The VA Parkinson Report

A Newsletter for the Parkinson's Disease Research, Education and Clinical Centers and The National VA Parkinson's Disease Consortium

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A Model for Providing Palliative Care in the PADRECCs and Consortium Centers

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Increasing awareness of the inadequacies in end-of-life care for Parkinson's disease (PD) patients has led the Philadelphia PADRECC team to collaborate with our Palliative Care Service to gain skills to assist patients and families with end-of-life issues. PD affects approximately 1.5 million Americans, and symptoms are classically described as resting tremor, rigidity, slowness of movement, and postural instability. Additionally, movement disorder specialists now recognize that nonmotor symptoms such as depression, pain, psychosis, and dementia, add to the complexity of clinical care, patient burden, and caregiver distress. In advanced disease, therapeutic options are limited, leaving patients and families to manage end-of-life care with little guidance from health care providers (Bunting-Perry, 2006). The VA health care system provides the optimal setting for specialists in palliative care and PD to join together to meet the needs of this complex population at end-of-life.

The precepts of palliative care provide a framework to guide care for patients with PD and related movement disorders throughout the entire course of the disease. The World Health Organization provides the following definition: "Palliative care improves the quality of life of patients and families who face life-threatening illness by providing pain and symptom relief and spiritual and psychosocial support from diagnosis to the end of life and bereavement" (WHO, 2007). This philosophy of care supports patients and their families by providing clinical services that incorporate advanced care planning, pain control, symptom management, hospice referral, and bereavement services.

In building a collaborative relationship with the palliative care team, PADRECC clinicians have gained skills by conversing with patients and families regarding: formulating advanced directives, the dying process, and benefits of hospice. In an effort to incorporate palliative care into PADRECC clinical services, obstacles to end-of-life hospice referral were highlighted. Patients and families often continue to seek aggressive acute care services, making hospice referral undesirable and unrealistic. The unpredictable decline to death in chronic disease and the uncomfortable conversation regarding end-of-life care between provider, patient, and family have also been identified as barriers to hospice referral (Casarett, D. & Quill, T., 2007).

By incorporating the precepts of palliative care into clinical services, PADRECC clinicians can prepare patients and their families for the difficult task of end-of-life care. The Philadelphia PADRECC model of palliative care can serve to assist other clinicians to reconsider current clinical practice and develop new systems to support patients and their families through the dying process. We can enhance end-of-life care for individuals with PD and related movement disorders through palliative care by promoting referrals to hospice and pain management specialists, allowing patients to die in the setting of their choice, and supporting families following the loss of a loved one (Bunting-Perry, 2007).

References:

Bunting-Perry, L. (2007). Palliative Care: Caring for Frail Elders with Parkinson's Disease. Chapter 7. pp. 181-197. In L.K. Bunting-Perry & G.M. Vernon (Eds.), Comprehensive Nursing Care for Parkinson's Disease. New York, Springer.

Bunting-Perry, L. (2006). Palliative Care in Parkinson's Disease: Implications for Neuroscience Nursing. Journal of Neuroscience Nursing, 38 (2), 105-112.

Casarett, D. & Quill, T. (2007). "I'm not ready for hospice": Strategies for timely and effective hospice discussions. Annals of Internal medicine, 146 (6), 443-449.

World Health Organization (2007). WHO Definition of Palliative Care. Retrieved November 12, 2007, from http://www.who.int/cancer/palliative/en/

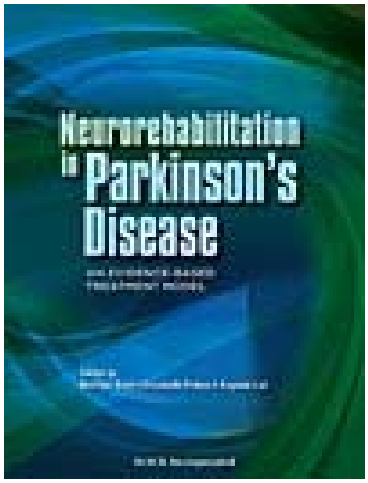
Considering DBS for Your Patient with Parkinson's Disease? Tips for Selecting a Good Candidate

