

# **Telehealth in Parkinson's disease**

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# Overview

- TH definitions, modes, opportunities, challenges
- TH in PD: What's been done?
- TH in PD: Other applications and Future Directions

# Telehealth Definitions

- *ATA: “Interchangeable”*
- **Telehealth:** *(Broader)* - remote care, imaging, education, call centers, apps...
- **Telemedicine:** *(Narrower)* - remote delivery of health care services (primary care, specialty care consultations...)

# Telehealth Modalities

- *Applications/services:*
  - *Live two-way video (video conferencing)*
    - *Virtual Visits: clinic-to-clinic, video-to-home (“virtual house calls”)*
  - *Asynchronous, “store-and-forward” (video, photos, imaging and other dx-tests)*
  - *Smart phones, apps*
  - *Patient portals, secure messaging*
  - *E-Consults*

# Telehealth Opportunities

- Improved **Access!**
  - Rural/Remote
  - Neurologic conditions = travel can be extreme hardship (impaired mobility and cognition, time off work, family care, etc...)
- Improved Health Outcomes
- Cost-efficiency
- Patient comfort/convenience, in their own home

# Telehealth Challenges

- Financial (Reimbursement)
  - Complex multi-payer system (US: Medicaid, Private, Medicare)
  - Heterogeneous & dynamic regulatory landscape
- Legal
  - Medical Licensure (US: state-to-state)
  - Credentialing at Spoke Centers
  - Liability (malpractice)

# Telehealth Challenges

- Technological
  - Limited broadband in some areas
  - More user-friendly software needed
  - Integrated EMR, imaging
- Clinical
  - Patient/Doctor relationship
  - Diagnosis without touching patient?
  - Unreliable aspects of neuro-exam
- Lack of evidence
  - To get policy change, there needs to be clinical trials to prove it cost-effective, efficacious (outcomes), pt satisfaction

# **Telehealth in Parkinson's disease**

# Telehealth is amenable in PD

- Chronic progressive - requires frequent visits
- Almost entire examination is visual
  - Except rigidity/pull test,... but *mUPDRS validated*
- Motor and ***Non-motor*** symptom assessment and effective treatments that can make an impact
- Subspecialty care usually restricted to metropolitan areas

# The Need: “*Caring for the Majority*”

- Access to neurologist associated with
  - decreased hospitalizations
  - decreased PD-related complications (14% ↓ hip fractures, 21% ↓ nursing home placement)
  - greater survival
  - Mechanism: prevention/early recognition of: drug side effects, falls, UTI, Psychosis, AMS, etc....
- Yet access to PD care is *very* limited
  - China, est 2 million with PD, only 50 PD specialists
  - US: only 40% of Medicare beneficiaries saw a neurologist in first 4 years of diagnosis
- Need only worsening:
  - By 2030; PD 33% increase in Europe, 110% in China

