



THE TRANSMITTER

July 2015

Article Review

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Survey of Health Care Workers Suggests Unmet Palliative Care Needs in Parkinson's Disease.

Advanced Parkinson's disease (PD) patients and their families have unmet palliative care needs and are rarely referred to Palliative Care services. This study investigated the knowledge and attitudes of Irish health care workers in the community and acute care settings regarding their knowledge and attitudes in end-stage PD and palliative care referrals. Out of 29 consultants deemed as the group most likely to make referrals, 48% of these consultants *had not made a palliative care referral* in the past six months and just 7% had referred only 10 patients. A major barrier to introduce palliative care services for people with PD is that health care workers are unsure of the appropriateness of palliative care in PD. Additional training in palliative care for 'life-limiting' disorders such as PD is needed for all health care workers. They recommend clear guidelines to promote timely referrals to a palliative care service for PD patients. There is a best practice discrepancy by health care workers between actual practice and recommendations for palliative care in PD.

Movement Disorders - Clinical Practice June 2015. Volume 2, Issue 2. 142-148.

<http://onlinelibrary.wiley.com/doi/10.1002/mdc3.12133/epdf>

Vascular Parkinsonism: Deconstructing a Syndrome

The term vascular parkinsonism has long been used to describe progressive ambulatory and postural impairment, so-called "lower body parkinsonism", in the presence of abnormal white matter signal on neuroimaging. However, the criteria are very poorly defined. It may be acute, delayed, or insidious in onset; unilateral or bilateral; there may be focal or diffuse lesions with no particular regard on location; and may or may not involve gait impairment. In this review article, Vizcarra et al. have critically reappraised the literature and suggest that the term is misguided. There are no abnormal structural imaging patterns specific to vascular parkinsonism and furthermore, there are disparities between brain MRI findings and presence/absence of microangiopathic brain disease on pathology. In addition the majority of patients after large or small vessel strokes do not develop parkinsonism, and extensive basal ganglia abnormalities can be present in non-Parkinsonian individuals (e.g. CADASIL patients). The authors consider that definitive vascular parkinsonism is only proven when there is a clear prior ischemic or hemorrhagic event that occurs in the substantia nigra or nigrostriatal pathway that leads to presynaptic dopamine transporter deficiency. However, even among patients who suffer stroke in the substantia nigra or elsewhere in the nigrostriatal pathway, most do not develop parkinsonism. The authors argue that many cases of vascular parkinsonism represents pseudovascular parkinsonism (e.g. Parkinson's disease or other neurodegenerative parkinsonism such as PSP that have nonspecific neuroimaging signal abnormalities), vascular pseudoparkinsonism (e.g. akinetic mutism from

bilateral mesial frontal strokes), or pseudovascular pseudoparkinsonism where the gait impairment is an expression of cognition rather than primary motor impairment (e.g. higher-level gait disorders such as NPH).

Movement Disorders July 2015. Volume 30, Issue 7. 886-894

In-Patient Multidisciplinary Rehabilitation for Parkinson's Disease: A Randomized Controlled Trial.

Current Parkinson's disease (PD) therapy is based on dopaminergic medications. These medications may not treat all motor symptoms and their doses may be constrained by bothersome dyskinesia or other side effects. Despite optimal medication management, PD motor symptoms are progressive and often accompanied by worsening cognitive-behavioral symptoms. Monticone and colleagues in Italy describe a randomized controlled trial with parallel groups undergoing an experimental inpatient multidisciplinary program compared to a control group receiving neuromotor techniques involving stretching, strengthening, balance, resistance and velocity training. They follow two groups consisting of 35 subjects each who have long duration PD and mild to moderate level of disability over a period of 8 weeks during inpatient hospitalization. Both groups received daily 90 min physical therapy sessions, while the experimental group received additional motor as well as cognitive and ergonomic education meeting regularly with a psychologist, physical therapist and occupational therapist. At the end of the trial improvement was seen in both groups. However, superior improvement was seen in the experimental group, with a 25 point clinically significant between-group difference in MDS-UPDRS-Part III (motor sub score), the primary outcome measure. This finding was maintained at 12 month follow up. This difference is higher than other similar studies, perhaps accounted for by the combination of task-oriented exercises, cognitive training and ergonomic education, which allows for more direct application to the home setting. Other findings of this study include improvement in Berg Balance Scale (BBS), Functional Independence Measure (FIM) and Parkinson's Disease Questionnaire-39 (PDQ-39). While cost may be the most limiting factor (this inpatient program cost €20,000), this study does show that it is possible to have clinically significant improvements in subjects with long duration PD and mild to moderate level of disability without new pharmacologic or surgical interventions.