1. Must have primary Parkinson's and NOT one of the parkinsonian variants
2. Age: no limit although under 80 is preferred
3. L-DOPA responsiveness.
4. Absence of dementia
5. Dyskinesia and tremor may have best response to DBS
6. If patient presents with gait/balance/falling problems *in isolation*, DBS may not benefit (*however* if gait/balance problems are present in the context of other PD features, improvement may occur)
7. Ideal patient:
    a) <75
    b) Good physical and cognitive status
    c) Responds to medication on/off fluctuations, short duration response with "wearing off" towards end-of-dose
    d) Dyskinesia, tremor
    e) Taking more medications with reduced benefit
    f) Hoehn and Yahr stage 2 to 4
    g) Positive attitude, stable moods, good support at home

Bradley Hiner, MD
Director, Movement Disorder Center
Clement J. Zablocki Veterans Affairs Medical Center
Milwaukee, WI

EES/GRECC developed Audio conference Series: January 31, 3pm EST (rebroadcast Feb 1): "Parkinson's Disease: Latest Developments" presented by Roger L. Albin, MD, Ann Arbor GRECC

Dial-in for audio portion 1-800-767-1750 access code 89095#. For handout and details on registration closer to the broadcast date go to: http://vaww.sites.lrn.va.gov/vacatalog. 1 hr of CEU credit if you register/evaluate within 2 weeks of each original broadcast.



March 7, 2008
Last day for abstract submission to the MDS 12th International Congress of Parkinson's Disease and Movement Disorders

New Text on Parkinson's Disease Due 2/2008

Neurorehabilitation in Parkinson's Disease: An Evidence-Based Treatment Model provides a comprehensive theoretical and clinical reference for the treatment of patients with Parkinson's disease. Editors Marilyn Trail, MOT, OTR (Co-Associate Director of Education, Houston PADRECC), Elizabeth Protas, PT, PhD, FACSM (Interim Dean and Ruby Decker Endowed Professor, University of Texas Medical Branch, Galveston), and Eugene Lai, MD, PhD (Director, Houston PADRECC) along with contributions from internationally recognized experts, bring together the discussion of theoretical approaches with the actual clinical treatment of patients.

Throughout the text, clinical case studies highlight evidence-based practice and provide practitioners with clinically relevant tools for treatment. In addition to providing comprehensive treatment models for allied health professionals, the text contains chapters devoted to pathophysiology, neuroplasticity, standardized instruments to measure motor and cognitive function, psychosocial issues, assistive technology, and home programs for physical therapy, occupational therapy, and speech-language pathology that will be valuable aids for clinicians, educators, and researchers in the field.

Measuring Quality and Outcomes of Care for Parkinson's Disease

Eric Cheng, MD, MS, Associate Director of Education, Southwest PADRECC

Neurologist-health services researchers at the Parkinson's Disease Research, Education, and Clinical Centers (PADRECC) based at VA Los Angeles, VA Portland, and VA Philadelphia have completed a series of studies to develop tools for measuring the quality of Parkinson's disease (PD) care and to use these tools to measure the quality of care that PD patients receive in the VA. Previously, efforts to measure the quality of care of patients with PD have been limited. In this series of studies, the research team engaged in a systematic process to identify quality of care indicators for care processes relevant to PD, employing a modified Delphi method. This process identified 29 quality indicators as having high validity and potential value for quality improvement interventions. [1] Researchers applied these indicators to investigate determinants of variations in levels of care quality for PD patients based upon explicit review of the medical records. Findings among a sample of over 400 veteran patients with PD in Los Angeles indicated that movement disorder specialist involvement was associated with higher adherence to care quality indicators than general neurologist involvement and non-neurologist involvement, with the largest variations observed for treatment of wearing-off and for assessments of falls, depression, and hallucinations. [2] Outcomes also suggested racial/ethnic disparities in PD care in this Los Angeles sample, particularly in the area of depression treatment. [3] Findings among a sample of 150 veterans with PD in the Pacific Northwest also indicated suboptimal screening of falls and depression. [4]