Willis et al, 2012 Neurol

Dorsey and Willis, 2013 MDS

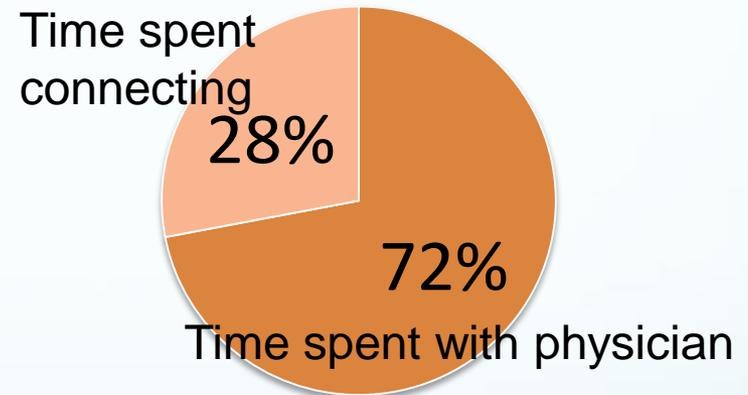
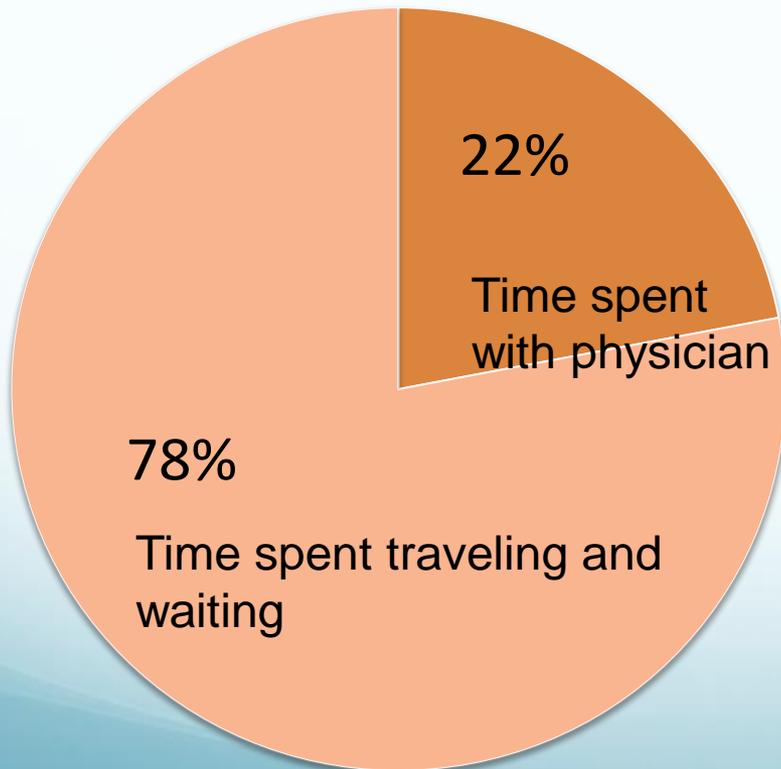
# TH for PD: Clinical Trials

- Samii 2006 (n=34), 100 visits at Seattle VA
  - Savings:
    - 1500 attendant hours
    - 100,000 km
    - \$37,000 in travel costs/lodging
- Biglan 2009 (n=1) case in SNF f/u 8mos via TH
- Dorsey 2010 (n=14), 2013 (n=20), etc...

# Virtual Visits *Flip* the Care Paradigm

Door-to-Door In-Person Visits  
100% = 255 minutes

On-to-Off Virtual Visits  
100% = 53 minutes



# Virtual visits offer patients care, convenience, and comfort

## Care

- “We had a good family crying moment after the appointment from just pure joy of finally having the opportunity for him to see a (Parkinson disease) specialist”
- “The (Parkinson disease) literacy was amazing”

## Convenience

- “It’s great not having to drive the 2 hours ... having the added expense of my wife missing an entire day of work, [and] saving on gas for the car, tolls, [and] parking”
- “I could have access to a movement specialist, which I currently don’t where I live”

## Comfort

- “I liked the interaction being personal despite the 3000 mile distance...it felt somehow ***protected by the veil of technology***, which enabled the exchange to be ***more honest***”
- “I am more relaxed in my home setting”

## Feedback from patients and families

# Clinical Trials TH in PD

- **CONNECT.Parkinson** (PCORI and NPF supported)
  - Randomized: usual care vs 4 Virtual House calls (in 1 year)
  - Feasibility: % complete visits
  - Efficacy: QOL (PDQ-39, EuroQoL-5D5L, Change in MDS-UPDRS, MOCA, GDS, time and travel savings, MCSI (Caregiver strain), health care utilization.
- **RACE-PD**
  - 1-time video-to-home consultation
  - feasibility on national level
  - QOL at 6 months
- Not just feasibility, but *efficacy, Patient-centered outcomes*
- **Completely remote recruitment**, consent, enrollment, protocol, outcomes

