doesn't stop the problem, your physician may need to order an anti-nausea drug. Patients should allow 3 to 6 months for the body to develop a tolerance to the *carbidopa/levodopa* before they are able to enjoy the full beneficial effects.

Constance Ward, MSN, RN-C
PADRECC Clinical Coordinator



Over 100 allied health professionals attended the PADRECC June 12, 2004 Symposium: Cognitive Issues and Depression in Patients with Movement Disorders. Left: Dr. Eugene Lai, Houston PADRECC Director, was a featured speaker.



Members of the PADRECC Allied Health Education Committee L to R: E. Lai, MD, PhD; B. MacNeill, PT, MEd; Elizabeth Protas, PT, PhD; Kathleen Crist, LMSW; R. Zabransky, OTR; M. Trail, MOT, OTR; J. Whitehead, SLP/CCC; Naomi Nelson, PhD



PADRECC June 3, 2004 Patient/Family Forum at the Michael E. DeBakey VAMC: Shown above is photographer Dr. Dorothy Lam Wong talking with veterans and their families about living with PD. Both Dr. Wong and Mr. Aubrey Calvin (see page 4) displayed some of their work at the Forum.

PADRECC Patient/Family Forum
October 22, 2004
11 AM, 4th floor auditorium, MEDVAMC
Aliya Sarwar, MD
PADRECC Neurologist
Sleep Disorders of Parkinson's Disease
 Free Valet Parking
 Contact Naomi Nelson 713-794-8938

Assessing the Quality of Life of Persons with Parkinson's Disease

Physicians and other health-care providers try to make treatment decisions based on the needs and values of their patients. However, in medical research, paying attention to what is important to patients is relatively new. Only in the past couple of decades has research focused on “patient-centered outcomes.”

Today, most medical researchers believe it is important to consider the quality of patients' lives when treatment methods are compared or new medications are considered. But it is one thing for a clinician to seek information about what is important to an individual patient. It is quite another for researchers to figure out what is important for all patients with a given disease. For example, epidemiologists estimate there are 1.5 million persons with Parkinson's Disease (PD) in the U.S. and 60,000 new cases each year (National Parkinson's Foundation). It would be impossible to find out what is important to every person who has PD. What medical researchers do instead is interview small groups. Based on what they learn, they make guesses about what may be important to most persons who have the disease. Often researchers will develop surveys to measure the different aspects of quality of life that are important to patients. This allows researchers to get input from much larger numbers of patients than would be possible with one-on-one or group interviews. Several research studies have tried to find out what is most important

to PD patients. This article describes one of them.

In 1998, Viv Peto and her colleagues published a study in the *Journal of Neurology* called, “*PDQ-39: a review of the development, validation and application of a Parkinson's disease quality of life questionnaire and its associated measures.*” They interviewed 20 persons who had PD and asked them to describe areas of their lives that were affected. Not surprisingly among the biggest concerns was mobility. But patients describe other areas of their life that were affected by PD – how the disease impacted their emotional well-being, their comfort in social settings, the amount of support they got from friends and family, how well they could concentrate, remember, and communicate with others, and the amount of pain and other discomfort they felt.

To see if the concerns raised by the 20 persons interviewed were shared by others with PD, the researchers mailed a survey to 438 additional people who had PD. The survey asked respondents to rate how often PD affected 65 areas of their life in the previous month. A total of 349 people completed the survey.. After studying the responses, the researchers chose 39 items the survey respondents said were most often affected by PD. These 39 items became the *PDQ-39*, a standardized measure that is frequently used in medical research in PD. The 39 items fall into 8 general areas. They are listed below along with

sample questions for each.

Mobility

How often have you had difficulty getting around in public places?

Activities of Daily Living

How often have you had difficulty dressing yourself?

Emotional Well-Being

How often have you worried about the future?

Stigma

How often have you felt worried by others' reaction to you?

Social Support

How often have you had problems with close relationships?

Cognitions

How often have you had problems with concentration?

Communication

How often have you had difficulty with speech?

Bodily Discomfort

How often have you had aches and pains?

There could be areas that concern you that are missing from the *PDQ-39*. And, it may be that some of the questions don't apply to you. Persons who have PD share things in common but they don't all have the same concerns and values nor does PD affect everyone the same way. A measure like the *PDQ-39* makes it easier for researchers to consider what patients value, but they do a poor job representing all the ways PD might affect the individual. Any concern important to you is important enough to share with your healthcare provider.

Karon Cook, PhD

PADRECC Associate Director of Research

Director's Corner

Patients with Parkinson's disease (PD) often complain of problems associated with sleep such as insomnia and nightmares. I want to take the opportunity this month to talk about some of these issues.

Patients with PD can experience sleep disturbances caused by depression, cognitive decline, and the physiologic changes (or changes the body undergoes due to PD) resulting from the disease itself. Parkinson's medications can also be responsible for increasing daytime sleepiness, and the aging process also plays a role.

Sleep problems common to PD include wakefulness, disruption of nighttime sleep, restless

leg syndrome (disagreeable sensations in the legs at night), nightmares, obstructive sleep apnea, sleepwalking, panic attacks, sleep talking, rapid eye movement sleep behavior disorder, and excessive daytime sleepiness.

Treatment often involves adjusting the antiparkinson's medications, and addressing any underlying factors such as depression and anxiety. Avoid stimulants such as caffeine or colas at bedtime, and consult your physician about a good sleep hygiene program. He/she may recommend additional medications to enhance sleep or reduce anxiety. A comprehensive sleep evaluation may be needed. I encourage you to discuss sleep problems and other concerns with your physician so that he/she can work with you to find

solutions.

I am pleased to report that the Houston Parkinson's Disease Research, Education and Clinical Center is beginning its fourth year of operation. Though we are proud of our accomplishments, we are focusing upon the future, particularly the year ahead. Our goals include expanding our outreach to veterans and designing new programs while continuing to improve the quality of existing ones. We welcome your comments and suggestions. I look forward to seeing you at the next Patient/Family Forum on October 22 where sleep disorders will be discussed in greater detail.

Eugene C. Lai, MD, PhD
 Director, Houston PADRECC



Pictured left: Mr. Aubrey Calvin exhibited some of his photos at the PADRECC Patient/Family Forum in June. Mr. Calvin's work (as was Dr. Wong's, page 2) was displayed at Houston FotoFest 2004.

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Serving Others: A Veteran with PD

Recently I visited with Mr. Aubrey Calvin, a veteran with Parkinson's Disease (PD) enrolled in the PADRECC at MED-VAMC. He speaks openly about living with PD. He was diagnosed 21 years ago at the age of 41. His first symptoms included

stiffness in his right hand and changes in handwriting. He has participated as a research subject in various clinical trials testing PD medications.

Upon receiving his degree from Rice, Mr. Calvin, a native Houstonian, attended the University of Texas Law School. He was commissioned as an officer in the

USAF and become a military judge in the JAG core.

Mr. Calvin, president of the board of the Houston Area Parkinson's Society, maintains his law practice and enjoys tai chi, bay fishing, hunting, and photography. "Stay active. Giving up is unacceptable," he says.

Naomi Nelson, PhD
 PADRECC Co-Associate Director of Education