In two ongoing components of this research, the feasibility, reliability, and validity of two PD-targeted and two generic health-related quality of life outcome measures are being compared, and veterans with PD seen at four VA facilities in the southwest United States are being surveyed to determine their access to care, unmet medical and information needs, and perceptions of care quality.

Physicians will incorporate results from these research studies into the design of a VA health care delivery intervention targeting areas of care in need of improvement that will be implemented and tested in the southwest United States, then potentially implemented throughout the six PADRECCs and the remainder of the Veterans Health Administration facilities.

References

1. Cheng EM, Siderowf A, Swarztrauber K, Eisa M, Lee M, Vassar S, Jacob E, Vickrey BG. Development of quality of care indicators for Parkinson's disease. Mov Disord 2004;19:136-50.
2. Cheng EM, Swarztrauber K, Siderowf AD, Eisa MS, Lee M, Vassar S, Jacob E, Vickrey BG. Association of specialist involvement and quality of care for Parkinson's disease. Mov Disord 2007;22:515-22.
3. Cheng EM, Siderowf AD, Swarztrauber K, Lee M, Vassar S, Jacob E, Eisa MS, Vickrey BG. Disparities of care in veterans with Parkinson's disease. Parkinsonism Relat Disord 2007.
4. Swarztrauber K, Graf E, Cheng E. The quality of care delivered to Parkinson's disease patients in the U.S. Pacific Northwest Veterans Health System. BMC Neurol 2006;6:26.

Mark Your Calendar!

The MDS 12th International Congress of Parkinson's Disease and Movement Disorders takes place in Chicago, June 22-26, 2008

Prasunamba Amaraneni, MD (pictured center row 1), a neurologist with the Colmery-O'Neil VAMC in Topeka, KS, participated in the Houston PADRECC Outreach Program sponsored by the National Parkinson's Disease Consortium. The program allows health professionals the opportunity to improve veterans' care by providing PD education from movement disorder specialists. Houston PADRECC staff pictured 1st row L-R: Diane Davis, RN,(Clinical Coordinator); Brenda Wade (AO) 2nd row: Eugene Lai, MD, PhD (Houston PADRECC Director); Naomi Nelson, PhD (Co-Associate Director of Education); Aliya Sarwar, MD ((Associate Director, Clinical Care); and Gabriel Hou, MD, PhD (Associate Director, Research).

Consortium Centers at a Glance

Augusta, GA
Augusta VAMC (Phone: 706-733-0188x3260)
Director: John Morgan, MD
The Movement Disorders Clinic, operational since 1985, is headed by Dr. John Morgan. Dr. Morgan provides subspecialty consults and botulinum toxin injections for patients with blepharospasm, hemifacial spasm, and craniocervical dystonia. He also serves as the PI and Sub-PI on various PD and Huntington's disease clinical trials.

Birmingham, AL
Birmingham VAMC (Phone: 205-933-8101x4734)
Director: Anthony Nicholas, MD
The Movement disorders Clinic, operational since 2005, provides subspecialty consults, referral for botulinum toxin injections, and patient selections and management services for DBS surgery. Dr. Nicholas, who is affiliated with the University of Alabama at Birmingham and The Kirklin Clinic, is the PI for an American Parkinson Disease Association funded study, "Post-translational Modifications of Histones in Levodopa-Induced Dyskinesia."