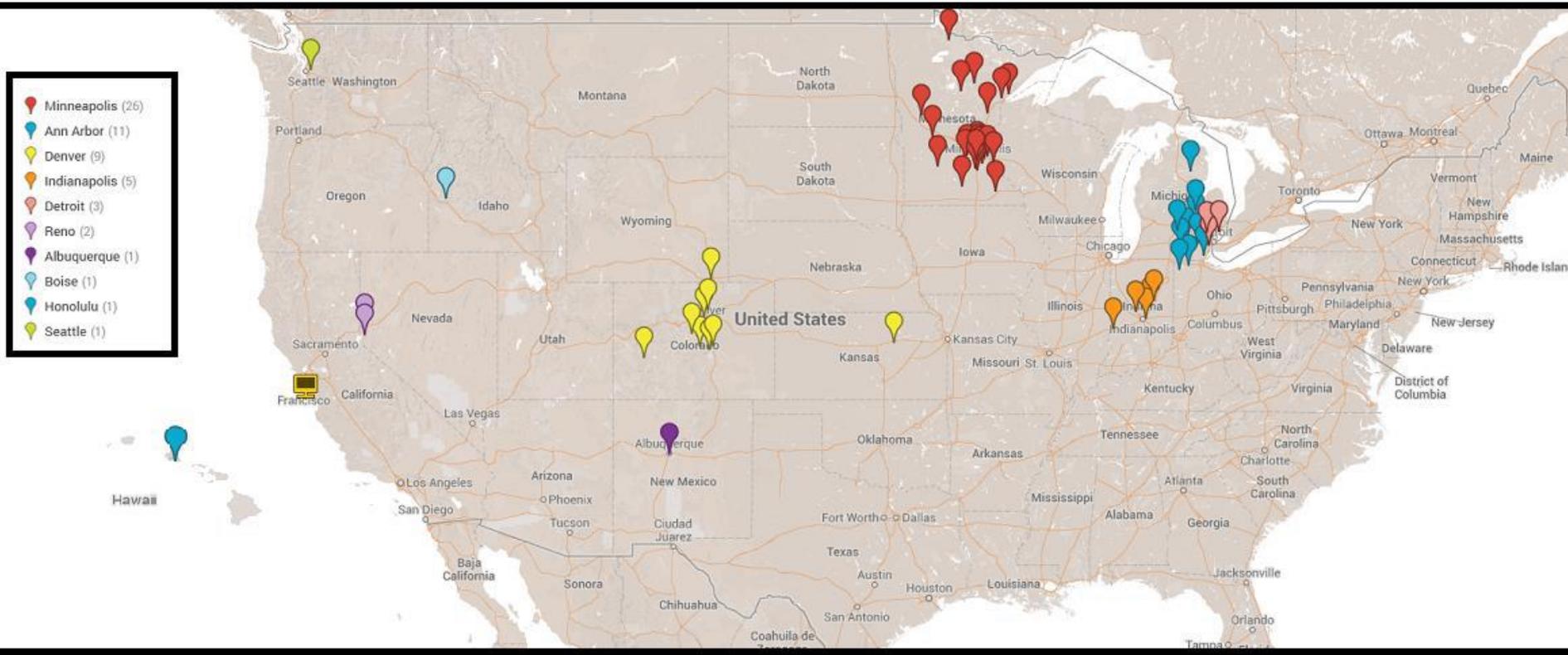
# TH for PD: Clinical Trials

- Wilkinson et al, Neurol Clin Pract 2016
  - Dual-active arm 12 months randomized trial
  - Satellite clinic-TH arm vs home-TH arm vs usual care
  - Primary outcome: Patient satisfaction
  - Results:
    - Similar in all groups
      - high levels of pt satisfaction
      - health care utilization similar in all groups
      - clinical outcomes similar in all groups
    - TH Groups had reduced travel burden, and greater satisfaction related to Convenience and Accessibility/distance

**TH in PD:  
Other Applications and  
Future Directions**

# Teleconsultation of DBS Candidacy

- 60 out-of-state referrals seen at SFVA, (34 TM, 26 InP)
- 100% referred by VA neurologists (42% by MDS)