Movement Disorders July 2015. Volume 30, Issue 8. 1030-1058. Article first published online: 11 JUN 2015 | DOI: 10.1002/mds.26256

<http://onlinelibrary.wiley.com/doi/10.1002/mds.26256/abstract?campaign=woletoc>

Committee Activities

Clinical Care Committee

- **Rotation of Committee Chair:** Leadership for the clinical care committee rotates amongst the PADRECCs. The Houston PADRECC leads the committee for July/August. Committee meets via conference call the first Tuesday of the month at 12pm (EST)
- **Standardize and Optimize Clinical Care:** Continues to discuss a variety of clinical issues to improve patient care and outcomes. The committee continues to provide clinical support to the

consortium network, and works on measures to standardize clinical care across the PADRECC network.

Recent agenda items have included new and ongoing discussion on:

- New treatment options for Parkinson's Disease including DUOPA™ (carbidopa and levodopa) enteral suspension delivered directly into the small intestine for the treatment of motor fluctuations for people with advanced Parkinson's disease. Discussion focused on development of standardized protocol for this therapy across the PADRECC network, logistical issues, education and support aspects.
- Current practice regarding the use of various Neurotoxins across the PADRECC network with the objective to improve this specialized clinical practice and develop neurotoxin selection criteria for various conditions in the Veteran population.
- Practical aspects regarding the use of DAT scans; Applications and pitfalls, including the issue of drug interference
- Palliative Care: Review of palliative care resources and practices in the PADRECCs
- Veteran's Choice Program, optimization of care across the PADRECC network.
- **PADRECC Transmitter:** PADRECC clinicians provide reviews of recent movement disorder publications that are included in the PADRECC Transmitter

Education Committee

- **PADRECC/EES Movement Disorder Series:** The 5th^d audio conference for FY 15 will be held **September 10, 2015-** "*Aspiration Pneumonia*" by Joe Murray, SLP at VAMC Ann Arbor/VAMC Gainesville. The audio conferences are archived on the National website www.parkinsons.va.gov under the Movement Disorder Series tab. All evaluations for CMEs are being done electronically via TMS and preregistration is required. Please see the **Dates to Remember** section below for a listing of upcoming audio conferences. Committee is submitting EES request to continue this program for FY16.
- **National Newsletter:** Currently accepting articles for the **2015 VA Parkinson Report**. The topic selection for this edition are focused on ongoing activities and research by the PADRECCs and their consortium members. If you are interested in submitting an article for the newsletter please email Linda Fincher (linda.fincher@va.gov) or Suzanne Moore (Suzanne.moore@va.gov).
- **Patient Education Video Project:** The My Parkinson's Story video series from FY 11 & 12 are available for viewing on the National PADRECC & VA Consortium Website: <http://www.parkinsons.va.gov/patients.asp> and on You Tube.
- **Enduring Materials Project:** In collaboration with EES, the committee developed an on-line TMS self-

study program that offers CME credit for a 3 year period. The purpose of this program is to provide VHA healthcare professionals with a broadened medical awareness of **Mood Disorders in PD**. The program is **NOW** available on TMS:

https://www.tms.va.gov/learning/user/deeplink_redirect.jsp?linkId=ITEM_DETAILS&componentID=14771&componentTypeID=VA&revisionDate=1343926380000

- **PADRECC Transmitter:** The committee continues to assemble and distribute this e-newsletter every other month.