Bronx, NY
James J. Peters VAMC (Phone: 718-584-9000x5915)
Director: Ruth Walker, MD
The weekly Movement Disorders Clinic is attended by 4 neurologists who see patients with predominantly PD and essential tremor but also dystonia and chorea, from VISN3 and beyond. Neurologists perform botulinum toxin injections, evaluate for DBS surgery, and carry out post-implantation programming. The Clinic offers a variety of activities, including the 6th James J. Peters PD Awareness for patients and caregivers and a series of patient educational seminars.

Cincinnati, Ohio
Cincinnati VAMC (Phone: 513-475-6318)
Director: Fred Revilla, MD
The Movement disorders Clinic, staffed by 2 fellowship-trained movement disorders neurologists, Drs. Revilla and Sahay, serves over 425 veteran patients from VISN 10, providing specialized care and evaluation for DBS surgery, and botulinum toxin injections. Since the VA Consortium brought the Clinic to attention at the national level, staff work with PD support groups to conduct activities such as lectures series and seminars. Geriatric fellows, residents, and students rotate through the clinic. A short term goal is to establish a fellowship program to increase education, research, and clinical activities related to PD and other movement disorders.

Gainesville, FL
Malcolm Randall VAMC (North Florida/South Georgia VHS) (Phone: 352-374-6058)
Director: Frank Skidmore, MD
The Movement Disorders Clinic, directed by Dr. Skidmore, follows several hundred PD veteran patients in the North Florida area, including those post DBS surgery who require programming. The Clinic also provides botulinum toxin injections. At present, Dr. Skidmore's primary area of research involves cognition in PD.

Lexington, KY
Lexington VAMC (Phone: 859-281-4920)
Director: John T. Slevin, MD
Established in 2000, The Movement Disorders Clinic is staffed by Dr. Slevin and a nurse practitioner. It provides subspecialty consultations, patient selection and management services for DBS surgery and botulinum toxin injections. Dr. Slevin, who is affiliated with the University of Kentucky Medical Center, serves as Director of Clinical Research for the UKMC Morris K. Udall PD Research Center of Excellence and is the PI and Co-PI on 2 industry and 4 NIH-sponsored clinical/translational studies that recruit subjects though the Clinic. (Continued on page 5)

Consortium Centers at a Glance

(cont from page 4)

Tuscaloosa, AL

Tuscalossa VAMC (Phone: 205-554-2000 x4136)
Director: Fernando Franco, MD
The Neurology Clinic, open one day per week, is a general neurological clinic where movement disorders represent about 20-25% of our veteran patient population. Other diagnoses include tremor disorders (40-50%), dystonia (10-15%), ataxia (5-10%), gait abnormalities (10%), drug-induced (5%), psychogenic disorders (5%), tics (2-3%). The Clinic treats about 20-25 patients per day.

We Want You!

The National VA Parkinson's Disease Consortium is actively seeking new medical centers to join in our mission of providing convenient specialty care to veterans throughout the healthcare system. The PADRECCs and Consortium are eager to network, train, and mentor VA colleagues who share an interest in the fields of PD and movement disorders. Our goal is to add a minimum of three new Consortium Centers in 2008. Interested parties are asked to contact the Consortium Coordinating Center at 215-823-5800 x2238 or dawn.mchale@va.gov. You can also visit our website at www.parkinsons.va.gov.

Jay Nutt, MD, NW PADRECC Co-Director, presents educational lectures to PD patients and caregivers at the Portland VAMC for the Parkinson's Disease Health Fair.

San Francisco PADRECC Initiates Video Conferencing

On November 15, 2007 the San Francisco VA PADRECC transmitted their first Parkinson's Disease Caregiver Conference using VA video conferencing technology. The outreach program had over 350 pre-registered veterans and caregivers who attended via 16 Vtel locations over 6 states.

Support for family and caregivers of veterans with Parkinson's disease was explored through presentations on Identifying and Managing Psychological Changes in Parkinson's Disease (PD), Identifying and Managing Depression, Identifying Sleep Disorders, Surgical Therapies for PD, Tips for taking Care of the Caregiver, and an Update on PD medications. This is the first time a conference for family and caregivers has been held via video-teleconferencing and based upon the positive feedback, it won't be the last.