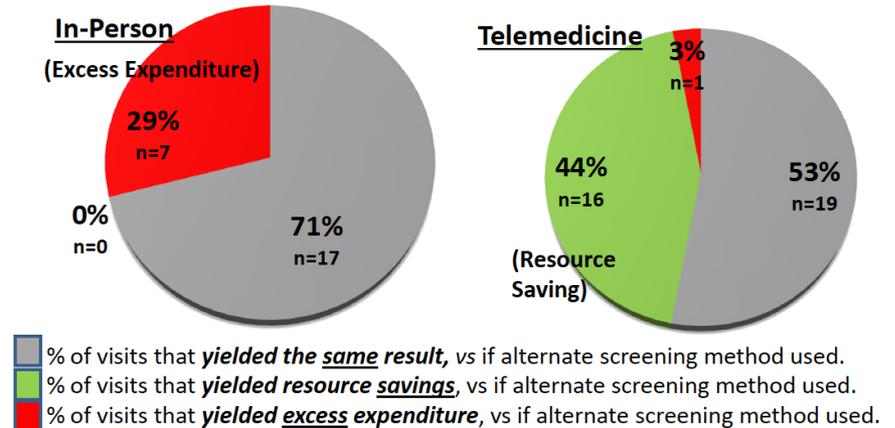
# Teleconsultation of DBS Candidacy

## Similar Accuracy of Identification of good candidates

- In-person: 95% accurate in predicting eventual DBS
- TH: 93% accurate in predicting eventual DBS

## TH savings of resources (travel, treatment, work-up, time off work...)

- TH saved resources by saving poor candidates travel, and by expediting work-up for possible candidates.
- TH expended resources due to misdiagnosis via TM (PD vs ET)



\*\* "Resource Utilization" includes: travel costs, health care costs (tx, work-up), patient or caregiver burden, time of work, etc...)

# Asynchronous Consultation

- **MDS Task Force on Telemedicine**
  - Project led by Mark Guttman in Ontario
  - Esther Cubo and 4 padrecc fellowship alumni (Aldred, Spindler, Galifianakis, Katz)
  - Neurologist in Lagos, Nigeria, uploads standardized video examinations to secure server
  - MDS Consultant reviews, and provides assessment, recs, and education/references
- Successful implementation, now expanding to another site in Nigeria, two in Tanzania, and one in South Africa

# Telehealth especially beneficial in advanced PD

- More advanced patient
  - Less mobile, more cognitive impairment, more dependant on caregiver
  - Travel frequently extremely difficult (WC, transport, caregivers lifting/transferring)
- Management of non-motor sx are manageable by TH, less dependent on examination findings
- Movement specialists with multidisciplinary teams are even more rare!
- **Was quickly obvious that our Pall Clinic patients at SFVA had trouble getting to our appts, so started VTH visits.**
- **Susan Heath has established TH-clinic with Yountville Veterans Home (inter-agency)**
- Very limited literature

# Tele-support group

- Shah *et al* 2015: Philadelphia VA PADRECC
  - 7 caregivers enrolled, weekly support groups x 8 wks
  - Intervention;
    - Education, skills training, problem solving, support
    - Cg roles, Cg self-care
  - Outcomes:
    - QOL, caregiver strain, mood (GDS) improved
    - Qualitative feedback “universally positive”

