

Doing More With Outcomes: Lessons from the Parkinson's Outcomes Project Peter Schmidt, Ph.D.

Science from Art

"Once a treatment enters the mainstream, science is left behind. The next questions when to use it and on which patients become matters of judgment, not measurement."





Feynman Said It First...

"Incidentally, psychoanalysis is not a science; it is at best a medical process, and perhaps more like witch-doctoring...."





However...



"If you are sick, I would advise that you go to the witch doctor because he is the man in the tribe who knows the most about the disease; on the other hand, his knowledge is not science."

Richard Feynman Nobel Prize, Physics, 1965



Success Here Isn't Enough





Developing Improvement Science

• Cystic fibrosis



1964 CF median survival:

<u>USA</u> 3 years Matthews Clinic 21 years



Witch Doctors?

Pt

Neurologist care in Parkinson disease

A utilization, outcomes, and survival study

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Improved risk with neurologist care



How Do We Reach Everyone?





The Parkinson's Outcomes Project



NPF's Parkinson's Outcomes Project is the largest clinical study of PD ever conducted with over 7,500 participants.



- 7+ years
- 14,000+ participants
- 20,000+ evaluations
- 20+ interventions
- 6 outcomes
- Goal: To find and understand the very best care so that we can teach others to provide it.



Age at Onset and Diagnosis



Across the Spectrum



NPF's Parkinson's Outcomes Project



Very Simple Tests...

CLINICAL CONDITION/OUTCOMES	
Timed up & go test (TUG)	
Without pushing off	5-30 in whole seconds; 30-unable to do; 999-not tested
if unable without pushing off, then pushing off from ohair	5-30 in whole seconds; 30-unable to do; 999-not tested
If unable without assist device, then using case or wellter	5-30 in whole seconds; 30–unable to do; 999–not tested
Cognition	
Immediate 5 word recall	0-5 words; 999=not tested
Verbal fluency (animal list)	# of words; 999-not tested
Delayed 5 word recall	0-5 words; 999-not tested



... But High Resolution

For all patients, by duration





Insight from Segments



You can't "adjust" this away.



Approach to Measurement

• Clinical Value Compass (Nelson, et al., 1996)





Learning to Fight Parkinson's Understanding Outcomes



Are There Outliers?



Are There Outliers?



Comparing Centers

- Goals for case-mix comparisons:
 - Minimal adjustment: results \sim reality
 - Map results to standardized domain so that we can look across outcomes
 - Comparisons inform further investigation, they are not answers



Case Mix: Sex and Comorbidities

• For each outcome, adjust individual results for sex and comorbidities as categorical variables.





Center Summary Score

Timed up-and-go results



Total Cohort

Comparing Centers



Comparing Centers



Comparing Across Outcomes





Center G: Leader in Cognition





Center A: Leader in Falls





Looking at All Outcomes





Exercise: Changing the Disease Course



Matched patients who started exercise **early (NEE)** versus started **late (NNE)**: change in health status.

MEDPAGE TODAY*

Exercise May Put Brakes on QOL Decline in Parkinson's

SAN DIEGO -- Parkinson's patients who exercise regularly have slower declines in quality of life, researchers reported here. In an analysis of data from the National Parkinson Foundation database, patients who reported exercising at least 2.5 hours...



Next Steps



Variance: Mobility



Variance: Mobility at Center 5



Variance: Mobility at Center 9



Where Would You Run Your Motor Trial?



3 -2

Center 5

Highly predictable longitudinal outcomes

Center 9

Highly variable longitudinal outcomes



Precision Care

- Improving outcomes while improving science
- Alternate/supplement to biomarkers?













"Mathematics is not a science from our point of view..."