The NW PADRECC Staff: Back from left: Gordon Campbell, FNP; Steve Gunzler, MD; Jeff Kraakevik, MD, Steve Johnson, MD; Matt Brodsky, MD; and Joseph Quinn, MD (NW PADRECC Director). Center from left: Kathy Chung, MD; Ron Blehm, PT; Marsha Andrews, (Program Support); and Penny Hogarth, MD. Front from left: Nicole Floyd, (AO); Susan O'Connor, RN; and Jeremy Cook, (Program Assistant).

Consortium Coordinating Center
Rebecca Martine, APRN, CS, BC, Chairperson
215-823-5934
Dawn McHale, Coordinator
215-823-5800 x 2238
Consortium Center Referral Line
Jackie Lumford
800-949-1001 x 2749

Visit our Website

www.parkinsons.va.gov

PADRECC SE worked with the American Parkinson Disease Association (APDA) to sponsor 2 conferences in October 2007. Pictured L-R are Miriam Hirsh (Neurosurgical Nurse, PADRECC SE), Lynn Klanchar (ADoE, PADRECC SE), John Argue (actor, educator, writer), Kathy Morton (President APDA Richmond Metro Chapter), and Susan Dietrich (Coordinator, APDA I&R Center of Virginia).

Nationwide PADRECCS

National Neurology Office
Robert Ruff, MD, PhD, National Director of Neurology, VHA
Louis Stokes VAMC
Cleveland, OH 216-791-3800 ext 5230
www.parkinsons.va.gov

Philadelphia PADRECC
Matthew B. Stern, MD, Director 888-959-2323
www.parkinsons.va.gov/Philadelphia

Southeast (Richmond) PADRECC
Mark Baron, MD, Director 804-675-5931
www.parkinsons.va.gov/Richmond

Houston PADRECC
Eugene C. Lai, MD, PhD, Director 713-794- 7841
www.parkinsons.va.gov/Houston

Southwest (West Los Angeles) PADRECC
Jeff Bronstein, MD, PhD, Director 310-268-3975
www.parkinsons.va.gov/Southwest

San Francisco PADRECC
William J. Marks, Jr.,MD, Director 415-379-5530
www.parkinsons.va.gov/SanFrancisco

Northwest (Portland/Seattle) PADRECC
Joseph Quinn, MD, Director 503-721-1091
www.visn20.med.va.gov/Portland/PADRECC/Index.asp

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PADRECC Education Calendar

Philadelphia PADRECC

Launch of PD 101 Seminars for Newly Diagnosed Patients
01/2008
Love, Intimacy & Parkinson's Disease Education Fair
04/11/2008

Southwest PADRECC (W. Los Angeles)

SW PADRECC Journal Club
12/11/2007
SW PADRECC Patient Education Seminar
Stimulating the Brain: Strategies for Maintaining Cognition
1/23/2008

Southeast PADRECC (Richmond)

Nursing Grand Rounds: DBS in Young Onset PD: A Case Study
1/17/2008
Essentials of Nursing Practice: PD and DBS presentations
3/17/2008
Annual PD Community Education Day
10/11/08

Northwest PADRECC (Portland/Seattle)

Parkinson's Disease Patient Education Classes -
Portland VAMC; Feb 8, May, July 11, 2008
(PD research, exercise, cognitive Issues)
Seattle VAMC; Feb 19, 4/15, 6/17/2008
(Topics include caregiving issues, medical/surgical treatment, alternative medicine)

Houston PADRECC

Houston PADRECC Patient Family Forum: Improving Mobility in PD
1/25/2008
5th Annual PADRECC Symposium on PD for Allied Health Professionals
06/07/2008

San Francisco PADRECC

PD Journal Club
1/15/08
Dystonia (Fellow's Presentation)
1/17/08
Chorea and Myoclonus
1/24/08