San Francisco PADRECC Service Area Update

San Francisco PADRECC

Director: Caroline Tanner, MD, PhD, FAAN

San Francisco VA Physician Honored at White House

Caroline M. Tanner, MD, PhD, FAAN, the Director of the Parkinson's Disease Research, Education and Clinic Center (PADRECC) at the San Francisco Veterans Affairs Health Care System (SF-VAHCS), was recently honored at a White House ceremony as a "*Champion of Change*" for her commitment to caring for people with Parkinson's disease, her research to improve treatment, and identifying causes with hopes to someday prevent the disease.



"I am proud to represent the many people with Parkinson's disease, friends, family, health care providers and researchers who have already accomplished so much, and who will continue to work to understand the causes and, ultimately, prevent or cure Parkinson's Disease," says Dr. Tanner. "Happily, they are too many to name. They are all Champions of Change."

"My dream is to prevent Parkinson's disease," says Dr. Tanner. "As a medical student, I was inspired to see immobile people walk after taking the simple chemical, L-dopa, but at the same time frustrated by the disabling side effects that often followed. I became a neurologist to tackle this problem, and later I trained in clinical neuropharmacology, environmental health science and epidemiology, to give me the skills I needed. I have been privileged to be a small part of a large dedicated community of people with Parkinson's disease, their friends and families, neurologists, laboratory scientists, epidemiologists and other medical practitioners and researchers who share my dream."

The Parkinson's Disease Champions of Change are inspiring volunteers, doctors, educators, and citizens who are building awareness and investing in research that may one day save the lives of the 500,000 to 1.5 million Americans living with Parkinson's disease.

The full list of PD Champions of Change: <https://www.whitehouse.gov/champions/parkinson's-disease>

San Francisco VA Health Care System uses Telehealth to Reach Yountville Veterans

The San Francisco VA *Parkinson's Disease Research, Education, and Clinic Center* (PADRECC) recently held its first "Clinical Video Telehealth" (CVT) visit to the Veteran Home of California in Yountville, much to the delight of some residents there.



Many Yountville residents receive their health care at the San Francisco VA Health Care System (SFVAHCS) — 59 miles away. Although transportation is provided for residents to and from SFVAHCS, the trip itself can be especially challenging for Parkinson's patients, who often require caregiver support for travel. Now Parkinson's patients living at the (California state) Veterans Home in Yountville can have most of their medical appointments without traveling.

The Clinical Video Telehealth (CVT) visits allow VA practitioners to see Parkinson's patients at the Yountville Veterans Home without the burden of travel. The patient does not have to give up an entire day for a one-hour appointment and patients can stay in their familiar surroundings at the Yountville Home to have their appointment: bringing specialty care closer to the patient.

Telehealth technology for Veteran outreach has been an ongoing goal of the PADRECC (Parkinson's Center). "We open Telehealth clinics between VA facilities as needed", explained Susan Heath, MSN, RN, "but this is our first Agency to Agency connection, allowing us access to Veterans at the California (state) Veterans home. The collaboration amongst the SFVAHCS Telehealth, V21 Telehealth, CalVet, and PADRECC teams is a testament to the focused determination to achieve this long-desired goal to bring access and quality care to our Veterans who reside at Yountville."

San Francisco PADRECC practitioners are so pleased to connect with Yountville and are grateful to our Telehealth team: Isa Baca of CalVet; Alan Jessen, Administrative Officer, Yountville State Home/CalVet; Sandra Murphy, VISN21 Telehealth Lead; PADRECC Movement Disorders Clinical Nurse Specialist Susan Heath, MSN, RN; Facility Telehealth Coordinator Nurse Manager Elaine Der, NP; CVT Lead Monica Smith; and SFVAHCS Telehealth Technician Michael Casdia."

VA providers from any location wishing to refer Veterans can call the PADRECC (Parkinson's Center) at SFVAHCS at (415) 379-5530.

San Francisco PADRECC's Scan-Echo

Scan-Echo is the acronym for *Specialty Care Access Network – Extension for Community Healthcare Outcomes*. It represents an extension of VA video health care beyond treating individual patients. Scan-echo's goal is to generate expertise across practices and extend specialty care to those who need it.

Unlike usual video teleconferencing (VTEL), which links *one* patient with *one* provider in another location, SCAN-ECHO uses VTEL technology to link several care providers simultaneously to a specialist.