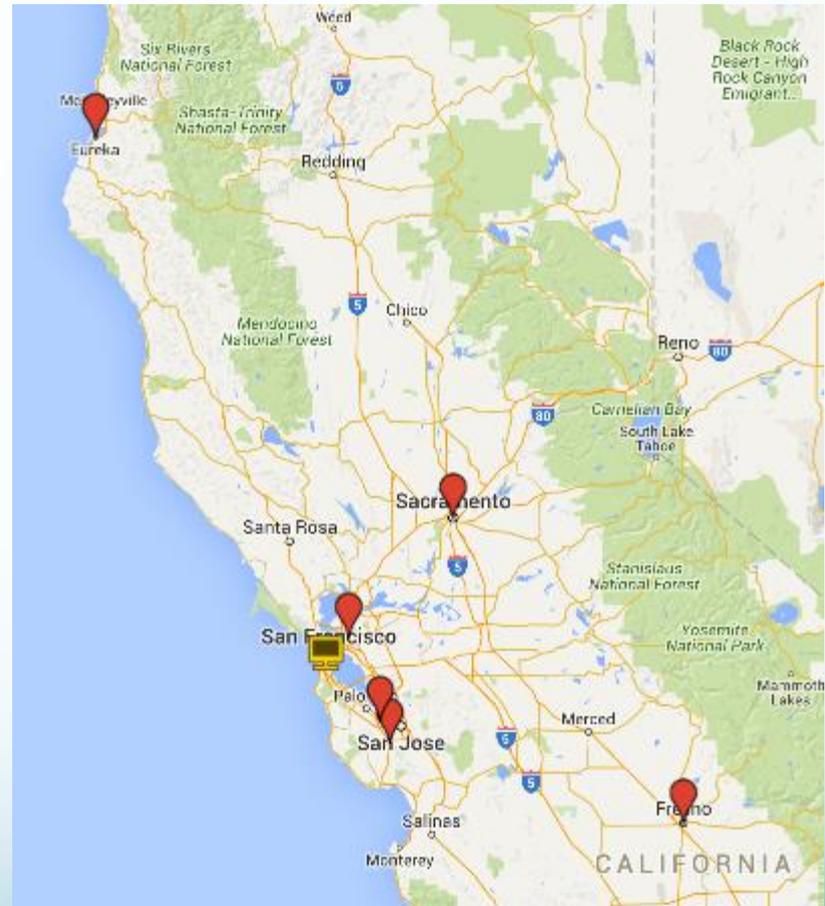
# TH + Palliative Care for PD

## Multidisciplinary and palliative care for PD via TH

- ***Does outpatient palliative care improve patient-centered outcomes in Parkinson's disease?***
  - Multidisc. palliative care vs usual care
  - All UCSF participants **offered TM study/clinic visits**
- **TH delivery of palliative care for Atypical Parkinsonism**
  - Pilot clinical project (MDS Telemed Task Force)
  - UCSF and JHU (Alex Pantelyat, former PADRECC fellow)
  - Looking at feasibility, best practices of this model
  - Qualitative look at roles (RN, SW, Chaplain)

# TH + Palliative Care for PD

- Pall Care for PD, Dissemination & Implementation study
  - R01, just funded
  - Hub-and-spoke model
  - (3 hubs, 6 spokes/ea)
- Intervention:
  - Community neurologists trained on Pall care
  - **Subjects will access our Multidisc team at UCSF via TH**



# Telehealth in PD: What else could be done?

- **Teleprevention of falls and fractures**
  - Operationalizing NPF's consensus recs for mgmt falls and PT delivered via TH
  - Tele-eval to confirm dx of parkinsonism, visiting nurse to administer IV (long-acting) bisphosphinate drugs
- **Telecare:** *technology that allows patients to stay safe and independent in their homes (home monitoring, mobile monitoring, wearables, alerts, etc...)*
- **Tele-education:** *SCAN-ECHO*
- **Training future neurologists:**
  - *Telemedicine Neurology Resident rotation at SFVA, ORH now funds 1.0 FTE resident, launched July 2016*

# Other Uses of Telehealth in PD

- Delivery of Lee-Silverman Voice Therapy
- Clinical Trials
  - Recruit, consent, enroll, retain
  - (CSP468f)
- Tele-rehabilitation
- Tele-mental health

# GAPS:

- Still lacking of evidence
  - What aspects of PD care are not effective via TH?
  - What's the best model of care? Clinic-to-clinic, Virtual house calls, Hub-and-spoke networks
- *Exaggerated Barriers in those who most need TH:*
  - *Rural: low-speed internet, lack of in-state specialists*
  - *Some elderly patients:*
    - *Less experience with technology (although rapidly changing)*
    - *Hearing loss, vision loss, cognitive impairment*

**Thank you!**