The San Francisco *Parkinson's Disease Research, Education, and Clinical Center* (PADRECC), uses their monthly Scan-Echo to discuss aspects of Deep Brain Stimulation. Each 1.5 hour session, includes a presentation from one or more movement disorders specialists, discussion of case studies, and can review specific patients submitted by providers. SF PADRECC's regular attendees are from Honolulu, HI; Palo Alto, CA; Phoenix, AZ; Albuquerque, NM; Minneapolis, MN; Salt Lake City, UT; and Denver, CO.

PADRECC believes in the Scan-Echo program's ability to generate communication and expertise across practices and by extension, deliver that quality to patients. VA providers interested in San Francisco PADRECC's Deep Brain Stimulation Scan-Echo, can call the Parkinson's Center at (415) 379-5530.

Teach the Teacher: SAFRA at San Francisco PADRECC

Edmond J. Safra Nurse Faculty Education program was held at San Francisco VA Health Care System's *Parkinson's Disease Research, Education, and Clinical Center* (PADRECC), July 13-14, 2015. This is the third year that PADRECC's Susan Heath (MSN, RN, CNS) has coordinated this Train-the-Trainer event, which educates Nursing Faculty about Parkinson's disease.

The course includes an impressive two-day didactic and 16-18 hours of clinical experience; it is taught by movement disorders specialists in neurology, neurosurgery, pharmacy, speech pathology and physical therapy.

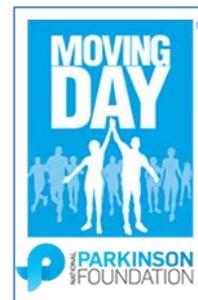
Nurses are critical to the medical management of the Parkinson's patient. Upon completing the coursework, nurse educators will be able to care for the Parkinson's disease patient and family, design teaching methods appropriate for student nurses and clinical nurses, integrate learning in to community settings, and will become a *Safra Nurse Scholar* in Parkinson's disease. If you are a Nurse Educator and interested in 2016 SAFRA training in San Francisco, you are welcome to call Susan Heath 415-379-5530.

<http://www.edmondjsafra.org/science-and-medicine/visiting-nurse-faculty-education-program>

***Shake-it-up-Baby!* NPF Walk in San Francisco**

San Francisco PADRECC Patient & Caregiver Support Group chose "*Shake it up Baby*" as their team name and warrior's cry for the 2015 National Parkinson Foundation fundraising Walk.

This year's walk was heralded by a Bag Pipe band, had 30 walkers from our San Francisco support group, and was number two in fundraising, collecting \$13,000 for the Foundation. We're proud of our *Shake it up Baby* walkers and a good time was had by all!



The San Francisco PADRECC Parkinson's disease **Patient and Caregiver support groups** meet monthly (with separate breakout sessions) on the third Tuesday of each month, 4:00pm – 5:30pm PST. These are held at the San Francisco VA Medical Center, 4150 Clement Street, building 200, room 1A-122 with free parking by the flag pole. Any questions: please call 415-379-5530.

Dates to Remember

September 10, 2015

EES/PADRECC Movement Disorder Series

Topic: Aspiration Pneumonia and Parkinson's Disease

<http://www.parkinsons.va.gov/>

September 11-12, 2015

Parkinson Study Group Annual Meeting and Symposium

Fort Myers, Florida

<http://www.parkinson-study-group.org/parkinson-research/parkinson-research/september-1112-2015>,

October 6-8, 2015

World Parkinson Congress Scientific Update 2015

Online Meeting-Live Webcast

Registration opens in August

<http://www.worldpdcoalition.org/?page=2015Webcast>

February 20-March 2, 2016

2016 PAN Forum

Washington, DC

<http://parkinsonsaction.org/events/forum/>

April 15-21, 2016

2016 American Academy of Neurology (AAN) Meeting

Vancouver, Canada

www.ann.com

June 19-23, 2016

2016 Movement Disorder Society International Congress

Berlin, Germany

www.mdscongress2016.org

September 20-23, 2016

4th World Parkinson Congress

Portland, Oregon

<http://www.wpc2016.org/>